

# The Social Determinants of Self-Management Capacity

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## Abstract

Chronic health conditions such as diabetes, arthritis, cardiovascular disease, and depression are common and frequently comorbid. These conditions require long-term treatment adherence and lifestyle modification to maintain function and minimise disease progression, and self-management ability is variable. Low-income and socially disadvantaged populations are known to experience more difficulty with self-management despite higher chronic disease prevalence. This thesis aims to explore the barriers to managing chronic disease effectively in rural community health settings, and to consider alternative models of care.

The research employed a mixed-methods approach, starting with a systematic review of self-management interventions and the differential impact of socioeconomic status. To understand the challenges of self-management in community health settings, qualitative interviews with multimorbid patients and their clinicians were undertaken. Additionally, a cross-sectional survey examined correlations between patient capacity domains and perceived treatment burden. The Cumulative Complexity Model was used to inform interview and survey development, and subsequent analysis.

Key findings were that the single disease model operating in most chronic care settings increased treatment demands, especially for those with few resources. Despite frequent physical/mental health comorbidity, patients and practitioners did not integrate management across different conditions. Self-efficacy theory, the foundation for self-management interventions, was found to contain assumptions at odds with both the lived experience and the resources available to community health patients. Consistent with the qualitative findings and wider literature, survey findings suggested that treatment burden was more closely correlated with psychosocial capacity rather than specific condition(s). This research argues for alternative approaches to self-management support, including broader skillsets and more flexible

professional boundaries for healthcare providers. The thesis concludes with a protocol for assessing the feasibility of an alternative model of care for multimorbid community health clients, shaped by this research and the Cumulative Complexity Model, which will be conducted as a postdoctoral project.

## Statement of authorship

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

Ruth Hardman 20 December 2021.



## List of Papers Published During this Thesis

### Chapter 2

R. Hardman, S. Begg & E. Spelten (2020). What impact do chronic disease self-management support interventions have on health inequity gaps related to socioeconomic status: A Systematic Review. *BMC Health Services Research* 20:150.

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### Chapter 4

R. Hardman, S. Begg & E. Spelten (2021). Healthcare professionals' perspective on treatment burden and patient capacity in low-income rural populations: challenges and opportunities. *BMC Family Practice* 22:50. DOI: <https://doi.org/10.1186/s12875-021-01387-y>

### Chapter 5

R. Hardman, S. Begg & E. Spelten (2021). Multimorbidity and its effect on perceived burden, capacity and the ability to self-manage in a low-income rural primary care population: a qualitative study. *PLoS ONE* 16(8): e0255802. DOI: <https://doi.org/10.1371/journal.pone.0255802>

### Chapter 6

R. Hardman, S. Begg & E. Spelten (2021). Self-efficacy in disadvantaged communities: Perspectives of healthcare providers and clients. *Chronic Illness* 1-14.

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During the course of my thesis I also contributed to the following published papers, which are unrelated to the current PhD project.

E. Spelten, R. Hardman, K. Pike, E. Yuen, C. Wilson (2021). Best practice in the implementation of telehealth-based supportive cancer care: Using research evidence and discipline-based guidance.

*Patient Education and Counseling* 104(11):2682-2699.

DOI: <https://doi.org/10.1016/j.pec.2021.04.006>

E. Spelten, J. van Vuuren, K. Naess, J. Timmis, R. Hardman, S. Duijts (2021). Making community palliative and end-of-life care sustainable; investigating the adaptability of rural Australian service provision. *Health and Social Care in the Community* 29(6):1998-2007

DOI: <https://doi.org/10.1111/hsc.13344>

# Declaration for Thesis Based or Partly Based on Conjointly Published Work

This thesis includes four published manuscripts, and one currently under review. All manuscripts were co-authored by my thesis supervisors, A/Prof Evelien Spelten and A/Prof Steve Begg.

Although both have been instrumental in clarifying my thinking and guiding the research direction, the conception, development, data collection, analysis and write up of this thesis was primarily my responsibility. The following table describes the relative contributions made by the authors for each paper.

<u>Publication status</u>	<u>Title of paper</u>	<u>Author contribution</u>
Paper 1  Published: BMC Health Services Research	What impact do chronic disease self-management support interventions have on health inequity gaps related to socioeconomic status: A Systematic Review	Initiation, literature search, development and writing up of the work:  80% R Hardman, 10% E. Spelten, 10% S Begg.
Paper 2  Published: BMC Family Practice	Healthcare professionals' perspective on treatment burden and patient capacity in low-income rural populations: challenges and opportunities.	Initiation, data collection, analysis, development and writing up:  80% R Hardman, 10% E Spelten, 10% S Begg.
Paper 3  Published: PLOS ONE	Multimorbidity and its effect on perceived burden, capacity and the ability to self-manage in a low-income rural primary care population: a qualitative study	Initiation, data collection, analysis, development and writing up:  80% R Hardman, 10% E Spelten, 10% S Begg.
Paper 4  Published: Chronic Illness	Self-efficacy in disadvantaged communities: Perspectives of healthcare providers and clients.	Initiation, data collection, analysis, development and writing up:  80% R Hardman, 10% E Spelten, 10% S Begg.
Paper 5  Under review: BMC Public Health	Self-reported capacity and perceived treatment burden in chronic disease patients: a cross-sectional study	Survey design, initiation, data collection, analysis, development and writing up:  80% R Hardman, 10% E Spelten, 10% S Begg.

All research procedures undertaken for this thesis were approved by the La Trobe University Human Research Ethics Committee and specific details regarding ethics approval are included in the relevant chapters.

## Abbreviations

AIC:	Akaike Information Criterion
BIC:	Bayesian Information Criterion
BREWS:	Theory of Patient Capacity
CVD:	Cardiovascular Disease
CCM:	Chronic Care Model
CD:	Chronic Disease
CDM/CDSM:	Chronic Disease Management/Chronic Disease Self-Management
CHC:	Chronic Health Condition
COPD:	Chronic Obstructive Pulmonary Disease
CuCoM:	Cumulative Complexity Model
DiPCare-Q:	Deprivation in Primary Care Questionnaire
DBIS:	Disease Burden Impact Scale
GP:	General Practitioner
HCP:	Healthcare Provider
MW:	Mann-Whitney U effect size
MatDCQ:	Material deprivation index
MDM:	Minimally-Disruptive Medicine
MTBQ:	Multimorbidity Treatment Burden Questionnaire

MSK:	Musculoskeletal Condition
NPT:	Normalisation Process Theory
PMCSMS-4:	Short-form Perceived Medical Condition Self-Management Scale
SM/SMS:	Self-management/Self-management Support
SES:	Socioeconomic Status
SocDCQ:	Social deprivation index
SR:	Spearman's rank effect size
T2DM:	Type 2 Diabetes

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## CHAPTER ONE

### Introduction and Thesis Summary

My PhD thesis has developed from both a fact and an observation. The fact is the consistent disparity in chronic disease prevalence and morbidity amongst socially disadvantaged populations. The observation, informed by my experience as a clinician, is that healthcare workers in these environments often feel overwhelmed and ineffectual. My thesis aims to explore the barriers to managing chronic disease effectively in these settings, and to investigate alternative models of care that might work better both for patients and providers.

This introduction covers the following areas:

- Epidemiology: The state of chronic disease epidemiology in Australia and its relationship to the social determinants of health.
- Chronic disease management: How the health system has changed; the Chronic Care Model and chronic disease self-management approaches; the emergence of 'healthcare workload'.
- Barriers and limitations: Limitations of chronic care and self-management approaches particularly for those experiencing multimorbidity, social complexity or resource constraints.
- PhD setting and context: The specific environment and context of my research: an industry PhD undertaken in partnership with a rural community centre.
- Knowledge gaps identified and initial research questions
- Thesis structure: A short summary of each of the remaining chapters.



## 1.1 Chronic Disease Epidemiology

### Prevalence and costs of chronic health conditions

Chronic health conditions (CHCs), described as “...health problems that require ongoing management over a period of years or decades”(1), are the main drivers of illness, premature mortality and healthcare utilisation in Australia and worldwide(2-5). These conditions occur over the lifespan but are more common as we age, often have a gradual onset, and whilst not immediately life-threatening, are the leading cause of disability and death. Two-thirds of Australia’s burden of disease (years lost due to premature death, plus years lost due to living in poor health) is due to CHCs, dominated by cancer, cardiovascular, musculoskeletal, and mental health conditions(2, 4, 5).

Whilst one in two Australians have a CHC, one in five also experience multimorbidity – the presence of two or more chronic health conditions(4, 5). This increases to one in two for those aged over 65 years. Multimorbidity is associated with poorer health outcomes and more complex management, due to interactions between different conditions and treatments. Having one CHC may trigger another, either due to similar disease processes (e.g. diabetes and cardiovascular disease), common lifestyle risk factors, or (e.g., with depression onset) in response to the demands and stresses of living with a chronic condition(6).

Chronic health conditions are costly both from the individual and population perspective. They impair people’s quality of life, independence, and ability to generate an income, as well as incurring enormous costs in our health and welfare systems. For instance, chronic musculoskeletal conditions absorb 11% of Australia’s total health expenditure, and chronic kidney disease is the cause of 17% of all hospital admissions(4).

### **Prevalence is not the main issue**

Ironically, the prevalence of chronic health conditions is the direct result of the improvements in public health over the past century. Most chronic health conditions are age related – for example, diabetes prevalence increases from 1 in 20 Australians aged under 55 to 1 in 5 of those over 75 years(5). Our high levels of chronic disease reflect our increased life expectancy and success in tackling conditions, such as cancer and cardiovascular disease, that were previously a death sentence(7).

The base problem, therefore, is not CHC prevalence. We have high rates of chronic conditions now because we live long enough to get them, and because they can be treated. Countries with greater life expectancies inevitably experience a greater number of years lived with CHCs(3). In Australia, despite a 24% reduction in premature death over the past 15 years, there has been no improvement in the number of years lived in poor health(8). Therefore, the challenge we face is to live well with these conditions and to minimise associated disability, rather than to eliminate the conditions altogether.

### **Chronic disease is socially determined**

Although our increased life expectancy and reduction in child mortality are the primary reasons why CHCs are now the major health challenge, there are significant differences in the population distribution of chronic disease. The social determinants of health – by which we mean the conditions that people live and work in, and the structures that create and sustain these conditions(9, 10) – are key predictors of CHC prevalence and severity. Social determinants include individual or ‘downstream’ factors such as health behaviours and beliefs; immediate environmental factors such as family, work, healthcare access, housing and income; ‘upstream’ structural factors such as class, gender, and ethnicity; and the influence of political, economic, and social forces on these factors(10, 11).

In particular, socioeconomic status (SES) has a consistent health gradient across countries and health systems(10, 12, 13). This association holds true regardless of whether SES is measured individually (using occupation, income, education level) or collectively (using socioeconomic area data, calculated from mean individual scores across specific geographical regions). Low SES populations experience higher prevalence, severity, disability, and mortality from CHCs(4, 12, 13). In Australia, this gradient translates to a 1.5–2 times increased risk of CHC prevalence, hospitalisation and death(4). This results in a life expectancy gap of up to six years for men and four years for women.

Multimorbidity is also strongly related to SES(14-17), occurring 10–15 years earlier for those living in low SES areas(14). The relationship between chronic disease and SES has been explained in reference to multifaceted interactions between structural factors (ethnicity, economics) and the social, political, and family environment, affecting individual psychology, health behaviours and (through chronic stress) biological mechanisms at the cellular level(10-12).

The importance of these factors on health outcomes is indisputable, but their level of complexity means that our knowledge and ability to target these pathways to improve health outcomes has been limited. Additionally, addressing 'upstream' macro-level structural and societal contributors relies on political will and vision. Consequently, most clinical interventions have been directed toward the 'downstream' (individual) determinants of health, with less attention paid to the 'upstream' contributors(18, 19). This creates a risk that interventions will favour those with fewer structural barriers, thus increasing health inequity(19-22).

## 1.2 Chronic disease management

### **Better treatment options, but increased health system complexity**

Along with the increased prevalence of chronic disease and multimorbidity, the last century has seen dramatic improvements in treatment efficacy. Cardiovascular conditions, cancer and HIV have evolved from terminal diagnoses to manageable chronic diseases as treatment options have multiplied. Medical care has become more sophisticated, with the proliferation of medical specialties and the movement of nurses and allied health workers from assistants to autonomous professionals. In the past, healthcare (such as it was) was limited to a relationship with the family doctor, who could provide care and comfort, but often little else. This relationship has changed dramatically. Many GPs are no longer primarily providers of care, but referral hubs, directing the patient into a highly complex and sophisticated health system which can be fragmented and difficult to navigate(23-25).

### **Reorienting health systems to manage chronic disease: The Chronic Care Model**

By their very nature, CHCs require long-term management and continuity of care; however, increased specialisation has led to health system fragmentation. In response to this, Wagner et al (24) developed the Chronic Care Model (CCM), which describes how healthcare provision can be restructured to improve outcomes for patients with chronic conditions(1, 24, 26, 27).

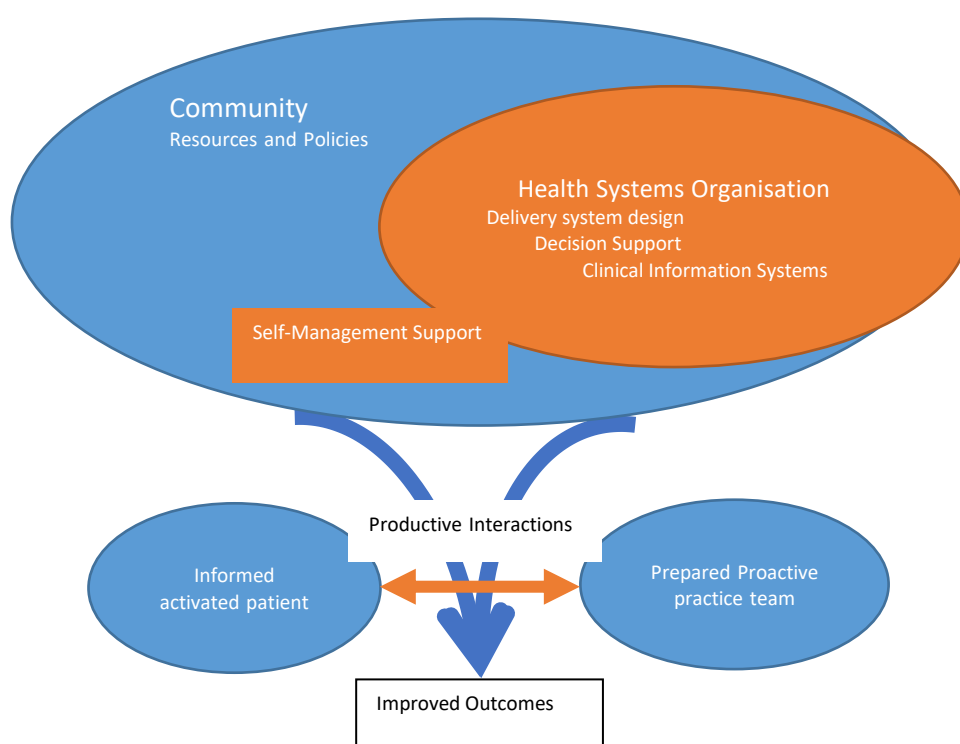
In this model, healthcare delivery is organised around the following components:

- Clinical information systems: patient databases and registries to facilitate timely and useful information exchange.
- Decision support: the provision of evidence-based guidelines and protocols that are integrated into patient care.

- Delivery system design: organising health system interactions to promote continuity of care, such as the use of care co-ordinators and multidisciplinary teams.
- Self-management support: providing education and support to patients and carers to assist them with day-to-day self-management.

As shown in figure 1.1 below, the elements in this model can enable the health system to work more effectively with chronic disease patients, encouraging greater interaction and patient participation and leading to improved health outcomes.

**Figure 1.1: The Chronic Care Model (24)**



The CCM is considered best practice in managing chronic health conditions worldwide, and versions of this model form part of health policy across many countries and settings(1, 5, 28). In clinical practice, the CCM has been established to various degrees in primary care settings

worldwide, especially in countries with universal healthcare(29, 30). Multiple trials of interventions incorporating the CCM or its elements have been undertaken(31-35). Australia's more fragmented funding model has limited the implementation of this model, although successful trials have been undertaken(36, 37). As in other countries, inconsistent levels of funding and political support have made it difficult to fully establish and entrench this model(38). Despite this, the overall evidence from systematic reviews suggests that the CCM, especially the components of delivery system design and self-management support, can provide modest benefit in health outcomes for a range of CHCs(29, 31-35).

### **The role of chronic disease self-management**

This thesis focusses on one component of the CCM, self-management support (SMS). Whilst acknowledging that self-management support cannot be viewed in isolation, either from the health setting in which it operates or from the other elements of the CCM, my research has been undertaken in the community health environment. In this environment, other elements of the CCM (such as shared care plans, shared health records, and multidisciplinary working) are already well-established. Additionally, SMS (and to a lesser extent delivery system design) is the CCM component that directly mediates the relationship between the patient and the health provider. Since the purpose of my thesis is to explore the intersection between the challenges facing socially disadvantaged patients, and the response of their healthcare providers, SMS is a logical place to start. Given the high percentage of community health clients with CHCs, the provision of SMS is a central role for health providers working in this setting.

'Self-management' refers to the process by which an individual with a long-term health condition copes with the demands from their condition, including specific skills and adjustment to changes in their physical, emotional and role function(39, 40). Self-management support (SMS) is the assistance, usually provided by a clinician, to optimise the patients' self-

management(27). Self-management differs from self-care in that it includes the healthcare system: the patient collaborates with health providers to develop the strategies and skills needed to best cope with living with chronic disease(41). This can include individual or group behaviour change interventions, although SMS is not limited to lifestyle interventions and encompasses anything which enables a better life with CHCs(27, 39, 42). Table 1.1 outlines common components of SMS interventions(27, 39, 40, 42, 43).

**Table 1.1: Common components of SMS**

Key element	Practical examples
Patient/provider relationship	<ul style="list-style-type: none"> <li>• Patient/client as a partner, provider as facilitator/coach</li> <li>• Development of agreed care plan based on patient preferences</li> <li>• Emphasis on problem-solving and building self-efficacy</li> </ul>
Education	<ul style="list-style-type: none"> <li>• Knowledge of the condition and treatment options available</li> </ul>
Symptom management and monitoring	<ul style="list-style-type: none"> <li>• Learning condition-specific skills (e.g. blood sugar monitoring)</li> <li>• How to monitor and manage changes/flare-ups in condition</li> <li>• Practical symptom management (e.g. relaxation)</li> </ul>
Healthy lifestyle	<ul style="list-style-type: none"> <li>• Exercise, nutrition, sleep, addressing smoking etc.</li> <li>• Goal setting and action planning to achieve this e.g. behavioural change strategies, motivational interviewing</li> </ul>
Psychological adjustment	<ul style="list-style-type: none"> <li>• Strategies to manage stress, anger, depression</li> <li>• Acceptance and reframing to adjust to CHC</li> </ul>
Role adjustment	<ul style="list-style-type: none"> <li>• Problem solving to enable engagement in preferred activities (social, family, leisure, work) within limitations of the condition</li> </ul>
Resource utilisation	<ul style="list-style-type: none"> <li>• Help to find and use community resources</li> <li>• How to work with providers and navigate the health system</li> </ul>

### **Chronic disease management and the emergence of ‘healthcare workload’**

Twenty-first century medicine is in every way superior to that of a century ago. Better medical care has allowed us to live long enough to develop CHCs and has provided us with treatments to manage those conditions. However, the long-term nature of CHCs, as well as the wider availability of treatment options, means that healthcare now requires ongoing work. People need to take prescribed medication, monitor their conditions, and attend appointments, often with multiple providers who may have different or conflicting recommendations(23, 44). Most chronic conditions are also the result of lifestyle risk factors, such as smoking, poor diet and insufficient physical activity(4, 5). Effective management of these conditions can require significant behavioural change, hence the importance of self-management. Our increased understanding of the role of lifestyle in the management of CHCs has also encouraged an expectation of increased self-responsibility for ones’ health and well-being. Instead of merely following (or not following) the instructions of their family doctor, patients are now encouraged to take control of their health, with the health provider acting as a facilitator or guide(45). Although a move away from the patriarchal doctor-patient relationship is to be welcomed, the upshot is that the patient is again handed more healthcare work, needing not just to carry out tasks as instructed but to become an ‘expert’ in their healthcare(23, 44, 46).

For multimorbid patients, the healthcare workload is multiplied by the need to undertake treatments specific to each CHC as well as to manage interactions between their different conditions or treatments (e.g. polypharmacy)(23, 44). Low SES also complicates the picture. These population groups have fewer resources, such as social support, health literacy, income, transport, or private health insurance, that would help to share or reduce the healthcare workload. They are also more likely to have inflexible work, greater caring responsibilities, and more complex family situations, meaning that the demands from their ‘life workload’ will be greater as well(47, 48).



Chronic conditions have become the dominant challenge in healthcare because we aren't dying from them now. Management of these conditions is a challenge not because the treatments aren't available or effective, but because of the patient work they have generated. Excessive patient workload is a known predictor of treatment adherence(23, 49, 50). Adherence to CHC recommendations in developed countries averages 50% for medication, with much lower rates for lifestyle recommendations(51, 52). The negative health outcomes associated with non-adherence, including disease escalation, hospitalisation, and mortality, highlight the need for a much greater awareness of the impact of patient work in CHCs.

### **1.3 Barriers and limitations of the CCM**

#### **The chronic care model: system-focussed, not patient-focussed**

The Chronic Care Model specifically aims to re-direct the health system from an approach designed to manage acute health conditions, to one that is appropriate for the long-term management of chronic health conditions(1, 24). Although some components of the model (e.g. SMS) directly target patients, and others (e.g. delivery system design) should reduce patient workload by promoting care continuity, the CCM is focussed on the health system rather than the individual patient. This has certain implications:

1. It doesn't account for patient work. The patients' healthcare workload, and how their additional 'life workload' (employment, caring responsibilities) might be affecting their ability to engage with the health system, are not considered. Some components of the CCM (particularly SMS and decision support) have been found to increase individual workload, especially for those with multimorbidity(53-55).

2. It doesn't account for multimorbidity. The CCM was designed for use in single CHCs (e.g. diabetes), rather than for the increasingly normal situation of multimorbidity. Adherence to 'best practice' clinical guidelines as described by the CCM when there are multiple chronic conditions can lead to patient overload and non-adherence(44, 54-56).
3. It doesn't account for individual resources or capacities. The CCM aims to reorganise the health system to provide what is needed to manage chronic disease, but there is little recognition that people might vary in their ability to engage with what the system provides. This is seen most clearly in outcomes from SMS interventions. Although these interventions can improve self-efficacy and quality of life(29, 39, 57, 58), most participants are well-educated, with lower levels of disability and better overall health markers(42, 59, 60).

### **Self-management support: an individual intervention that isn't rooted in the individual person**

SMS interventions have been criticised because of their focus on individual responsibility(18, 61, 62) whilst ignoring structural ('upstream') barriers to behaviour change(61, 63, 64). This may be because, as noted above, SMS (as a component of the CCM) is part of a health system-focussed intervention rather than an approach that has emerged in consultation with the individual patient. SMS originated in the health system, not from the patient; and its primary task was to assist the patient to successfully manage their CHC, not to achieve patient-determined personal goals.

As a result, health providers and patients often hold quite different views about self-management, both about its purpose and its content(18, 61, 65). For healthcare providers, there can be an assumption that once a patient is informed and instructed, they will (and should) automatically take more responsibility for their health. Inability or unwillingness to do so may be seen as a moral failing(18, 61). Healthcare providers may also be influenced by government

narratives which promote self-management as an opportunity to reduce healthcare costs(45, 65).

On the other hand, for patients, self-management is simply what happens in the process of living with a CHC, regardless of whether that 'self-management' is compliant with healthcare recommendations or not(18, 62). Therefore, some forms of 'self-management' undertaken by the patient (e.g. presenting to the emergency department) may appear to the health provider to be abdicating responsibility for ones' CHCs. Instead, they may simply reflect an honest appraisal of the individuals' resources and capacities(62, 66, 67).

### **Barriers to self-management include individual and system factors**

Regardless of the tensions and inconsistencies concerning the purpose and role of self-management, it is unarguable that effective maintenance of CHCs is reliant on the quality of self-management and by implication, on SMS. Multiple studies of facilitators and barriers to effective self-management have been undertaken, and findings are consistent across conditions and populations. These can be summarised under four headings as outlined below.

#### Socioeconomic disadvantage

Many systematic reviews across a range of CHCs have found that socioeconomic factors, particularly income, but including social support, education, and health literacy, can make self-management more challenging(68-70). Although low SES groups are known to encounter more barriers to self-management(71, 72), we have limited knowledge about the effectiveness of SMS interventions in these populations, especially when compared to more advantaged groups(42, 60, 73). Researchers have recommended the need for specific research with less-engaged populations (men, minorities, low SES groups)(61, 73, 74) and for subgroup analysis to assess equity differences(75) in interventions.

### Multimorbidity

People with multimorbidity experience both greater health workload and higher illness burden: that is, the symptoms of illness such as pain, fatigue, and nausea. This means that they have more treatment work to do, yet fewer physical resources to do it with, resulting in greater difficulty in self-management. Although multimorbidity is a known barrier to self-management(68-70), our understanding is limited by the fact that most SMS interventions focus on a single disease(15, 76, 77), either excluding multimorbid patients or not recording their status. Additionally, most research that does explore SMS in multimorbidity focusses on the elderly, with little research into multimorbidity in working age people(78). This is a significant gap since younger multimorbid people are more likely to experience social disadvantage(14), with fewer resources yet greater life demands such as the need to earn an income or provide care to children or parents.

### Psychological factors

Active involvement in one's healthcare requires a certain level of motivation and engagement. This includes both cognitive (understanding the importance of self-management) and emotional (desire for a particular outcome) elements. Some established 'psychological' barriers to self-management may be better categorised as related to socioeconomic disadvantage (e.g. poor health literacy(69, 79)) or multimorbidity (e.g. presence of depression(80, 81)). However, there remains ample evidence that one's health beliefs, including illness perceptions, outcome expectations, self-efficacy and sense of control are strong and consistent predictors of self-management ability across a range of CHCs (82-84). The role of self-efficacy, or one's confidence in their ability to self-manage, is particularly important since it forms the theoretical basis for most SMS interventions(39, 40, 85). However, it is also connected to other self-management barriers, with low self-efficacy associated both with multimorbidity(86) and low SES(48, 87).

### Health systems

SMS is only one component of the CCM, and effective self-management requires that the patient has timely access to co-ordinated and integrated health services. Since self-management involves a partnership between the patient and their health service/providers, access barriers – whether due to cost, transport, location, or waiting lists – will impair self-management. Again, socially disadvantaged and multimorbid individuals will bear the brunt of a poorly organised, fragmented, costly or inaccessible healthcare system(88-90).

At the individual provider level, rapport between the clinician providing SMS and the patient is also an important factor(68, 69). High levels of satisfaction with provider support and communication are associated with improved self-efficacy, adherence, and self-management ability(91, 92). However, health providers have been noted to over-focus on motivational and biomedical factors in SMS provision and to overuse didactic approaches(21, 93). Such an approach can ignore the social context and devalue the patients' lived experience and priorities(61). This may be more important in low SES settings due to powerlessness and mistrust of the medical system(90, 94).

## **1.4 PhD setting and context**

### **Rural Community Health Setting**

This thesis has been undertaken as part of a La Trobe Industry PhD scholarship. The industry partner is Sunraysia Community Health Services, based in Mildura, an outer regional town in north-west Victoria. Community Health Centres have a specific commitment to the health and social well-being of underserved and disadvantaged groups(95). Therefore, the broad remit of

this thesis was to explore models of care in chronic disease which better account for, and address, the social determinants of health.

‘Social determinants of health’ and ‘socioeconomic status’ are generalist terms, embracing ill-defined concepts such as class and ethnicity. For this reason, I chose to focus on income level. This is the most significant contributor to health inequality in Australia(4). In Victoria, low income level (less than \$40,000 p.a.) predicts poor health amongst the greatest number of adults, causing 21% of the total burden of disease(96). Many of these adults live in rural Victoria, where over 40 per cent of local government areas (LGAs) are in the ‘most disadvantaged’ SES quintile(97). This includes the Mildura LGA, which has 45% of its population living on a poverty-level income of less than \$400/week(98).

The second contextual aspect of my research is that it is undertaken in a rural setting. In Australia, living in a rural environment has long been associated with a range of negative health impacts, including higher rates of risky health behaviours, CHCs and mortality(4, 99). Rural and regional populations are more socioeconomically disadvantaged, and have more limited opportunities for work and education, which can exacerbate health inequities(96). People also face many barriers accessing healthcare, such as transport and service availability. Health workforce distribution is a major challenge in rural Australia, especially in terms of general practitioner (GP) and medical specialist services. GP availability in remote areas declines to almost half the number per person in major cities, despite greater health needs(99-101). This can lead to lack of timely healthcare, or intermittent service provision by locum and transient providers. Rural areas are therefore often more dependent on non-medical providers (nurses and allied health workers) to fill the gaps in service provision, and community health centres often play an important role in these services.

Community health centres provide integrated health and social care for vulnerable populations, particularly those experiencing social and economic disadvantage. There are 28 independent

community health centres in Victoria providing a range of services from child and youth health, drug and alcohol services, palliative and aged care(95). Most also offer chronic disease management (usually disease-specific) including SMS provision, often incorporating multidisciplinary teams. Typical community health chronic disease clients are low income, older and experiencing both multimorbidity and social complexity (e.g. family trauma, substance use, housing difficulties). This is a population that encounters high levels of morbidity and mortality but is not well-represented in chronic disease or self-management research.

### **My perspective**

This research topic has emerged from my work as a clinician. For the past 20 years, I have worked as a pain management physiotherapist in multidisciplinary teams, assisting people to self-manage persistent pain conditions. I have been interested in treatment engagement and adherence for many years, having observed that pain self-management could be very effective – as long as people did it. In common with many clinicians, I was aware that people who had the greatest difficulty in engagement with self-management were often those with the fewest resources and the most complicated lives. Conversely, it appeared that the people who gained most from self-management were already well-resourced. I was concerned that this was increasing health inequity. My Master of Public Health (MPH) in chronic condition management focussed on the social determinants of health and included research into the factors associated with dropout from self-management. This PhD thesis builds on my longstanding interest in this area and has also been an opportunity for me to explore the relationship between self-management support, as delivered by the provider, and the patients' lived experience of chronic illness.

There is also a personal perspective for me in this PhD topic. My now-adult children have both had significant health and disability issues, and my daughter lives with a disabling lifelong health

condition. As a carer, I have had first-hand experiences of dealing with overwhelming treatment workload whilst trying to achieve the even more important task of creating a meaningful life which encompasses chronic illness. Even though I am privileged and well-educated, this has been a struggle. It has made me very mindful of the far greater demands and challenges faced by many of my clients and patients and the importance of respecting their values and priorities.



### **1.5 Thesis objectives and research questions.**

Low-income and socially disadvantaged populations are known to experience more difficulty with self-management despite higher chronic disease prevalence. The objective of this thesis is to explore the barriers to managing chronic disease effectively in rural community health settings, and to consider alternative models of care.

The following research questions emerged from the literature review and form the basis of my thesis.

1. Are there differences in participation in, or outcomes from SMS interventions based on socioeconomic status?
2. Do SMS interventions increase inequity between low and high SES groups?
3. How do multimorbid patients in rural low-income settings manage their health workload and self-manage their CHCs? Is this different from more advantaged populations?
4. Is the emphasis on building self-efficacy through SMS appropriate in low-income or resource-constrained settings?
5. What is the impact of health system and organisational factors on the self-management capacity of rural low-income patients with CHCs?
6. Are health providers working in SMS in these settings aware of the social and contextual factors facing their clients and how do they address them?
7. Is it possible to identify people who are likely to struggle with self-management?
8. What Model of Care is most appropriate to assist multimorbid patients in rural low-income settings in managing their CHCs?

## 1.6 Thesis Structure

### Methodology Statement

The thesis takes a mixed methods approach. It includes a systematic review (published); three qualitative studies (all published); a quantitative cross-sectional survey (under review) and an unpublished protocol paper describing a proposed mixed-methods intervention.

Each paper describes and provides justification for the specific methodological approach taken. Supplementary information related to the methods for each paper, including the systematic search process, interview protocols, survey tools and qualitative coding frameworks, are available in the appendices.

### **Chapter Two: What impact do chronic disease self-management support interventions have on health inequity gaps related to socioeconomic status: A systematic review.**

This was published in BMC Health Services Research in February 2020 and aims to address questions 1 and 2:

- Are there differences in participation in, or outcomes from SMS interventions based on socioeconomic status?
- Do SMS interventions increase inequity between low and high SES groups?

In this paper I conclude that, although important, SES is not in itself 'high-risk'. Other workload and capacity factors interact with SES, creating complexity. There is a need to understand how these elements interact and impact on self-management ability, and ideally to be able to screen people to identify those most in need of support. I chose to use the Cumulative Complexity Model, which describes how individual workload and capacity domains combine to either enable

or prevent effective CHC management, to use as a theoretical framework for my remaining PhD chapters.

### **Chapter Three: The Cumulative Complexity Model**

This bridging chapter provides detail on the Cumulative Complexity Model, which is the theoretical approach that has informed and directed my thesis.

### **Chapter Four: Healthcare professionals' perspective on treatment burden and patient capacity in low-income rural populations: challenges and opportunities.**

This was published in BMC Family Practice in January 2021 and aims to address questions 5 and 6:

- What is the impact of health system and organisational factors on the self-management capacity of rural low-income patients with CHCs?
- Are health providers working in SMS in these settings aware of the social and contextual factors facing their clients and how do they address them?

Data was analysed using the Cumulative Complexity Model as the framework. In this paper I conclude that health providers were conscious of social and contextual factors and had a range of strategies to address them, but that health organisation factors often created barriers. In addition, some actions of HCPs, although designed to help, actually led to increased patient workload.

**Chapter Five: Multimorbidity and its effect on perceived burden, capacity, and the ability to self-manage in a low-income rural primary care population: A qualitative study.**

This was published in PLOS One in August 2021 and aims to address question 3:

- How do multimorbid patients in rural low-income settings manage their health workload and self-manage their CHCs? Is this different from more advantaged populations?

Data was analysed using the Cumulative Complexity Model as the framework. In this paper I conclude that multimorbid patients prioritised conditions causing functional impairment (e.g., chronic pain), above low symptom but high workload conditions such as diabetes. This related to the differential impacts of these conditions on physical, financial, and psychological capacity. Multimorbid patients also experienced greater treatment burden due to difficulties in managing interactions between their CHCs and received little support in this area from HCPs.

**Chapter Six: Self-efficacy in disadvantaged communities: Perspectives of health providers and clients.**

This was published in Chronic Illness in October 2021 and aims to address question 4:

- Is the emphasis on building self-efficacy through SMS appropriate in low-income or resource-constrained settings?

Data was analysed using Bandura's theory of self-efficacy. In this paper I concluded that the assumptions about agency, development of self-efficacy, the role of outcome expectations and desired outcomes were different in a low-income community health setting. This was found to be related to both past experiences, which informed expectations, and resource constraints. SMS interventions based solely on self-efficacy theory may disadvantage people in these settings.

**Chapter Seven: Exploring the ability of self-report measures to identify risk of high treatment burden in chronic disease patients: a cross-sectional study.**

This is currently under review, pending revisions, by the BMC Public Health journal. It aims to address question 7:

- Is it possible to identify people who are likely to struggle with self-management?

The paper describes the results from a cross-sectional survey which used existing validated measures of treatment burden and the following capacity domains: physical, psychological, social, personal, and economic.

Logistic regression analysis was conducted to correlate capacity measures with treatment burden level. High perceived treatment burden was correlated with younger age, material deprivation, low self-efficacy, and usual activity limitation, but not to overall disease burden or specific medical diagnosis. This suggested that psychosocial factors may be more important than specific diagnoses in risk identification. The paper also aimed to see if self-report capacity measures could act as a screening tool, to identify those at risk of high treatment burden. Initial progress has been made, with further development needed using a larger sample.

**Chapter Eight: Care for Complexity in Community Health (the 3C trial): Protocol for a feasibility study.**

This chapter aims to address question 8:

- What Model of Care is most appropriate to assist multimorbid patients in rural low-income settings in managing their CHCs?

The paper is a protocol for a feasibility trial, to be conducted over 2 years from 2022-2024, which will pilot an alternative Model of Care to assist vulnerable multimorbid people in the community health setting in self-management of their CHCs. The trial will be jointly funded by Sunraysia

Community Health Services and the Violet Vines Marshman Centre for Rural Health Research.

The paper will be submitted to a journal in early 2022 pending ethics approval for the trial.

## **Chapter Nine: Discussion and Conclusions**

This short chapter provides an overall thesis summary and synthesis of my findings and discusses further research directions.

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## CHAPTER TWO:

# What impact do chronic disease self-management support interventions have on health inequity gaps related to socioeconomic status: A Systematic Review

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The published version and supplementary files for this paper are provided in Appendices A and B.

## 2.1 Abstract

**Background:** The social gradient in chronic disease (CD) is well-documented, and the ability to effectively self-manage is crucial to reducing morbidity and mortality from CD. This systematic review aimed to assess the moderating effect of socioeconomic status on self-management support (SMS) interventions in relation to participation, retention and post-intervention outcomes.

**Methods:** Six databases were searched for studies of any design published until December 2018. Eligible studies reported on outcomes from SMS interventions for adults with chronic disease, where socioeconomic status was recorded and a between-groups comparison on SES was made. Possible outcomes were participation rates, retention rates and clinical or behavioural post-intervention results.

**Results:** Nineteen studies were retrieved, including five studies on participation, five on attrition and nine studies reporting on outcomes following SMS intervention. All participation studies reported reduced engagement in low SES cohorts. Studies assessing retention and post-intervention outcomes had variable results, related to the diversity of interventions. A reduction in health disparity was seen in longer interventions that were individually tailored. Most studies did not provide a theoretical justification for the intervention being investigated, although four studies referred to Bandura's concept of self-efficacy.

**Conclusions:** The limited research suggests that socioeconomic status does moderate the efficacy of SMS interventions, such that without careful tailoring and direct targeting of barriers to self-management, SMS may exacerbate the social gradient in chronic disease outcomes. Screening for patient disadvantage or workload, rather than simply recording SES, may increase the chances of tailored interventions being directed to those most likely to benefit from them.

Future interventions for low SES populations should consider focussing more on treatment burden and patient capacity.

**Trial registration:** PROSPERO registration CRD42019124760. Registration date 17/4/19.

**Keywords:** Self-management, socioeconomic status, health inequity, patient capacity, chronic disease



## 2.2 Background

Chronic health conditions are increasingly common, with some population groups, such as those of lower socioeconomic status (SES) having both a greater incidence of chronic disease and a poorer prognosis (1-3). The long-term nature of these conditions means that the patient is largely responsible for day-to-day disease management (4, 5) and since many chronic conditions are lifestyle-related (6), the quality of patient self-management is important. Self-management support (SMS) approaches have been developed to give people the skills to more effectively manage their health. These interventions involve both education and behaviour change strategies to address the medical, physical, emotional and social challenges associated with CD, aiming to help the person adapt to their changed circumstances whilst still leading a meaningful life (4, 5, 7) .

Although SMS interventions are now widespread, outcomes have been mixed, with the benefits being limited to short-term improvements in psychological variables such as self-efficacy, rather than sustained clinical or behavioural changes (4, 6, 8, 9). Most SMS interventions are theoretically grounded in Bandura's concept of self-efficacy (5) and utilise specific techniques to enhance self-efficacy (5-7, 10, 11). Self-efficacy theory refers to an individual's belief or confidence in their capacity to undertake tasks or achieve goals, which can translate into health behaviour change and by implication, improved health status (4, 5).

Persisting questions remain, however, about the effectiveness of SMS in low SES and other disadvantaged groups. The original SMS trials were conducted in self-selected, higher SES populations (4, 6, 10) and studies in disadvantaged populations have reported poorer outcomes and lower levels of adherence (12, 13). Several writers have theorised that the individual patient focus of SMS limits its effectiveness in these groups. By prioritising individual self-efficacy and activation, the potential barriers to self-management within the patient's wider social context

(e.g. literacy, resources, social supports) are ignored (6, 10, 11, 14, 15). Although the dominant role of the social determinants of health is acknowledged in CD epidemiology, their influence on treatment engagement is rarely addressed (15).

Effective chronic disease (CD) management should include both an improvement in overall population health and a reduction in health inequities (16-18). An intervention that appears more effective in a better-off population may widen the disparity gap, and there are strong suggestions that individually-focussed 'downstream' interventions, such as SMS, can increase disparity (17, 19, 20). Specific targeting of disadvantaged groups is one way to deal with inequity, and tailored SMS approaches for these groups have been trialled, but systematic reviews have shown inconsistent and dose-dependent benefits (13, 21). In addition, such interventions may have positive outcomes, but still not address the disparity gap (18).

Although there are suggestions that SMS interventions may be less effective in low SES groups, this can only be determined by comparing SMS outcomes between more and less advantaged groups. There have been no previous reviews on this topic, despite many researchers stressing the importance of addressing and quantifying the equity gap in CD (18-20, 22, 23). This is partly due to statistical challenges, since the evidence will emerge from subgroup analyses (19, 24, 25). However, given the strong connection between the social determinants of health and health outcomes, subgroup analyses need not be post-hoc data dredging but can be planned and valid approaches to answering these questions (26-28).

This review aims to examine studies that have looked at differences between socioeconomic groups undergoing SMS interventions, in order to answer the following questions: 1. Is there evidence that SES influences participation rates in SMS interventions? 2. Is there evidence that SES influences rates of retention or dropout from SMS interventions? 3: Is there evidence that SES affects clinical, behavioural or other specified outcomes following SMS interventions?

## 2.3 Methods

### Search strategy and data abstraction

We conducted a systematic review of the literature using the PRISMA reporting guidelines (29) to structure the report. We searched for full-text articles in English to December 2018 in the following databases: Cochrane database; PubMed; Cinahl; Embase; Proquest and Psycinfo. The search terms covered the following areas, using MeSH terms and synonyms: (1) Chronic condition, including diabetes, cardiovascular disease, musculoskeletal conditions and chronic pulmonary disease; (2) Self-management; (3) Socio-economic status, including associated terms such as inequity, disparity, 'vulnerable groups'; and (4) Terms related to outcomes, efficacy, retention or participation. The PubMed search strategy is available in additional file 1. No date filter was employed in order to obtain the widest possible search. In the course of the search thirteen related systematic reviews were located and their references were screened resulting in seven additional papers.

### Inclusion criteria

Inclusion and exclusion criteria are outlined in Table 2.1. We looked for four main chronic conditions: cardiovascular disease (CVD), musculoskeletal conditions (MSK), pulmonary disease (COPD) and diabetes. All these conditions contribute significantly to the burden of disease and share many common risk factors. We included studies of co/multimorbidity since this is representative of the CD population. A decision was made to focus only on socio-economic status (SES), which has well-documented and consistent effects on chronic disease, rather than on other WHO PROGRESS+ factors such as gender and ethnicity, which can vary between countries (19). All studies needed to provide a comparison between a less and more advantaged

group, based on income, education or socioeconomic area. Comparisons based on literacy or ethnicity were only included if there was a quantifiable relationship between these variables and other SES measures. As well as post-intervention outcomes such as behavioural or clinical changes, outcomes related to participation and dropout were included to fully capture potential areas of disparity. Study designs could include randomised controlled trials with subgroup analyses, pre-post designs, cross-sectional or longitudinal data analyses.

**Table 2.1: Inclusion/exclusion criteria**

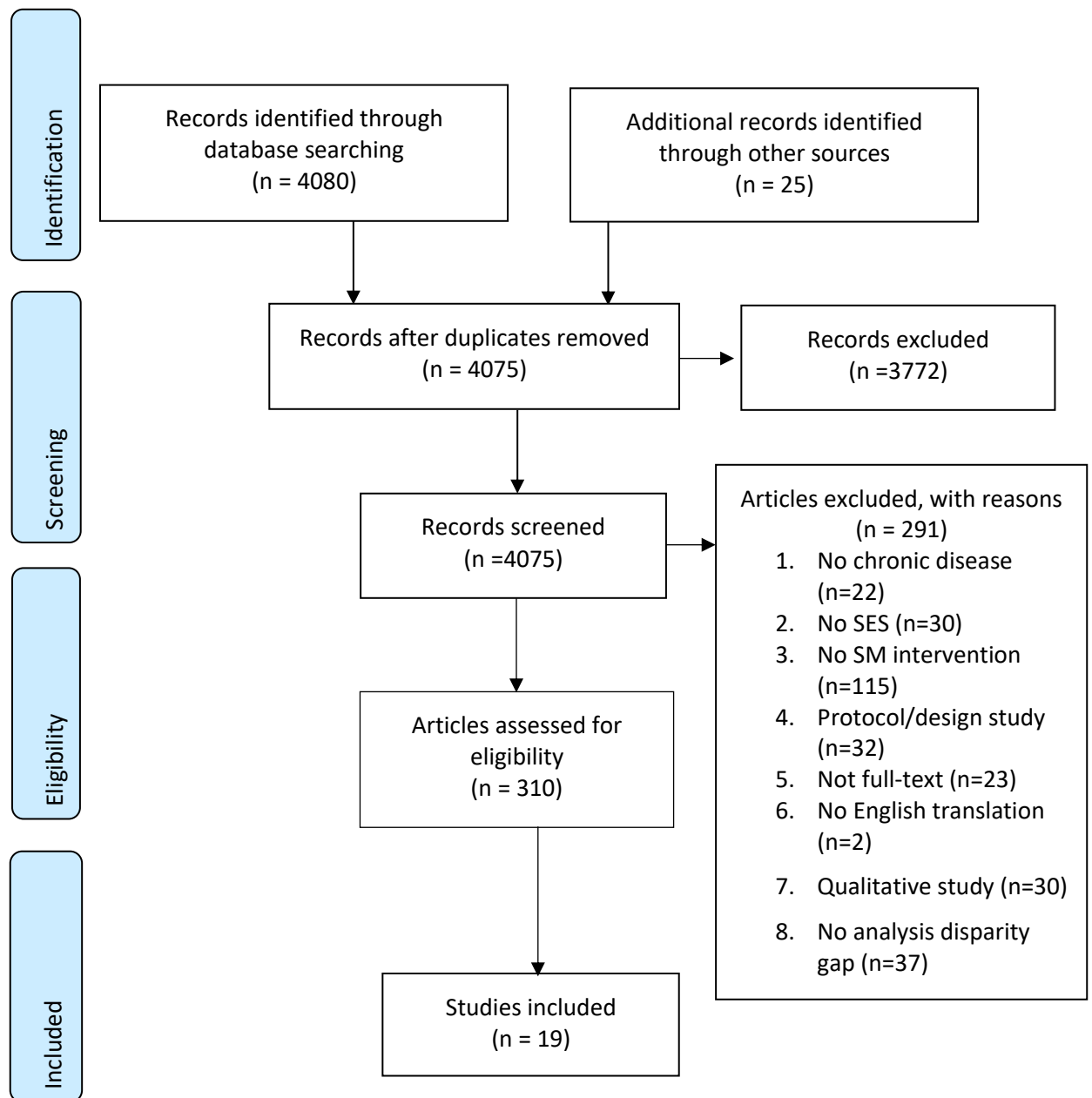
PICO	Inclusion Criteria	Exclusion Criteria
Population	Over 18 years	
	Industrialised countries	
	Diagnosed with diabetes, COPD, cardiovascular disease, chronic musculoskeletal pain and any additional comorbidities	At-risk patients (e.g. prediabetes)
	SES described in terms of education, income, area or occupation.	‘Disadvantaged’ (e.g. ethnic minority) population without quantifiable reference to SES.
Intervention	Includes a self-management support intervention incorporating at least 3 recognised elements of SM <sup>1</sup>	Single-component SMS intervention (e.g. education, medication adherence only).
Comparison	Includes analysis of whether the response to the intervention differs according to SES.	No measurement of SES disparity in reporting of outcomes.
Outcome	Reporting of outcomes which may be clinical, behavioural, psychosocial or related to participation/attrition.	

1. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns*. 2001;48:177-87

### Search outcomes

Title and abstract screening reduced the number of papers to 310. Articles were excluded according to the criteria outlined in table 2.1. Common reasons for exclusion were no SMS intervention (e.g. studies of self-care or adherence behaviours); SES not quantified, and no measurement of SES disparity. A full list of reasons for exclusion of the 291 full-text articles is available in additional file 2. Figure 2.1 illustrates the search process undertaken. One reviewer (RH) completed the initial search and a second reviewer (ES) independently assessed the final papers to ensure agreement on inclusion criteria. Nineteen studies were included in the review.

Figure 2.1: PRISMA diagram



### Data abstraction

The data was summarised on the setting, study design, type of CD, sample size, description of intervention and control, outcomes or variables measured, follow-up time, results and study quality (Table 2.2). Table 2.3 summarises data related specifically to SES and disparity, including the theory behind the SM intervention (or study question for participation/attrition studies), intervention description, SES adaptations made, SES status of population, results in relation to SES, dropout rates and overall impact on SES disparity. Related papers were retrieved to provide additional data about the population or intervention as needed (30-37).

Quality analysis was undertaken using the Joanna Briggs Institute checklists (38) for randomised controlled trials (RCTs) and observational studies, and the Sun/Oxman criteria (27, 28) for subgroup analyses.

### Data synthesis

No meta-analysis was possible due to the diversity of study designs, interventions and outcome variables.

#### **Table 2.2:**

- a) Studies examining disparities in outcomes following SM interventions, stratified by quality.
- b) Studies examining disparities in participation or attrition from SM interventions, stratified by quality

#### **Table 2.3:**

- a) Effects on socioeconomic disparities: Studies examining outcomes following SM interventions, stratified by quality.
- b) Effects on socioeconomic disparities: Studies examining participation or attrition, stratified by quality.

(a) (a) Studies examining disparities in outcomes following SM interventions, stratified by quality<sup>1</sup>

Author <sup>1</sup>	Country and setting	Study design	Chronic Disease	Sample size	Intervention description, healthcare providers (HCPs), SM Components <sup>2</sup>	Control	Outcomes measured	Follow up	Results	Quality rating
Rothman 2004 (Rothman 2005)	USA Public primary care clinics	RCT with subgroup analysis	Diabetes	217	Individual Phone and face-to-face SMS over 12/12 Pharmacist and nurse 1,2,3,5,6,7	Single session with pharmacist	Hb A1c and blood pressure	12/12	HbA1c improved significantly from baseline for both I/C. For higher literacy participants group there was no difference between I/C but those with low literacy had a HbA1c change of -1.4% (adjusted), CI -2.3 to -0.6%, p<0.001, favouring intervention. BP improved in intervention group regardless of literacy, p=0.006	JBI 11/12 S/O 11/11
DeWalt 2012 (DeWalt 2006)	USA Hospital clinics	RCT with subgroup analysis	Chronic heart failure (HF)	605	Individual Education session then phone support for 12/12 Health educators 1,2,3,5,7,8	Single 1-1 education session	All-cause hospitalisation, death, HF hospital admission, HFQOL	12/12	In low-literacy participants adjusted incident rate ratio (IRR) was 0.73 for all-cause hospitalisation and death and 0.48 for HF hospitalisation, favouring intervention; IRR for high literacy was 1.16 for all-cause and 1.34 for HF hospitalisation, favouring control.	JBI 10/12 S/O 11/11
Bosma 2011 (Lamers 2010)	Netherlands Public primary care clinics	RCT with subgroup analysis	Diabetes or COPD with mild to moderate depression.	361	Individual Home-based CBT and SMS for 6/52 Nurses 1,3,4,6,7,8	Usual GP care	Depression primary outcome (Beck Depression Inventory); also health-related quality of life (QOL); control beliefs (mastery); self-efficacy.	9/12	Interaction between education level was significant (p<0.05) or nearing significance (p<0.10) at 3 and 9 months for all outcomes with no benefit for low educated. Clinically significant (>50% improvement) in depression at 9 months for high educated only.	JBI 11/12 S/O 9/11
Moskowitz 2013 (Thom 2013)	USA Public primary care clinics	RCT with subgroup analysis	Diabetes	299	Individual Phone and face-to-face peer support over 6/12 Peer health coaches 1,3,4,5,6,8	Usual GP care	HbA1c	6/12	HbA1c reduced by 1.07% (intervention) vs 0.3% (control), p=0.01. HbA1c decrease was predicted by SM ability and medication adherence. Those with low SM ability benefited most; ethnicity and education did not differentially affect the outcome.	JBI 10/12 S/O 9/11
Powell 2010	USA Hospital clinics	RCT with subgroup analysis	Heart failure	902	Group SMS classes over 12/12 Health professionals 1,2,3,4,5,6 Group 1,2,3,4,5,6,7,8	Education sheets plus phone follow-up Usual care	Death/HF hospitalisation, medication adherence, salt intake, SM ability, cardiac QOL, SF 36, depression. Cardiac QOL (Kansas City Cardiomyopathy Questionnaire)	2.5years 12/12	Depression, self-efficacy and salt intake improved in both intervention and control groups. Low income participants in the control group had a non-significant (p=0.056) trend to earlier cardiac event (death/hospitalisation). Short-term improvement in cardiac QOL in intervention group but not at 6 or 12/12. Lower educated patients improved more than higher educated (p=0.018) throughout the follow-up period.	JBI 11/12 S/O 6/11 JBI 10/12 S/O 7/10
Smeulders 2010 (Smeulders 2006)	Netherlands Hospital clinics	RCT with subgroup analysis	Chronic heart failure	317	Group Stanford CDSMP for 6/52 Nurse and peer leader 1,2,3,4,5,6,7,8	Waitlist	Depression, valuation of life, control beliefs (mastery); self-efficacy, cognitive function.	6/12	Mastery (p=0.01) and Depression (p=0.05) scores improved from baseline in the intervention group at 6/12 (small effect size); subgroup analysis showed improvements in mastery (p<0.05) were limited to the lower educated and those with better cognitive function.	JBI 6/12 S/O 5/11
Jonker 2012	Netherlands Elderly daycare facility	RCT with subgroup analysis	Frail elderly; unspecified chronic disease (mean of 2 CDs)	63 (intervention group)	Group Stanford CDSMP for 6/52 Nurses 1,2,3,4,5,6,7,8	Waitlist	Health behaviour changes, arthritis score, pain/fatigue scores, mastery, depression, self-efficacy.	8/52	Increased frequency of exercise (p<0.001) and relaxation (p=0.05) in intervention group but not for those with depression or perceived low SES.	JBI 5/12 S/O 5/11
Nour 2006	Canada Public community health centres	RCT with subgroup analysis	Arthritis and housebound	58 (intervention group)	Individual Home-based CBT and SMS for 8/52 Allied HCPs 1,3,4,5,6,8	None	Blood pressure, lipids, exercise tolerance, BMI, depression, adherence.	3/12	Outcomes improved significantly p<0.05 across all education and income levels. Adherence and attendance similar across all groups. Baseline measures were significantly lower in low educated.	JBI 9/11
Govil 2009	USA Insurance funded clinics	Cohort study	Cardiovascular disease	785	Individual and group 3/12 lifestyle programme Range of HCPs 1,3,4,5,6,7,8					

1. Studies listed in order of quality as measured by Johanna Briggs Institute (JBI) criteria (38) and Sun/Oxman (S/O) subgroup analysis (for RCTs) criteria (27, 28). RCTs listed first, followed by cohort studies.

2. Includes additional studies from the same research group where supplementary information was obtained.

3. Numbers correspond to the key components of self-management interventions as listed by Barlow et al (Barlow): 1. Information 2. Drug management 3. Symptom management 4. Psychological management 5. Lifestyle management 6. Social support

7. Communication 8. Other (action planning, goal setting, decision making, problem solving, spirituality).



### (b) Studies examining disparities in participation or attrition from SM interventions, stratified by quality<sup>1</sup>

Author <sup>2</sup>	Country and setting	Study Design	Chronic Disease	Sample size (intervention group)	Intervention	Variables measured	Results	Quality rating
Podaval 2018 (Murray 2017)	UK Urban public primary care practices	Subgroup analysis of RCT	Diabetes	299	Comparing 2 internet SM programmes +/- support	Gender, age, ethnicity, education.	No difference in frequency of programme use or registration according to any demographic predictors. User characteristics were reflective of the overall target population of the area.	JB1 12/12 S/O 10/11
Thorn 2011 (Day 2010)	USA Rural public primary care practices	Subgroup analysis of RCT	Chronic pain	109	Predictors of use Low-literacy pain SM (education and CBT) groups.	Demographics, literacy, pain catastrophising, disability, depression, QOL, pain intensity/interference.	Dropout before programme started was associated with low education ( $p<0.02$ ), low literacy ( $p<0.05$ ) and catastrophising ( $p<0.01$ ); failure to complete programme associated with income (under/over \$13000 – $p<0.01$ ) and low education ( $p<0.02$ ).	JB1 12/12 S/O 9/11
Dattalo 2012 (Boult 2011)	USA Primary care (both insured and public patients)	Subgroup analysis of RCT	Multimorbid chronic disease	241	Stanford CDSMP Completion predictors	Demographics, health status, health activities, patient activation, patient-rated quality of care.	22.8% of eligible adults completed (attended at least 5 of 6 sessions). Attendance was associated with dissatisfaction with GP (OR=2.8) and having higher SF-36 physical health scores (OR=2.3). Age, sex, education, race and SES were not significant.	JB1 11/12 S/O 5/11
Cauch-Dudek 2014	Canada National database analysis	Cohort	Diabetes –first 8/12 post diagnosis	46553	Any type of DSME Participation predictors	Age, sex, immigrant status, comorbidity, mental illness, rural residence, SES	22% of people attended DSME within 8/12 of diagnosis. Non- attendance was associated with older age, lower SES, recent immigration or physical/mental health comorbidity (all $p<0.001$ ).	JB1 10/11
Adjei-Boakye 2018	USA National telephone survey	Cross-sectional	Diabetes	84179	Any type of diabetes SM education (DSME) Participation predictors	Race, education, marital status, income, sex, health insurance, BMI, insulin use, self-care behaviour.	53.7% reported attending DSME, with attendance less likely amongst men (adjusted OR=0.85), Hispanics (aOR=0.81), high school only (aOR=0.71) or less than high school educated (aOR=0.51), income <\$15000 (aOR=0.70) or <\$25000 (aOR=0.81) and the uninsured (aOR=0.87). Attending DSME was significantly associated with adherence to SM behaviours.	JB1 8/8
Glasgow 2018	USA Database analysis (health insurance organisation)	Cross-sectional	Diabetes	2603	Internet SM programme Participation predictors	Socio-demographics, reason for declining service, HbA1c BP, BMI, lipids, SF36, ADL, number of comorbidities	Participants were likely to be younger ( $p=0.041$ ); not Latino ( $p=0.002$ ); earning >\$30,000 ( $p<0.0001$ ), greater than high school educated ( $p<0.0001$ ), non-smokers ( $p<0.0001$ ) with lower blood pressure ( $p=0.028$ ). Self-selected participants were the most likely to be white, better educated and healthier.	JB1 8/8
Horrell 2017	USA National database analysis	Cross-sectional	Multimorbid chronic disease	19365	Stanford CDSMP Participation and completion predictors	Enrolment and completion of CDSMP compared to high/low SES area	83.6% of participants lived in the least impoverished areas (<25% of population below poverty line) and 0.3% of participants lived in the most impoverished areas (>50% below poverty line). SE area was significantly correlated with ethnicity and education level. Course completion was not associated with SES – poorer people had a higher (but non-significant) completion rate.	JB1 8/8
Hardman 2018	Australia Rural community health centre	Cross-sectional	Chronic pain	186	Tailored pain SM Drop-out predictors	Demographics, self-efficacy, pain catastrophising, opioid dose, comorbidities.	Early dropout associated with social stressors ( $p=0.002/0.029$ , OR=0.08/0.30); pain causal beliefs ( $p=0.005$ , OR=5.01) and pain catastrophising ( $p=0.048$ , OR=1.03) Low income significant in bivariate analysis ( $p=0.011$ ) only.	JB1 8/8
Kure-Beigel 2016	Denmark Urban community health centre	Mixed-Cross-sectional + qualitative	Diabetes, COPD or CVD	104	Tailored SMS Drop-out predictors	Education, age, gender, cohabitation, whether 1 <sup>st</sup> meeting cancelled.	Non-completion associated with younger age (below 60) ( $p=0.03$ , OR=3.38). Non-significant trend of lower education associated with lack of completion. Qualitative study suggested comorbidity and low job control in low educated were factors.	JB1 8/8
Santorelli 2017	USA State-wide telephone survey (New Jersey)	Cross-sectional	Diabetes	4358	Any type of DSME Participation predictors	Age, sex, race, income.	42% reported attending DSME, with attendance less likely amongst lower educated (high school or less), Hispanic or 'other' ethnicity, those diagnosed under 2 years ago (all $p<0.001$ ); the uninsured ( $p<0.004$ ) and those without a HCP visit for diabetes in the past year ( $p<0.002$ ). DSME attendance was not correlated to the number of certified DSME courses available in the area.	JB1 6/8

1. Studies listed in order of quality as measured by Johanna Briggs Institute (JB1) criteria (38) and Sun/Oxman (S/O) subgroup analysis (for RCTs) criteria (27, 28). RCTs listed first, followed by cohort and cross-sectional studies.
2. Includes additional studies from the same research group where supplementary information was obtained.

(a) Effects on socioeconomic disparities: Studies examining outcomes from SM interventions, stratified by quality.

Study	Theory behind intervention	Individual or group?	Intensity and duration	SES adaptations made (if any)	Demographics and SES status of population <sup>1</sup>	SES subgroup Comparison	Results (in terms of SES only)	Dropout by group and SES	Impact on disparity
Rothman 2004	CDSM in low SES groups is best managed by a multidisciplinary approach that is tailored to the patient's needs and barriers.	Individual	2-4 phone or direct contacts a month (mean 38min/month) over 12/12	Literacy adaptations, practical help to address barriers	Age: 56y mean Sex: 42%M Race: 67%EM Edu: 62%<12yrs Income: 74%<\$20000 Literacy: 38%<6th grade <sup>3</sup>	Literacy – above/below 6th grade. Correlated to education, income and insurance status.	Significant HbA1c improvement with intervention for low literacy group only; high literacy group did not differ between I/C.	Dropout low both before (study refusals) and during intervention; no difference for I/C or SES.	Reduced
De Walt 2012	People with low literacy have knowledge deficits. SMS should be adapted for their needs and provide ongoing support until mastery is achieved.	Individual	Education session + ongoing phone support for 12/12 (mean 14 calls)	Literacy adapted, intervention length varied depending on need.	Age: 60y mean Sex: 52% M Race: 61% EM <sup>2</sup> Edu: 26%<12yr Income: 68%<\$25000 Literacy: 41% <sup>3</sup> low	Literacy (S-TOFHUA). Education and subjective SES also assessed in subgroups but were weaker predictors than literacy.	Phone support more effective in low literacy group, control intervention (education session) favoured high literacy. Literacy was a stronger predictor than education/income.	Dropout equal for I/C groups and did not differ by literacy.	Reduced
Bosma 2010	SMS is focussed on increasing control and returning responsibility to the patient	Individual	2-10x1hr face-to-face sessions (mean 4) for 6/52	Extra sessions if needed	Age: 70y mean Sex: 49% M Edu: 33% primary only	Education level (primary; some high school; completed high school).	No benefit for low educated. Gains only in higher educated groups.	Increased dropout from intervention in low educated.	Increased
Moskowitz 2013	Low SES patients have more challenges with SM and need assistance with literacy, depression and social support.	Individual	0-29 phone or direct contacts (median 5) over 6/12	Patients choose own coach, language and ethnicity catered for	Age: 56y mean Sex: 49%M Race: 55% EM Edu: 36%<12yr	Education (less than high school; high school; some college; college degree).	Benefit for those with low medication adherence and SM ability. Education level did not affect outcome.	Dropout low both before (study refusals) and during intervention; no difference for I/C or SES.	No change
Powell 2010	SMS groups aim to motivate people to participate in their care by teaching SM skills.	Group	18x2hr over 12/12	No	Age: 63y mean Sex: 53%M Race: 40% EM Edu: 44%<12yr Income: 52%<\$30000	Education (high school or less; above high school) and income (above/below \$30000)	No improvement overall but low-income patients in intervention group had non-significant improvement on one outcome.	Dropout high both before and during intervention (in intervention group only); not reported by SES.	No change (n.s.reduction)
Smeulders 2010	The CDSMP aims to increase patient responsibility for SM by increasing self-efficacy.	Group	6x2.5hr over 6/52	No	Age: 67y mean Sex: 72% M Edu: 64%<12yr	Education (under or over 12 yr education).	Low educated improved more than high educated in cardiac QOL outcomes.	Dropout high before intervention (study refusals) but no difference during intervention between I/C.	Reduced
Jonker 2012	SMS works by increasing self-efficacy and improving one's control over life and health.	Group	6x2.5hr over 6/52	No	Age: 82y mean Sex: 10%M Edu: 50%≤9yr	Education (over/under 9 years)	Lower educated improved on mastery (p<0.05) but no other benefits from multiple outcomes.	Low dropout rate (but programme part of day-care centre activities).	Reduced (one outcome)
Nour 2006	Arthritis SM is achieved by increasing knowledge and adopting health behaviours.	Individual	6-7x1hr over 8/52	No	Age: 77y mean Sex: 10%M Edu: 47%<9yr Perceived SES: 12% 'financially insecure'	Education (over/under 9 years) and perceived SES	Overall minor gains, but not for those with depression or perceived low SES.	Low dropout rate	Increased
Govil 2009	SMS aims to make lifestyle changes and improve health habits.	Both	104hr over 3/12 (4hr, 2x/week)	No	Age: 60y mean Sex: 67%M Race: 5% EM Edu: 4%<12yr Income: 22%<\$25000	Education (high school or less; some college; college degree; postgrad degree).	All benefited equally – no difference across education levels, although lower educated had lower baseline measures.	High attendance, low dropout, unrelated to SES	No change

**(b) Effects on socioeconomic disparities: Studies examining participation and attrition, stratified by quality.**

Study	Study question	Outcome	Intervention Description	SES adaptations made (if any)	SES status of population	Results (in terms of SES)	Impact on disparity
Podualv 2018	Can a DSME internet intervention engage people of differing demographics without increasing health inequity?	Use (more than 2 log-ins post registration)	Internet SM programme + email/text support and assistance to register and access site	Low literacy, developed with input from target population	Age: 58y mean Sex: 55.5%M Race: 55%EM Edu: 30%<12yr	No difference in use according to education. Users were reflective of the target population (inner London).	No change
Thorn 2011	Is pain SMS (CBT or education) effective in low SES groups and what are the predictors of engagement?	Initial participation and dropout	SMS groups CBT and education for 10x1.5hr over 10/52	Literacy adaptations and teaching	Age: 53y mean Sex: 20%M Race: 79%EM Income: 86%<\$30000 Literacy score: mean 21% (50% is population mean)	Non-attendance associated with low education, literacy and income; dropout associated with low income.	Increased
Dattalo 2012	Which subgroups of multimorbid older adults are most likely to attend CDSMPs?	Completion (attend 5 or more sessions)	Stanford CDSMP 6x2.5 hours	None	Age: 67-95yr Sex: 43%M Race: 51.8%EM Edu: 24%<12yr	No effect of SES variables on course completion	No change.
Cauch-Dudek 2014	Are there disparities in utilisation of DSME soon after diagnosis?	Initial participation	Certified public health DSME programmes	Unspecified (multiple programmes)	Other SES: 42% 'financial strain' All diabetics in Ontario, Canada diagnosed from Jan-June 2006 and followed up for 8/12.	Low SES area associated with increase in non-attendance, p<0.001.	Increased
Adjei Boakye 2018	Are there are subgroups who do not participate in diabetes SM education (DSME)?	Initial participation	Diabetes SM education (DSME) - unspecified	Unspecified (multiple programmes)	Cross section of US population with diabetes	Non-participation associated with low education and low income; association stronger as education/income reduced.	Increased
Glasgow 2018	How representative of the diabetes population are those who participate or volunteer for an internet DSME study?	Initial participation	Internet DSME programme +/- support (phone calls and groups)	Available in 2 languages, no specific SES adaptation	Age: 58y mean Sex: 50%M Race: 31%EM Edu: 34%≤12yrs Income: 29%<\$30000	Higher income and education increased chance of participation, especially for self-selected people	Increased
Horrell 2017	Do those in low income areas attend CDSMPs and how can we promote higher enrolment?	Initial participation and completion	Stanford CDSMP 6x2.5 hours	None	USA attendees of CDSMP courses Age: 58y mean 83.6% of attendees lived in the least impoverished areas.	Lowest SE area was associated with low participation (0.3% of participants) but not with low completion.	Increased (participation) No change (completion)
Hardman 2018	Do the social determinants of health affect engagement with pain SMS programmes?	Dropout (attend 3 or less sessions)	CBT-informed tailored SMS, individual or group	Programme tailored to preference/need	Age: 55y mean Sex: 42%M Income: 82% on welfare benefit Other SES: 27% 'social stressor'	Income not significant post-regression but social stressors (substance abuse history, victim of abuse/assault) significantly associated with dropout.	Increased
Kure-Beigel 2016	Is there a social difference between those who do and don't complete SMS programmes?	Course completion	Tailored SMS individual or group over 6-12 weeks	Programme tailored to preference/need	Age: 78%>60yrs Sex: 50%M Edu: 57%<high school graduate	Education not significant post-regression but qualitative interviews suggested social factors (job/carer demands) were important.	No change - suggestive of increase
Santorelli 2017	What determines DSME participation and is it affected by the availability of DSME services?	Initial participation	DSME - unspecified type.	Unspecified (multiple programmes)	Survey sample of people living in New Jersey with diabetes	Lack of participation correlated with low education and ethnicity (p<0.001) but not with income.	Increased
4.	Population SES status terms have been structured to maximise comparability between papers.						
5.	EM= ethnic minority						
6.	Literacy was used as an SES measure where it was clearly correlated with education and income.						

## 2.4 Results

### Key study characteristics

Nineteen studies were identified, all published in English. Five studies looked at participation in SMS; five studied attrition from SMS programmes and nine assessed outcomes from SMS interventions. Interventions were very diverse, ranging from studies of the group-based Stanford Chronic Disease Self-Management Programme (CDSMP – 4 studies) to highly tailored 1-1 interventions. Table 2.2 details the main features of all studies.

### Methodological quality

Most studies were of moderate to good quality although two RCTs (39, 40) and three subgroup analyses (39-41) rated poorly. A summary of quality ratings is included in table 2.2 and a detailed table describing how each study was assessed is available in additional file 3.

### Responses to study questions

1. Is there evidence that SES influences participation rates in SMS interventions?

Four cross-sectional studies and one cohort study looked at initial participation in SMS programmes. All were large population surveys ranging from 2,600 to 80,000 people. There were three reports on diabetes SMS education programmes (42-44), one on the Stanford CDSMP (45) and the final study examined recruitment to an internet diabetes SMS programme (46). In all studies, low SES (as measured by education, income or location) was significantly and consistently associated with lower levels of participation, suggesting that disparity in CDSM starts here. Some studies (43, 45) suggested that this imbalance was related to course

availability, cost or marketing strategies. However, the studies which did match attendance to course availability and cost (42, 44) found that this did not influence participation in the low SES population. Glasgow (46) also compared participation rates in a self-selected (via media advertising) population to a referred population and found even greater disparity. As well as being of higher SES, the self-selected participants were those at lowest risk and least in need of the intervention.

There is consistent evidence that low SES is associated with lower levels of participation in SMS interventions, and some evidence that this is unrelated to access to SMS interventions.

## 2. Is there evidence that SES influences rates of retention or dropout from SMS interventions?

Five studies examined attrition: two cross-sectional studies and three RCTs with subgroup analysis, with sample sizes from 100-300. Two RCTs (41, 47) were of more advantaged populations. Of these, one reported low (22.8%) completion rates of the Stanford CDSMP (41), but predictors were related to poor physical health rather than SES. Since this was a high-risk multimorbid rather than a low SES population, dropout likely reflects increased treatment burden, as noted in other multimorbid populations (48). The second study (47), of a diverse urban population, reported no difference in use of a supported internet programme in terms of SES (education). This intervention had been carefully tailored to maximise engagement across population groups and included extensive community involvement in the design process. Three studies (49-51) focussed on low SES populations. Two cross-sectional studies (49, 50) reported that dropout rates correlated to social stressors and lack of job flexibility, suggesting that attrition within a low SES population may be influenced by socioeconomic factors that are not captured by education or income alone. Finally, a small RCT (51) of a tailored group programme found that high levels of dropout were significantly associated with low income and education.

By contrast, Horrell et al (45) noted that although SES area predicted enrolment in the Stanford CDSMP, it did not affect rates of completion.

SES is not consistently associated with dropout from SMS interventions. SES may be one of a number of factors associated with programme attrition, as suggested by qualitative studies on this topic (52).

3: Is there evidence that SES affects clinical, behavioural or other specified outcomes following SMS interventions?

Nine studies looked at outcomes following SMS interventions, with four describing group interventions (including 2 of the Stanford CDSMP) and five individual (1-1) interventions. Only two of the RCTs (53, 54) were sufficiently powered for subgroup analysis and most had follow-up periods of six months or less.

Three of the nine studies featured outlier populations (in terms of age, sex and/or level of disadvantage), including the two lower-quality studies (39, 40) and the cohort study (55). The findings from these studies may not be reliable or relevant to the wider low SES population.

The remaining six studies, of moderate to high quality, described broadly similar populations in terms of age, sex, education and income. Of these studies, one reported increased disparity following the intervention; two reported no change; and three studies reported a reduction in SES disparity.

Three of the studies, all individual interventions, described programmes specifically tailored for low SES groups, including extra supports and literacy adaptations. These included a 6-month peer support programme (56) and two 12-month phone support programmes (53, 57) (conducted by the same research group, but with different chronic diseases and interventions).

All studies reported clinically and statistically significant changes in either hospitalisation rates

(53) or HbA1c (56, 57) in favour of the intervention. Two of the studies also reported a reduction in SES disparity from the intervention, with low-literacy patients experiencing greater benefit from the intervention than their higher literacy counterparts. In an already low-SES population, this was found to be a stronger predictor than income or education. The third study (the peer support programme) reported no change in disparity, with benefits across all education levels and the greatest benefit experienced by those with poorer medication adherence and self-management ability.

The remaining studies – comprising one individual and two group interventions – did not provide specific tailoring for low SES participants. The individual intervention (58), a 6-week CBT programme designed to increase self-efficacy, found clinically significant improvements in depression only in the higher educated, with no change and higher rates of dropout in the lower educated. The group interventions, which were both for people with heart failure, included the 6-week CDSMP and a year-long SMS group programme. The CDSMP study did show short-term benefits as compared to usual care, but no overall gains at 6 or 12 months. The lower educated patients did better than their higher educated counterparts in terms of cardiac quality of life (QOL) ( $p=0.018$ ) over 12 months, suggesting a reduction in SES disparity, although it was not clear whether this was clinically significant. The second group programme (54) used an active education control and found no additional benefit from an SMS group. Low-income participants receiving the intervention did have a longer time to cardiac event (death or hospitalisation), but this was not statistically significant. Overall there was no change in SES disparity, nor any added benefit from the intervention.

There is limited evidence to suggest that SES does affect outcomes following SMS interventions. Interventions that were tailored for low SES participants reported significant improvements in clinical outcomes, which in some cases also included a reduction in SES disparity following the intervention.

## 2.5 Discussion

### Main findings

This systematic review of disparities related to SMS interventions has reinforced observations (18-20, 22, 25) that there is a lack of research in this area. Although many studies of low SES groups have been undertaken, very few have focused on whether the outcomes compare favourably to those in higher SES groups. There are practical and statistical challenges in comparing population subgroups. Many studies had SES groupings that were fairly homogenous, limiting the ability to compare outcomes within the analysis, and almost all subgroup analyses were insufficiently powered. Larger studies and co-operation between different study populations are needed so that there is a more distinct contrast between SES levels across groups.

### Responses to study questions

#### 1. Is there evidence that SES influences participation rates in SMS interventions?

This review confirms that low SES groups are significantly less likely to participate in SMS interventions (42-46). Thus, healthcare disparity is increasing before an intervention even commences. In order to reach those who need the intervention, targeted recruitment and retention strategies will be needed. Self-selection runs the risk of spending limited resources on those who need them least (46).

#### 2. Is there evidence that SES influences rates of retention or dropout from SMS interventions?

The findings in relation to retention and dropout are less clear-cut, with few studies and small sample sizes. Social factors do appear to be important (49-51), although a simple measure of SES may not capture the barriers to engagement.



3: Is there evidence that SES affects clinical, behavioural or other specified outcomes following SMS interventions?

With the limited number of high-quality studies available, there was some evidence that SES does affect outcomes following SMS interventions, depending on the type of intervention on offer. No trends were observed in terms of the SM components, which varied little between studies, or the type of service providers involved.

Programme structure (group or individual) did seem to affect both dropout rates and outcomes, with fewer benefits observed in the group interventions. In the few programmes that recorded dropout by SES, it appeared that attrition was also greater from group programmes (see Table 2.3). High rates of dropout from group programmes have been reported in several reviews of CD interventions in low SES and other vulnerable groups (21, 59), while other reviews (13, 60, 61) have noted that individually tailored interventions appear to reduce disparity. Other authors have noted that although group programmes provide beneficial social support and peer modelling (5), they can also present many barriers to a low SES population who may have less flexibility in terms of work, transport or caring demands (21, 59). In the current review, interventions over longer time periods (6-12 months) also seemed to be more effective at reducing disparity (53, 56, 57), consistent with a CD review on similar populations (13).

### Interpretation of findings

#### 1. 'Low SES' is a heterogeneous group

This review suggests that SMS interventions may impact differently on low SES populations, and that more individualised treatment over longer time periods may be needed. Some writers have suggested that SES could be used as a 'high risk' predictor to identify those needing an earlier or more intensive intervention (23, 62), although this encompasses a large population group and

has significant resource implications, emphasising the need for appropriate targeting of interventions.

Data from the current review indicates that low SES groups are heterogeneous, with additional factors such as literacy, social stressors and social capital influencing SM ability, engagement, health outcomes (49, 50, 53, 57) and thus disparity. Therefore, some low SES groups may benefit simply from better marketing of and access to generic SM courses (45) and lower-level interventions, while others will require a more intensive, tailored approach. The ability to accurately identify these groups, perhaps by using a triage instrument, could lead to more effective resource allocation, increased participation and better outcomes in terms of both efficacy and equity.

## 2. Are self-management mechanisms different in low SES populations?

Few studies reviewed described the theory behind the proposed SMS intervention, as noted in other reviews of SMS (12, 63), although several referred to the role of self-efficacy (40, 54, 58, 64), as described in Bandura's social-cognitive theory (4, 5). The studies which targeted a low SES or otherwise diverse population did note particular challenges for disadvantaged groups in terms of knowledge or literacy (47, 53, 56, 57), and those which adapted to these challenges often had better outcomes. In contrast, 'one size fits all' programmes (45, 46, 54, 58) had fewer benefits, and in some cases increased disparity.

SMS approaches informed only by self-efficacy have been criticised as overly individualistic (10, 11, 15) and it has been observed that the relationship between self-efficacy and self-management ability is weaker in vulnerable groups (65), indicating that other barriers play an important part. Furthermore, since the development of self-efficacy depends both on one's behaviour and on social/environmental feedback (66), several authors (11, 58) have suggested that increasing self-efficacy may be harder if environmental feedback (e.g. job or housing insecurity) negates a belief in control over one's circumstances.

### 3. What other factors are important for self-management in low SES groups?

This suggests that for SMS interventions to be effective in low SES populations, attention should be paid to other factors that influence self-management ability. Health provider/system issues (67, 68); resources (literacy, financial, job/carer demands) (67, 69-71); and condition demands (multimorbidity, treatment burden) (48, 71, 72) have been consistently identified in qualitative reviews as barriers to self-management. Each of these factors will impact disproportionately on a low SES population. Health providers/systems can be less accessible due to cost, literacy levels and a limited understanding of the social determinants of health by providers (67, 68). Although few studies of SM in disadvantaged populations look at interventions at the health provider/system level (18, 21), it would seem a potentially effective way to reduce disparity without increasing the patient's treatment burden.

Barriers related to resources and condition demands are far greater for the low SES population (73-75), who have fewer financial and social resources; higher levels of overall social complexity (job/housing insecurity, family demands, trauma history (3)); and higher rates of multimorbidity at earlier ages (76). They experience both more disease-related workload (treatment burden) and non-disease workload (life burden) (73, 77). Unfortunately, many SMS interventions, especially those requiring regular attendances or homework, will increase workload. Approaches that reduce patient workload or increase access to resources are rarely tried, but are likely to be important in low SES groups (73). Phone consultations, problem-solving of specific barriers, integrating healthcare with social services and directing interventions toward healthcare practitioners rather than individual patients can all reduce treatment burden and maximise resources. Coventry (76), in a qualitative study of SM and multimorbidity, identifies three factors required for engagement in SM: capacity (resources, knowledge and energy); responsibility (shared understanding between the patient and provider about how to manage the treatment workload) and motivation. All three are negatively impacted by low SES, yet many SMS

interventions (10) aim to increase motivation without recognising responsibility or capacity, and thus may contribute to increasing disparity in low SES groups.

### **Strengths and limitations**

This review identifies important gaps in knowledge and potential directions for future research. It reveals the assumptions informing SMS approaches and the inadequacy of using 'low SES' to define a population group. The study limitations include the lack of published research on disparity in SM interventions. It was difficult to conduct a comprehensive literature search of this topic because many subgroup analyses were a relatively small part of the overall paper. It is possible that some studies were missed that may have provided useful data. Meta-analysis was not possible due to the variety of studies available; therefore, no strong conclusions can be formed. In addition, the methodology of many of the studies prohibited causal inference: several studies were cross-sectional and most subgroup analyses were underpowered or did not formulate a priori hypotheses.

### **Conclusion**

This review has identified several important themes in relation to self-management and socioeconomic disparity. First and most obviously, there is a great need for equity considerations to be included in CD studies, as advocated by Cochrane reviewers (22, 25). Given the strength of evidence available about social determinants of health, it should be possible to establish a priori hypotheses and sample sizes sufficient for subgroup analysis (including the availability of relevant comparator groups) for many interventions.

Secondly, any intervention in a low SES or otherwise disadvantaged group should consider its theoretical basis. Social-contextual approaches, rather than self-efficacy approaches, may be

more effective. Paying greater attention to the large and consistent body of qualitative studies on barriers to SM can provide both theoretical and practical guidance as to interventions that can address disparity. Approaches such as the Cumulative Complexity Model (77), which is founded on patient burden-capacity balance, have much to offer.

Finally, levels of disadvantage vary, and there is a need for risk identification within the low SES population. For many people, improving access to simple SM interventions (e.g. assistance with childcare or transport, free programmes at community locations) may be all that is needed. For others – especially those with multimorbidity, poor literacy or social complexity – an individually tailored approach will be needed to be effective. Research to develop a risk assessment system may ensure that those most in need receive the greatest support as opposed to the current situation.

### **List of abbreviations**

SES: socioeconomic status; SMS: self-management support; SM: self-management; CD: chronic disease; CVD: cardiovascular disease; MSK: musculoskeletal; COPD: chronic obstructive pulmonary disease; RCTs: randomised controlled trials; CDSMP: chronic disease self-management programme; DSME: diabetes self-management education.

### **Declarations**

**Ethics approval and consent to participate:** Not applicable

**Consent for publication:** Not applicable

**Availability of data and material:** Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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## CHAPTER THREE:

### The Cumulative Complexity Model

#### **3.1 Systematic review implications**

At the conclusion of my systematic review, I stressed the importance of considering the theoretical basis for self-management interventions. Noting that many current SMS interventions were grounded in self-efficacy theory, I suggested that interventions in low SES groups may need to focus more on context – looking at what the surrounding environment is, rather than just how the individual reacts in that environment. I also noted that ‘low SES’ is a very broad term describing a diverse population, not all of whom are necessarily at risk of poor health outcomes.

Trying to address the enormous range of factors that might compromise one’s healthcare can be both overwhelming and incoherent. I found that the Cumulative Complexity Model(1) (CuCoM) offered an alternative theoretical basis to make sense of these issues, and chose to use this approach to guide my subsequent research.

#### **3.2 What is the Cumulative Complexity Model?**

The model takes as its starting point that there are many contextual influences on health outcomes, including individual, social, environmental and treatment factors(1, 2). These

elements interact with each other to either promote or detract from a desired health outcome. However, without a systematic approach to analyse the different contributors, devising alternative care delivery approaches is difficult. Rather than listing all possible factors, Shippee et al(1) proposed two categories, based on how each contributor affects patient care and ability to interact with the health system.

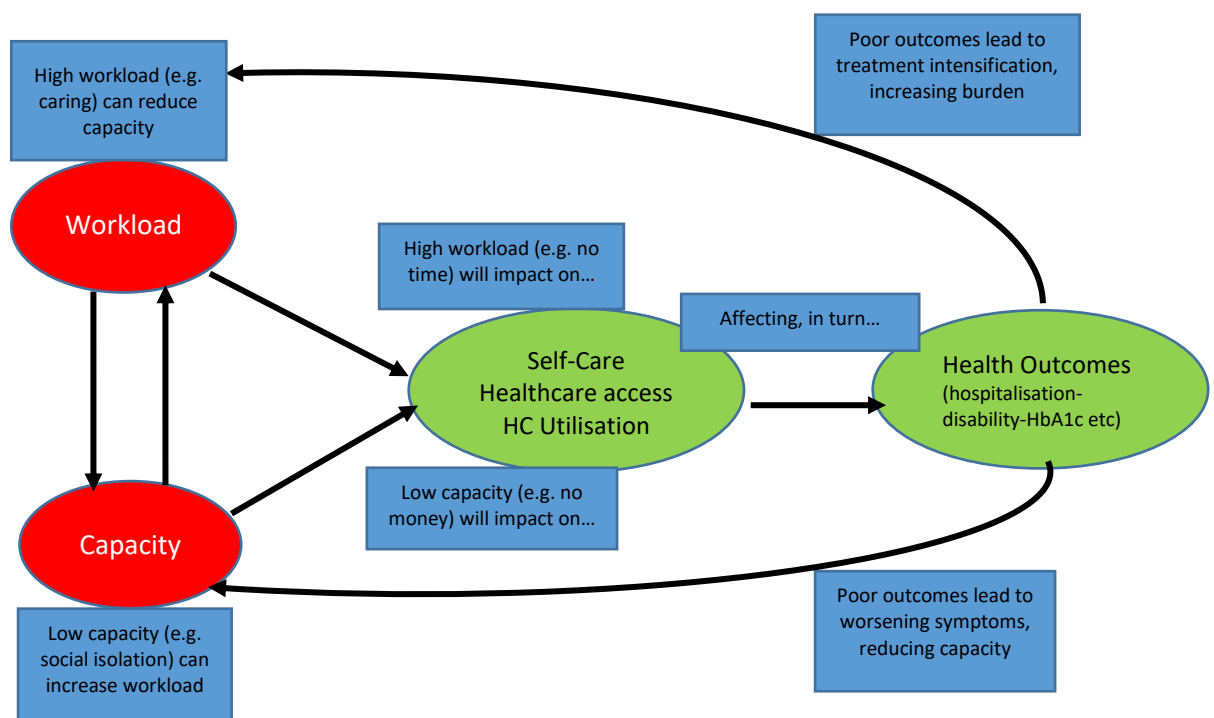
1. Workload: Demands experienced by the patient – both the requirements of treatment (e.g. medication adherence, self-care, attending appointments, lifestyle changes, self-education, completing paperwork) and everyday life (e.g. job, family/domestic, childcare, transport, other priorities).
2. Capacity: Ability to handle the work in terms of capabilities or resources. This includes social support, socioeconomic resources, literacy, resilience, attitudes/beliefs, and level of mental/physical functioning (impact of depression, fatigue, pain, insomnia, other somatic symptoms, stress).

The model posits that patient care becomes disrupted due to capacity-workload imbalance: specifically, when capacity is insufficient to meet the required workload. Even a very high workload can be managed with sufficient capacity, whilst low capacity (e.g. a person experiencing homelessness and mental illness) will impact on even the simplest workload. Imbalance can lead to neglect of treatment and self-management tasks, potentially worsening the health condition. Feedback loops result because a worsening condition may reduce capacity (e.g. due to increased pain or fatigue) whilst simultaneously increasing workload (e.g. requiring more appointments or treatment interventions). Complexity therefore becomes cumulative. This is illustrated in figure 3.1.

The CuCoM was developed in recognition that multimorbidity, and the social and environmental factors that affect healthcare, are not explained or integrated in a way that can provide direction for research or the development of innovative models of care(1). The model fits well with the

population I am researching because it embraces multimorbidity and is highly relevant to low SES groups, who experience capacity deficits in terms of material resources, literacy, and education.

**Figure 3.1: The Cumulative Complexity Model**



### 3.3 Current research incorporating the Cumulative Complexity Model

Using the lens of workload and capacity to look at chronic disease care means a focus on the individual patient rather than the healthcare system. The model also recognises that workload and capacity can be matters of perception rather than hard facts, thus privileging the patient experience. Much of the research in this area has therefore been qualitative explorations of the

patient experience(3-6). This research has generated coding frameworks through which burden and capacity can be analysed(3, 7, 8), and which I have continued to use in my research.

Additionally, there has been cross-fertilisation between the CuCoM and research into treatment burden(9-12). As noted in chapter one, there is an increased awareness of the healthcare workload generated by multimorbidity. This has led to a growing literature on treatment burden. Treatment burden is defined as the specific tasks of healthcare (medication, appointments etc.) and the impact on one's daily life, including work, social and caring responsibilities(9, 13). Thus, it incorporates both aspects of the 'workload' category originally defined by Shippee et al(1). and these terms are often used interchangeably.

Finally, the CuCoM has implications for clinical practice. If the problem is burden-capacity imbalance, the solution is to reduce burden and/or increase capacity. These aims correspond closely to that advocated by Minimally Disruptive Medicine (MDM), which is ...

"...a patient-centered approach to care that focuses on achieving patient goals for life and health while imposing the smallest possible treatment burden on patients' lives."(14)

Although the ideas behind MDM predate the Cumulative Complexity Model(15), MDM has become an approach to healthcare delivery that uses the CuCoM to structure interventions, by initially assessing burden and capacity levels, and selecting treatments based on whether they reduce burden and/or increase capacity(14, 16, 17). The emphasis is on aligning the right treatment (compatible with burden and capacity levels) with the right person (concordant with patient values and preferences). This means identifying what is wanted and needed, but also a willingness to discard what is not wanted or needed.

There are well-developed conceptual frameworks and 'toolkits' for MDM(16, 18), but as yet there have been few trials to establish efficacy or pinpoint barriers to implementation(14, 16).

### 3.4 How this model has informed my thesis

Current research on burden, capacity and complexity has been dominated by patient studies, often in secondary care populations (e.g. stroke, dialysis)(4, 8, 10, 19). Although I acknowledged the primacy of the patient experience, I was interested in how health providers viewed the concepts of burden and capacity as well, since this had not been well explored. Understanding the perceptions and opinions of health providers would also be vital for any future intervention. Additionally, I wanted to see how this model might fit with primary care, socially disadvantaged populations.

I was also keen to explore how self-management and SMS (as opposed to medical management) contributed to perceived capacity and burden. Potentially, effective self-management could build capacity, but it could also increase burden. Therefore, my qualitative study focus was on clinicians who provided SMS, and patients who received it.

My first two qualitative papers (chapters four and five) explore the understanding (for health providers) and experience (for patients) of burden and capacity, and the influence of multimorbidity and poverty. Since I wished to compare my research with literature that has already been produced, I also used a framework method that has been utilised in previous studies: Normalisation Process Theory to analyse burden(8, 9), and the Theory of Patient Capacity to analyse capacity(3).

My third qualitative paper (chapter six) takes a different route. Instead of focussing on the CuCoM, it revisits the current basis of SMS – that of self-efficacy theory. It argues that this approach may be less helpful in populations experiencing cumulative complexity and reiterates the importance of context and environment in any SMS intervention.



The cross-sectional paper (chapter seven) returns to the CuCoM by analysing the relationships between different elements of capacity, and treatment burden. Finally, my protocol paper (chapter eight) describes a pilot study based on the principles of minimally disruptive medicine (MDM). The proposed intervention will include health provider education and skill building in the areas of treatment burden, patient capacity, cumulative complexity, and minimally disruptive medicine.

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## CHAPTER FOUR:

Healthcare professionals' perspective on treatment burden  
and patient capacity in low-income rural populations:  
challenges and opportunities.

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The published version and supplementary files for this paper are provided in Appendices C and D.

## **4.1 Abstract**

### **Background**

The challenges of chronic disease self-management in multimorbidity are well-known. Shippee's Cumulative Complexity Model provides useful insights on burden and capacity factors affecting healthcare engagement and outcomes. This model reflects patient experience, but healthcare providers are reported to have a limited understanding of these concepts. Understanding burden and capacity is important for clinicians, since they can influence these factors both positively and negatively. This study aimed to explore the perspectives of healthcare providers using burden and capacity frameworks previously used only in patient studies.

### **Methods**

Participants were twelve nursing and allied health providers providing chronic disease self-management support in low-income primary care settings. We used written vignettes, constructed from interviews with multimorbid patients at the same health centres, to explore how clinicians understood burden and capacity. Interviews were recorded and transcribed verbatim. Analysis was by the framework method, using Normalisation Process Theory to explore burden and the Theory of Patient Capacity to explore capacity.

### **Results**

The framework analysis categories fitted the data well. All participants clearly understood capacity and were highly conscious of social (e.g. income, family demands), and psychological (e.g. cognitive, mental health) factors, in influencing engagement with healthcare. Not all clinicians recognised the term 'treatment burden', but the concept that it represented was familiar, with participants relating it both to specific treatment demands and to healthcare

system deficiencies. Financial resources, health literacy and mental health were considered to have the biggest impact on capacity. Interaction between these factors and health system barriers (leading to increased burden) was a common and challenging occurrence that clinicians struggled to deal with.

### **Conclusions**

The ability of health professionals to recognise burden and capacity has been questioned, but participants in this study displayed a level of understanding comparable to the patient literature. Many of the challenges identified were related to health system issues, which participants felt powerless to address. Despite their awareness of burden and capacity, health providers continued to operate within a single-disease model, likely to increase burden. These findings have implications for health system organisation, particularly the need for alternative models of care in multimorbidity.

### **Keywords:**

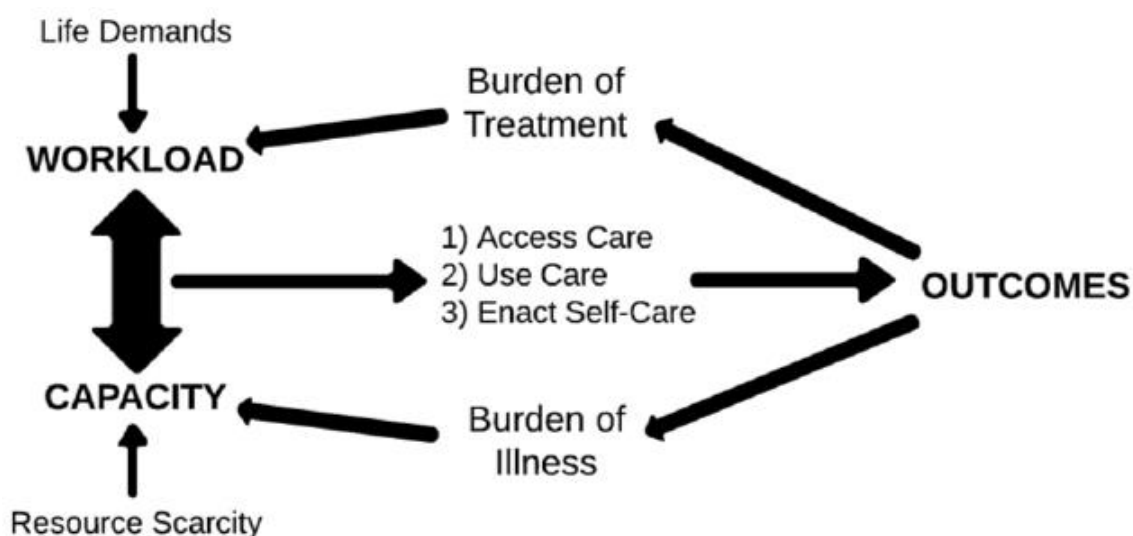
Treatment burden, Patient capacity, Healthcare providers, Qualitative research, Self management, Multimorbidity.

## 4.2 Background

Lifestyle-related chronic diseases (CDs) such as diabetes, arthritis, cardiovascular and respiratory conditions require a long-term commitment to active self-management; however ongoing adherence is often poor. Known barriers to successful CD self-management include social, cognitive, biomedical and health system factors (1-5). These factors frequently interact, leading to reduced adherence and CD escalation.

Shippee's Cumulative Complexity Model (CuCoM) (6) describes how different factors (such as poverty or polypharmacy) come together with the patient, their social environment and the healthcare environment to either promote or detract from a desired health outcome. In this model, complexity is not a medical diagnosis but a dynamic balance between patient workload (including self-management tasks, interactions with the healthcare system and everyday life demands) and capacity (including social support, socioeconomic resources and level of mental/physical functioning). The patient requires sufficient capacity to service their workload. Inadequate capacity or overwhelming workload may cause symptoms to escalate, which is then dealt with by intensifying treatment. Ironically, this increases workload even further and can result in a spiral of cumulative complexity (6-8), as illustrated in figure 4.1. The CuCoM is particularly applicable to people with multimorbidity (because of higher treatment workloads) and to those who are socially disadvantaged (since they have fewer resources), and can explain the poor outcomes and reduced adherence commonly seen in these groups (1, 4).

**Figure 4.1: The Cumulative Complexity Model (6, 8)**



The concepts of workload and capacity have been explored in several qualitative studies (1, 9-11). Although Shippee's original concept of 'workload' refers to both direct treatment work and life demands, to increase clarity and consistency with the wider literature, we will hereafter use the term 'treatment burden' rather than 'workload'. In line with other researchers, we define treatment burden as consisting of both direct treatment work and the impact on daily life, including work, social and caring responsibilities(12-14). May (12), working with this definition, has proposed Normalisation Process Theory (NPT) (15, 16) as an appropriate tool to analyse treatment burden. This describes how new practices, such as learning how to manage chronic health conditions, become integrated into daily life, and has been successfully applied in several patient qualitative studies of treatment burden (13, 17). Less attention has been paid to the concept of patient capacity as described in the CuCoM, although several taxonomies of capacity have been proposed (13, 18). Boehmer (18) in a large qualitative review and synthesis used the acronym 'BREWS' to describe capacity as the interaction between **R**esource mobilisation, **W**ork realisation and **S**ocial functioning accomplished within a person's **B**iographical reframing and **E**nvironment. This approach



recognises that capacity is more comprehensive than a list of individual abilities or resources, and highlights its interactive, dynamic nature.

Although the Cumulative Complexity Model is supported by evidence from patient qualitative studies (1, 9, 11, 13), the concept is yet to be embraced by the healthcare system, as evidenced by reviews of medical records, clinical guidelines and CD management interventions (19-21). Patients report that individual healthcare providers (HCPs) are often ignorant of burden and capacity factors (9, 10); studies of HCPs support this view, noting a limited understanding of treatment burden (22), an ad hoc approach to the assessment of capacity (23), and discordant patient-practitioner perceptions of factors contributing to treatment burden (24).

Understanding burden and capacity is important for HCPs, not just because of their effect on treatment adherence, but because HCPs can directly influence these factors either negatively (by excessive treatment demands), or positively (by supporting capacity and reducing burden)(2). This is even more applicable in vulnerable or disadvantaged populations who experience high levels of CD prevalence and multimorbidity, and whose life experiences may diverge significantly from the HCPs with whom they engage.

This study aims to explore how clinicians working in self-management support with rural socially disadvantaged populations understand and address burden and capacity factors in their patients. Short written vignettes describing patients were used to investigate HCP assessment and decision-making. Vignette responses have been shown to more closely approximate a clinician's real-world behaviour than interviews, especially when looking at clinical decision-making, while also allowing motivators behind decisions to be explored in greater depth than in an observational study (25, 26). The knowledge generated is intended to provide direction on ways of incorporating the concepts of workload, capacity and cumulative

complexity into clinical practice, leading to improvements in treatment adherence and health outcomes.

We aimed to answer the following research questions:

1. Can HCPs working in chronic disease self-management support (CD-SMS) identify burden and capacity factors in patient case-studies (vignettes)?
2. How do HCPs working in CD-SMS understand burden and capacity, as described by Normalisation Process Theory (NPT) and the Theory of Patient Capacity (BREWS)?
3. What strategies do HCPs use to reduce burden or build capacity and what barriers do they identify?

### **4.3 Methods**

#### **Overall study design.**

This was a pragmatic qualitative study, analysed using the Framework Method (27). We used the COREQ checklist for reporting of qualitative studies (see additional file 1). Research was conducted in accordance with national ethics guidelines and approval was granted by the La Trobe University Human Research Ethics Committee.

#### **Participants and setting**

All participants were clinicians (nurses and allied health professionals) working in chronic disease self-management support at two large (150-200 employees) regional community health centres in Victoria, Australia. SMS includes education, behaviour change interventions, goal-setting, symptom management and assisting with condition impacts on physical,

psychological and social functioning (28). In Australia, nurses and allied health professionals are the dominant providers of CD-SMS, both as first-contact providers and in collaboration with general practitioners (GPs). Community health centres cater for disadvantaged and low-income populations, many of whom experience complex multimorbidity. HCPs working in adult CD management at each health centre who described SMS as an integral part of their job were emailed with information about the study and invited to participate. Interviewees were purposively selected to ensure a range of different professions and years of experience. Data saturation was obtained after ten interviews, but a further two interviews were undertaken for confirmation.

### **Interview process**

Prior to commencing the interview, participants completed an informed consent form and a brief survey recording their demographic details. HCPs were then asked to read a vignette case study (described below) and to imagine that it was a referral for a new patient, presenting to them in their current role at the Community Health Centre. They were encouraged to verbalise any initial thoughts, using the 'think aloud' method (29), which reflects how clinicians typically respond when presented with a new patient. They were then asked to consider the vignette from two points of view - the patient, and the health provider – and reflect on the likely tasks that would need to be undertaken (burden) and skills required (capacity) for that person to successfully manage their health. Two vignettes (from a total of six case-studies) were selected for each clinician to view, chosen to closely reflect the HCP's reported patient profile. Each vignette was commented on by four HCPs.

The second half of the interview consisted of general questions about the concepts of treatment burden, patient capacity and complexity, including the HCP's thoughts about how such challenges could be overcome. Interview questions, including all vignettes, were trialled

with two clinicians experienced in chronic disease management and modified in response to feedback. The interview protocol is available in additional file 2.

### **Vignette development/procedure**

Six vignettes were constructed using interview data from thirteen multimorbid patients attending the same community health centres, who were part of a wider study. This approach enabled us to maximise data validity, by using case studies that closely represented the HCP's usual patient population, whilst also addressing privacy concerns (since both patients and HCPs lived and worked in the same two rural communities) by blending and merging patient stories. Additional file 3 contains all six vignettes.

When writing a vignette, the use of both controlled variables, which provide the setting and context of the case-study but are not considered to greatly influence responses, and manipulated variables, which relate directly to the research questions, is recommended (25). Table 4.1 describes each variable and their role in the vignettes. In this study, the controlled variables were age, gender and number and type of chronic conditions. Manipulated variables were of two types: information about environmental conditions (housing, family structure and source of income) and narrative features representing differing levels of patient capacity. The controlled and environmental variables were abstracted directly from the patient interviews and distributed across the six vignettes based on their frequency of occurrence in the patient interviews.

The narrative features were based on four areas of patient capacity – physical, social, personal and employment – identified from the chronic disease management literature (3, 13, 18). These features of patient capacity had previously been identified in the patient interviews and were distributed across the vignettes. Since this was a qualitative study it was not considered

necessary to allocate variables using a factorial method; instead the aim was to provide a wide range of scenarios that closely represented the HCP's daily caseload. All vignettes were written in the form recommended by Evans (25) to maximise realism and rigour.

**Table 4.1: Vignette design**

	Variables	Variables in each vignette ( ) indicates number of vignettes which included the variable
<b>Controlled variables</b>	Age	50-60 yrs (3 vignettes); 60-75 yrs (3)
	Gender	Male (3) Female (3)
	Chronic conditions	All vignette patients had at least 3 of the following conditions: musculoskeletal pain/arthritis (6); type 2 diabetes (4); diabetic sequelae (2); mental health (4); gut/bowel (3); cardiovascular (3); respiratory (2).
<b>Environmental variables</b>	Income source	Age pension (2); disability pension (1); unemployed (2); part-time work (1)
	Family situation	Living with spouse (3 - all 60+ yr); spouse and children (1); single parent (1); alone (1).
	Housing	Rental (3); own home (2); mobile home (1).
<b>Narrative (capacity) variables</b>		<b>These factors were distributed across the vignettes</b>
	Physical	Diabetes complications, blood sugar control, multiple surgeries, functional or mobility impairments
	Personal	Mental health issues, motivation, memory
	Social	Family proximity, carer demands, quality of family relationships, family stressors (e.g. substance use), socially engaged or isolated.
	Employment	Job loss, manual work history, self-employment, voluntary work, carer demands

## **Analysis**

Since our intention was to explore whether HCPs' understanding was similar to or different from that of patients, we did not structure the interviews around the BREWS or NPT frameworks, instead asking general questions about burden and capacity. We wished to see whether HCPs were able to spontaneously identify burden and capacity domains (as described by BREWS and NPT) that had previously been identified from patient qualitative studies. After interview completion, we applied the same thematic constructs as in patient studies (BREWS and NPT) and tracked any data that did not fit this framework. We used the Framework Method for data analysis, working through each stage from familiarisation to interpretation (27). Data was initially coded into the broad categories of burden and capacity. All data relating to burden was then coded to the four NPT themes of sense-making, relationship work, enacted work, and appraisal. All capacity data was coded to the five BREWS themes of biography, resource mobilisation, environment, work realisation, and social support. Table 4.2 describes key features of each burden (NPT) and capacity (BREWS) factor. All interviews were transcribed verbatim and initially coded by RH by hand. NVivo 12 software was then used and coding was reviewed and further explored by SB and ES. Disagreements were resolved in discussion with all three researchers.

**Table 4.2: Burden and Capacity coding**

<b>Normalisation Process Theory (NPT)</b>		<b>Patient capacity (BREWS)</b>	
Coherence (Sense-making)	Understanding the condition and treatments, planning care, setting goals	(B) Biography	Reframing to create a meaningful life that includes illness and treatment
Cognitive participation (Relationship work)	Obtaining support from family, friends and HCPs; managing difficulties in relationships.	(R) Resource mobilisation	Access to, and ability to mobilise physical (energy, physical function); cognitive (literacy, memory); personal (resilience, self-efficacy); financial; and instrumental (time, transport etc.) resources.
Collective action (Enacting work)	Carrying out work – adhering to treatments, making lifestyle and psychological adjustments, attending appointments.	(E) Environment	Healthcare and social environments that fit with healthcare needs without interfering with other priorities.
Reflexive monitoring (Appraisal)	Monitoring symptoms, reflecting on work undertaken and adjusting as necessary.	(W) Work realisation	The experience of, and ability to normalise treatment workload as well as other life roles.
		(S) Social functioning	Ability to socialise; practical social support; social acceptance of the patients' CD and limitations; relations with HCPs.

## 4.4 Results

### Participant and interview characteristics

Twelve interviews were conducted with health professionals. Due to the COVID-19 pandemic, six interviews were via phone and six via video link, depending on interviewee preference and technology capacity. Eleven interviews were conducted by RH and one by SB. Six of the interviewees were known to RH who worked part-time as a clinician at one of the centres, but none of the participants were in a subordinate or supervisory relationship with RH. Interview duration ranged from 38 to 60 minutes (average 45'). Following interviews, brief field notes were made to record the key themes and impressions of the interview. All interviews were audio recorded and transcribed verbatim by RH. Table 4.3 records key characteristics of the health professionals and their reported patient profile.

**Table 4.3: Characteristics of health professional interviewees**

Location	Site 1: 7 participants, Site 2: 5 participants
Gender	All female
Age	24-56 years, mean 41 years
Profession	2 nurses; 4 diabetes educators (all nurses); 3 occupational therapists; 1 physiotherapist; 1 exercise physiologist; 1 podiatrist.
Years since graduation	1-34 years, mean 13 years
Years in CDSM	1-18 years, mean 9 years
Specific postgraduate training in CDSM	7/12 reported formal training in CDSM.
Reported typical patient population	Low socioeconomic status: blue-collar workers or healthcare card holders  Age group: over 50  Chronic health conditions: Diabetes, COPD, cardiovascular disease, chronic pain, arthritis, anxiety/depression, obesity and multimorbidity.



### **Vignette validity**

We addressed rigour and realism in the written vignettes by modelling the case studies on actual community health clients, trialling the vignettes with experienced clinicians and then presenting them to the participants in the form of a referral letter. During the interviews, we took further steps known to maximise validity (25) including matching the vignettes to each HCP's reported patient population, asking the HCPs to respond as if the patient presented to them in their current role, and using a 'think aloud' process when responding to vignettes. We also asked participants to confirm that the vignettes were representative of their usual patients. This was strongly supported by the HCPs, who commented:

*"they are so typical... both of them" (B4)*                      *"it sounds like one of my clients..." (S3).*

### **Ability of HCPs to identify burden and capacity factors in vignettes.**

HCPs were initially asked to 'think aloud' about each vignette, and then to consider barriers and enablers to CD management from both the patient and the HCP perspective. During both the 'think-aloud' and patient perspective responses, HCPs focussed on environmental stressors, especially life demands (work, caring), finances, social situation, and functional difficulties, rather than specific health conditions. When considering the vignette from the HCP perspective, the focus changed to treatment options, onward referrals and concerns about engagement with self-management. We compared the HCP 'patient' responses with the key capacity issues described in each vignette, based on the variables outlined in table 4.1. This confirmed that all sociodemographic and capacity variables featured in table 4.1 were identified and referred to by the participants and that the controlled variables were not unduly influencing responses. Table 4.4 illustrates the key issues in each written vignette and the participant responses. HCPs were easily able to identify the key issues in vignettes and often expanded on how these factors might impact on health management, especially in terms of

the person's ability to prioritise health in the face of other life demands, and their ability to access healthcare services to support them.

**Table 4.4: HCPs' responses to each vignette in relation to key capacity features**

<b>Vignette no.</b>	<b>Key capacity issues in vignette</b>	<b>Issues discussed by at least 3 HCPs</b> (each vignette was reviewed by 4 HCPs)
1 'Pete'	Complex multimorbidity and functional impairment, housing situation, limited family support.	Likely high treatment demands, difficult housing situation, ability to access healthcare, reduced family support.
2 'Angela'	Insulin dependent diabetic, some carer responsibilities, good social support.	Low income, ability to prioritise health due to carer demands, good social support, needs good support for diabetes management.
3 'Lyn'	Poor diabetes control, poverty, carer demands, lack of social support, family dysfunction, mental health.	Inability to prioritise health due to life demands, mental health, social isolation, financial stress, needs significant support from healthcare system but access may be difficult.
4 'Steve'	Work demands/stress related to business, long history of depression, poor diabetes management.	Financial stress, depression, prioritising work over health leading to escalating health issues.
5 'Mark'	Rural/isolated location, functional impairments, poverty.	Functional limitations for day to day tasks, social isolation, ability to access healthcare, housing security, financial stress, health literacy.
6 'Irene'	Caring responsibilities, social isolation, pain-related functional limitations, anxiety.	Carer responsibilities affecting ability to prioritise health, social isolation, ability to access healthcare services.

**HCPs' understanding of burden and capacity, as described by the Theory of Patient Capacity (BREWS) and Normalisation Process Theory (NPT).**

HCPs discussed capacity and burden specifically in relation to the vignette studies, but also more generally in terms of barriers and enablers, including ways to build capacity or reduce burden.

**Analysis of capacity**

All HCPs were familiar with the concept of patient capacity and most reported undertaking a formal assessment of physical, social, economic and cognitive capacity for their patients. The Theory of Patient Capacity (BREWS) fitted the data well. Quotations related to a specific vignette have been noted (as V1,2 etc.)

**Biography**

HCPs discussed biography in terms of an individual's future orientation. They discussed three possible responses for the vignette characters in managing their health. Firstly, denial and ignoring the future, associated with resistance to change and often (in the vignette portrayals) relating to the perception that immediate life demands were making it difficult for the person to prioritise their health.

*"... they haven't prioritised their own health for quite a while and they've just been working and putting food on the table ... so sometimes there's some resistance to change ..."(S3, V4)*

Secondly, viewing the future as an inevitable decline into old age and increasing disability.

*"...they just think they're getting older and this is just normal... we just put up with it..." (B5, V6).*

Finally, reframing which meant coming to terms with loss, seeing the future as positive and having meaningful goals.

*“...an acceptance of the situation and a hope for the future... understanding that you have this pain, the pain’s not going to go away but having hope that there [are] ways that you can manage it...” (S2, V5)*

HCPs considered that the ability to reframe identity and live a meaningful life with goals was vital for effective self-management. Some clinicians recognised that coming to this point could be very difficult since it meant dealing with loss and the realisation that life had changed permanently.

*“...it’s not just for 6 or 8 weeks but for a lifetime and that’s a lot to take on board...” (S1, V3)*

*“...there’s sort of no quick fix for them there’s no we’ll fix it with this ...it’s you have a chronic disease it’s going to be there for the rest of your life...” (B4)*

#### Resource mobilisation

Resources fell into three categories: Physical, practical and personal. *Physical* resources related to illness burden and the functional impact on a wide range of daily activities, mood and sleep.

HCPs identified chronic pain as the greatest contributor to illness burden, although other symptoms (fatigue and shortness of breath) were also discussed.

*“...he is probably noticing his back pain more than his erratic sugar levels...for people that have chronic pain it is often hard to see past the pain...” (B2, V4)*

*“...I would imagine (the pain) would have an effect on all the other things that are happening... so that would probably be where I would imagine Mark would want to ...is get to the bottom of the pain...” (S6, V5)*

*Practical* resources included financial status, access to government or organisational support, and personal resources such as transport or computer literacy. Financial resources were considered by all interviewees to be one of the most significant barriers to capacity. Lack of

money was particularly discussed in terms of its impact on treatment burden, affecting one's ability to pay for appointments, medication, transport, healthy food and support services.

*"...financially he is on Newstart and he is rurally isolated ... there is going to be the fuel cost plus the financial cost of paying the gap payment to see any specialists..." (S1, V5)*

*"...they are on the age pension they may or may not have money difficulties... transport or services..." (S2, V6)*

*"...she has been on the pension for the past 10 years...she'll probably be under some financial stress..." (S7, V2)*

Personal capacity included health literacy, cognitive abilities and mental health issues. HCPs rated health literacy (along with financial resources) as the most important contributor to capacity, but also saw it as closely connected to mental health, cognitive capacity and motivation.

*"... for some people, there are some huge health issues that have kind of never been explained to them properly by any health professional..." (S1)*

*"...[to] have the confidence to ask the right questions that I need to ask for my health... for example why am I taking that medication how is it going to help... if that doesn't work what is next what's my next step so having that confidence..." (S4)*

Potential mental health difficulties were discussed by most HCPs for every vignette, especially their interaction with physical symptoms, cognition and motivation.

*"...he's got a history of depression which is probably compounded now by all these other things...sometimes until that is dealt with they're not going to move forward with and they're not motivated to make the other changes..." (S3, V4)*

*"...when people have a lot of pain and then ... that affects their mental health their ability to problem solve becomes quite impaired..." (S6, V5)*

## Environment

Nearly all clinicians stressed the importance of a healthcare environment where a patient felt supported and listened to as important to build capacity, and saw the provision of this as an important part of their role. They also recognised that without this, patients often disengaged from healthcare.

*"... humans are about building relationships and that is in terms of your health relationships as well... you need to feel confident and comfortable with the healthcare professional that you are going to see..." (S5, V2)*

*"...trust and rapport... that really helps with self-management because they feel valued ...that makes a big difference to the outcomes that the client has..." (S7)*

*"...I think a really big important one is the services that they have been engaged with in the past ...if you've had a bad experience previously you are just likely to live with a bad health condition and not address it ..." (S1, V5)*

The patient's home environment was discussed both in terms of their housing suitability and security, and whether their life demands allowed people to prioritise their own health (most commonly referred to in relation to women with caring responsibilities).

*"...I think if she's got a lot going on in her life...it can be difficult to get people to worry about themselves when they are worrying about other people a lot..." (B1, V3)*

*"...he lives in a local caravan park which in my mind becomes relevant because of his living conditions... whether that is safe with his chronic back pain..." (B3, V1)*

*"...I would dare say that she probably puts other people's needs before her own and you know that will lead to a decline in her diabetes management ..." (S5, V2)*

Stressful government-service environments such as the unemployment and child support systems were also referred to as factors that could impact on capacity.

*“...he’s on Newstart...that system is just going to set him up to drive that pain even further because of the stress that will put him under...” (S6, V5)*

### Work Realisation

Many HCPs acknowledged the difficulty of successfully incorporating self-management work into daily life. Demands related to employment or caring were often associated with people not prioritising their health and thus reducing self-management ability. Most HCPs emphasised the importance of taking small steps and prioritising based on patient-identified goals and values. On the other hand, the successful achievement of treatment tasks was considered an important way to build capacity, by both increasing self-efficacy and reducing illness burden.

*“...at the next session say how did you go with that ... I'll say you did do well maybe we can build on that ... that increases their capacity to do things because they can see the benefit of what they've done ...” (S3).*

### Social Functioning

All HCPs referred to the importance of social networks and being connected to family, friends and community in terms of overall health outcomes, especially mental health. HCPs recognised that physical limitations and mental health interacted with social capacity.

*“...if we are talking about being socially isolated as well it's all that stuff drives people's mental health which will have an effect on his pain and vice versa...” (S6, V5)*

*“...how are those family connections and how does he feel about that... is he depressed or upset about that... is that going to affect his ability to look after his health...” (S5, V1)*

HCPs noted that social connections could increase access to resources (money, transport, home help) and enable the pursuit of meaningful activities, thus building biographical capacity.

## Analysis of burden

Apart from the diabetes educators, most HCPs were unfamiliar with the term ‘treatment burden’, but all presumed that it meant the demands of healthcare work. HCPs had a broad view of these demands and described both direct tasks such as pill-taking and attending appointments, but also life impacts such as the clash between treatment needs and family responsibilities, and the patients’ emotional burden of unremitting healthcare. Several also related it directly to patient capacity, describing how psychosocial stressors or resource deficits could lead to increased treatment burden. HCPs saw treatment burden as emerging both from specific treatment tasks and from difficulties in dealing with the healthcare system. This dual aspect of treatment burden has also been observed in patient studies (13).

## Coherence

All HCPs considered that a patient’s understanding of their health condition(s) was vital for self-management and an important element of treatment work.

*“...I’d guess number one is finding out if Mark has any idea about pain... you really can’t manage that until you get a good understanding of what the condition is...” (S6, V5)*

Participants had a broad conception of ‘Sense-making’. Making sense of health conditions was seen to be much more than learning a series of condition-specific skills or facts. It could enable people to take control of their health and plan a meaningful future. People’s beliefs, expectations and health literacy could make this task difficult. Some HCPs also acknowledged that the amount of knowledge required for effective self-management when there was co-morbidity could be overwhelming for patients.

*“...they don’t have that knowledge so we have to provide that knowledge to them but then again it does become overwhelming the amount of knowledge that we are providing ...” (S5)*



The literacy level of many educational resources, as well as differing and often inconsistent messages from different HCPs, was frequently identified as an issue.

*“...a lot of people just give out brochures and things like that and expect people to read them but they don't they just go in the bin...” (B1)*

*“...it can be overwhelming for people to be told lots of different things by lots of different health professionals who are looking after lots of different things...” (S1)*

### Cognitive Participation

HCPs all stressed the importance of the patients engaging with multiple HCPs to manage their health. Each HCP recommended the involvement of at least three different HCPs per vignette, despite simultaneously recognising that this would increase the burden.

*“...people who are seeing multiple specialists ...sometimes people are just ticking a box they are going to an appointment at times they are not sure why they're there and they are too overburdened to actually take anything on board...” (S1, V4)*

*“...the issue is what we all like to do is send people off to 7 different Professionals and then that can be ...that's where we lose them sometimes isn't it so that's an issue” (S6)*

They also stressed the importance of the therapeutic alliance and their role as a facilitator working on mutually agreed goals, rather than a director of care. Many HCPs also recommended social services for the vignette patients (respite, home help, financial counselling) but noted that access was often limited.

Poor health service communication and co-ordination was acknowledged as a universal issue and a major contributor to burden. HCPs felt powerless to address these failings, which they believed could only be dealt with by more integrated technology and increased funding. Several HCPs reported that these failings resulted in their own ‘treatment burden’ since they

were often working outside of their roles to compensate for shortfalls in the system. This required time and emotional energy.

*“...it's not so much the number of clients that we are seeing in a day it's the level of...like there's an awful lot of emotional energy that goes into our work...” (B4)*

#### Collective action

HCPs listed a range of self-management tasks that the vignette patients would need to complete, including management of medication, appointments, blood sugar testing, diet, exercise, mental health and sticking to a routine. Integrating chronic disease management into daily life was recognised as potentially very time consuming especially for diabetics, those with caring responsibilities and those with multiple health conditions.

*“...things you can no longer do... you can no longer eat your time is not your own anymore because you have appointment after appointment after appointment at all different places ... trying to keep up and manage your life around your health...” (B5)*

*“...lots of medications to take at home... things like exercise programs that people have to do at home ...not being able to live the rest of your life because you're always having to do things for your health...” (B1)*

Treatment costs, particularly specialist and psychology appointments, travel costs (given the rural setting) and the costs of home help or equipment were identified as burdensome.

Services that were more affordable inevitably had long waiting lists or restricted eligibility.

HCPs also described how patients often needed to attend multiple locations or appointments due to poor health service co-ordination. Improved service co-ordination, afterhours access and co-location were identified as factors that could assist patients to complete their treatment tasks.

*"...if you do a referral that's one thing but getting into that appointment or accessing the dietitian or the physio it's sometimes restricted and then they think oh what's the point I haven't got in so I won't bother..." (S3, V3)*

*"...some people just cannot afford the gap payments for psychologists...if you ask them to find \$80 a fortnight some people just cannot afford that..." (B4)*

*"...not all services are in the same place and some services can change quickly depending on government funding..." (S4)*

### Reflexive monitoring

HCPs referred to this in the vignettes when discussing patient priorities and the need for the patient to decide what was important to them in terms of their health management.

*"...for Mark it's a case of ... getting him to prioritise what would he like to achieve in life and then what would it take to get where he wants to be so what steps could we put in place..." (S1, V5).*

They recognised that many people would not be able to achieve all treatment tasks and that it was appropriate to reflect on and plan for what was possible rather than ideal.

*"...you're not trying to solve all of their health issues ...just if you can make one thing easier for them today sometimes that's a really important thing... and I think that is often missed... there [are] constant demands that the patient achieves everything all of the time and it is unrealistic ... that if they can achieve something they should be really proud of that..." (B3)*

### **Strategies to reduce burden and increase capacity, and barriers identified.**

#### **Building capacity**

HCPs reported that the combination of insufficient income, excessive life demands and poor mental health often impacted capacity cumulatively.

*“...the psychosocial stuff in the background that makes it complex ...the finance, the family situation, the culture, the language... all those additional things that are outside of the biomedical situation ...” (S7)*

*“...they have numerous health conditions or a range of health conditions... their home situation they might have a complex family or socioeconomic status whether there is a range of barriers...” (B2)*

They considered that accepting, understanding and being confident in treatment management was key to increasing capacity, although most felt that patients would find it difficult to do this on their own and would need ongoing support from a HCP, as well as available time and the right ‘head space’ to achieve this.

*“...a lot of it does come down to relationships with our clients and linking them into services that can help... link them in and sticking to what's important to a person...” (S2)*

HCPs considered that health literacy (which included both understanding and accepting chronic health conditions) and financial resources were the most important factors influencing capacity, closely followed by mental health status. Participants felt that they could assist in building capacity by improving health literacy, providing symptom management strategies and creating a supportive environment, but they often felt powerless to address issues related to finances, life demands and mental health.

*“...finances, finances, finances and finances... I think the vast majority of people that we see are surviving very few are thriving...” (S1)*

*"...oh god we just need more money... people with complex care needs need to be able to access things without having to pay a gap..." (B3)*

*"...one of the biggest challenges when their mental health is a long-standing mental health issue that has never been adequately addressed ... sometimes we are seeing people and it has been 40 years...when that's been something that has driven a lot of their health concerns the whole time and trying to unpack that 40 years later is challenging..." (S6)*

*"...I think someone's mental health is going to be one of the most important things... if they're mentally not in a space that they feel that they can change or where they feel they are not in control then I think you're fighting a battle that is out of your control..." (S7)*

### **Reducing Burden**

Interviewees thought that a patient's ability to reduce burden independently of HCPs or the health system was quite limited, apart from prioritising and routinizing self-care tasks where possible. They noted that capacity-building strategies (as listed in table 4.5) could also assist with perceived treatment burden. HCPs struggled with many health system barriers which increased treatment burden but could not be easily addressed either by the patient or the individual HCP. Lack of adequate and consistent funding for services, and service co-ordination were identified as the biggest factors contributing to treatment burden.

*"...where there are multiple services if they are all in one place it helps to co-ordinate your care..." (S4)*

*"...there is a lot of jumping to and fro between various organisations as well..." (B5)*

*"...we have some clients who aren't eligible with home care packages but it really would be beneficial for them...so I think funding has a lot to do with it..." (B2)*

HCPs frequently suggested ways to reduce treatment burden, then immediately discounted them as being unrealistic.

*“...it would be really nice if we had multiple access to multiple providers in one location that they could get into at one time...that would be nice... it's a bit pie in the sky...” (B3)*

Many saw telehealth as a positive development to reduce costs and increase access, but there were concerns about computer literacy and broadband access in low income populations.

Disengaging from healthcare altogether was noted to be one way that patients might deal with a high treatment burden. The issue of multiple appointments with different people, each focussing on a different part of the body, was recognised as a challenge that could not be easily solved, especially due to the sheer number of treatment options available.

*“...it's lovely that we have so many services but that just adds to the [feeling of] being overwhelmed really doesn't it...” (S6)*

Several participants noted that many patients did not have a strong relationship with their general practitioner (GP). This was a common issue in rural areas due to workforce shortages and transient staffing and reduced the likelihood of co-ordinated care.

*“...when I have had someone who has come in and they are complex it's not often that the general practitioner is all over it...I think that the GP can become overwhelmed in that scenario...” (S5)*

These factors are summarised in table 4.5.

**Table 4.5: HCPs views: Factors that reduce burden or build capacity**

<b>Reducing burden</b>	<ul style="list-style-type: none"> <li>• Assistance with system navigation</li> <li>• Knowledge of available resources and greater access (waitlists, funding for equipment and social services)</li> <li>• Improved access to specialists and mental health services (telehealth, transport support, no gap payments, address waitlists and workforce).</li> <li>• Technology to improve service co-ordination (shared healthcare information plus time to read it)</li> <li>• Supportive HCPs who are patient-centred</li> <li>• Sustainable (long-term) service funding</li> </ul>
<b>Increasing capacity</b>	<ul style="list-style-type: none"> <li>• Available income</li> <li>• Understanding their condition and the point of treatment, being confident in management</li> <li>• Acceptance of condition and recognition of the need to address it</li> <li>• Ability to prioritise health</li> <li>• Living in a healthy environment</li> <li>• Availability of services (home help, respite)</li> <li>• Having goals and a purpose</li> <li>• Early provision of services (before people become too disabled)</li> <li>• Good mental health</li> <li>• Good social relationships</li> </ul>
<b>Both</b>	<ul style="list-style-type: none"> <li>• Established routine/integrating treatment into life, able to troubleshoot and prioritise</li> <li>• Manageable life demands (e.g. caring role)</li> </ul>

## 4.5 Discussion

### Main findings

This study aimed to investigate how HCPs working in CD-SMS understood the elements of complexity, as described by the Cumulative Complexity Model. Our use of structured

vignettes, rather than patient histories, allowed us to concentrate on specific capacity variables without compromising anonymity. All study participants were able to identify and discuss burden and capacity factors in the vignettes, and the data could be analysed using Normalisation Process Theory (NPT) and the Theory of Patient Capacity (BREWS), previously only explored with patients. HCPs listed a wide range of strategies to reduce burden or build capacity, but frequently reported health system challenges in implementing these strategies. HCP views were consistent across a wide range of disciplines and years of experience, although experienced clinicians were more likely to highlight the interaction between motivation for self-management and contextual factors such as low education.

## **HCPs views compared with the literature**

### Patient literature

The study findings are strongly consistent with literature exploring the taxonomy of burden and capacity (11, 13, 18), with the HCP accounts describing all burden and capacity components. The interacting nature of burden and capacity (9, 13, 30, 31), especially how increased capacity can reduce burden, was also discussed by the HCPs. The HCPs also characterised burden as comprising both treatment tasks and health system deficiencies, as described by Gallacher et al (13).

### Health provider literature

The ability of HCPs to recognise patient burden and capacity constraints has been questioned in several studies (9, 10, 22). HCPs are reported to focus on biomedical (24, 32) or motivational (23) rather than social-contextual factors when assessing treatment burden or capacity to self-manage. The current study offered a different perspective which may be related to the setting.



Study participants were all HCPs working with rural populations in community health settings, where there is an explicit commitment to the social model of health. In this setting, HCPs were highly cognisant of burden and capacity issues, and their comments on the vignettes were comparable to the patient literature. Other studies have interviewed GPs (physicians) and practice nurses in primary care, where there may be less understanding of SMS (33, 34) and limited access to interdisciplinary services. In contrast, community health CD services are often structured around the Chronic Care Model (35) and HCPs working in this environment generally have more time, greater expertise in SMS (with 7/12 interviewees reporting formal postgraduate training in this area) and access to interdisciplinary services.

Several studies have recommended that HCPs become more aware of access, resource and treatment burden factors in individual patients and tailor treatment accordingly (10, 23, 30), including an increased focus on patient-identified values, preferences and non-medical goals (10, 18, 24, 36, 37). In the current study, such approaches appeared to be well-established. Even if participants were unfamiliar with the specific term 'treatment burden', they all recognised the importance of avoiding overwhelming treatment demands. Formally identifying and prioritising burden and capacity factors using available tools and measures (38, 39) could provide additional assistance to patients and HCPs, but many burden-capacity challenges require system-level changes that are out of reach of the individual patient or health provider. This echoes findings in a review of integrated care for multimorbidity (40), which noted that successful implementation needs macro-level change, but that most interventions occur at the micro- or meso- level.

### **Recommendations and challenges**

All HCPs felt that their efforts to assist with burden and capacity were limited by contextual factors over which they had little power. Consistent with other literature (41, 42), some

experienced their own personal 'treatment burden' in trying to fill the gaps of poor service provision, and others stepped outside of their role to provide additional support or co-ordination if it was unavailable in their healthcare setting. They felt that many barriers could only be dealt with by the injection of more money and practical approaches including better technology, administrative support, stronger linkages between health and social services and time allocated for HCPs to communicate directly to each other.

HCPs also recognised that some of their own actions could increase treatment burden, for example referring the patient to multiple services, most of which were not 'joined-up'. Even with increased funding, the single disease model of healthcare inevitably leads to patients being reduced to body components, with each piece needing treatment by a different person. Without care co-ordination, this results in excessive burden or disengagement. Several HCPs described the care co-ordination role as an 'extra' job they often assumed to help the patient, but to be effective this role needs to be both remunerated and formally recognised by the patient and all other HCPs working with that patient, especially the GP.

Dealing with mental health issues within the context of multimorbidity was seen as particularly challenging. Often the only response was to send the patient off to yet another service provider, this time to deal with their 'head'. Despite the prevalence of co-occurring mental and physical health conditions (43), HCPs and health services continue to work within single-disease models (33, 40, 44) and alternative approaches are needed to avoid burden-capacity imbalance. One suggested approach is for HCPs to use and promote treatments that are effective in a range of conditions (e.g. exercise) so that the same intervention can address multiple health conditions (44). Greater emphasis on generalist skills that reflect common comorbidities may also help to support patients who cannot manage yet another referral. Given the two-way relationship between anxiety, depression and many chronic health

conditions, skills such as capacity coaching, trauma-informed care and mental health first aid (45-47) are likely to be particularly useful.

### **Strengths and limitations**

A strength of this study is the vignette methodology, which enabled us to explore how HCPs might actually respond to patients rather than being reliant on their explicit or theoretical knowledge. By using NPT and the theory of patient capacity, we could compare the data to the wider patient literature, strengthening the validity of the research. Interviewing HCPs who directly provide SMS, rather than GPs in primary care for whom SMS is a secondary role (48), resulted in a different perspective: one informed by negotiating the practical details and challenges of self-management. Requesting HCPs to imagine the patient's perspective when viewing the vignettes (which is known to affect empathy) may have contributed to increased recognition of burden and capacity; however, these factors were also identified at the initial 'think aloud' stage.

The study findings are limited by the fact that the setting is a low income rural population with HCPs who work within a specific model of healthcare and may therefore be more aware of social-contextual issues. Despite this, the community health environment is valuable to explore because there are likely to be greater numbers of people with psychosocial complexity and multimorbidity. Such individuals are at greater risk of burden/capacity imbalance and disengagement from the healthcare system than more advantaged populations. Additionally, in this setting many of the recommendations to address burden and capacity (such as increased HCP awareness and tailored care based on patient priorities) have already been addressed, yet significant challenges remain.

Although challenges related to healthcare costs and accessibility are more relevant in settings with resource and workforce shortages, system co-ordination issues are widespread across all health systems (31). Therefore, it is likely that the study findings are relevant in other settings.

## **4.6 Conclusions**

HCPs in community health settings have a good understanding of burden and capacity, and the impact of these factors on the ability of their patients to self-manage chronic health conditions. Many of the barriers to address burden and capacity are at the health system or societal level and are difficult to address. Despite their understanding of burden and capacity constraints, HCPs still operate according to a single disease model which may lead to increased burden. More systematic approaches to support patients (e.g. care co-ordination) and/or alternative care models for multimorbidity are needed to support patients in their chronic condition self-management.

**List of Abbreviations:**

CD: chronic disease; CuCoM: cumulative complexity model; NPT: normalisation process theory; BREWS: theory of patient capacity; HCP: healthcare provider; SMS: self-management support.

**Declarations:**

**Ethics approval and consent to participate:** Research was conducted in accordance with the Declaration of Helsinki and national guidelines. Ethics approval was granted by the La Trobe University Human Research Ethics Committee (HEC19363). Signed informed consent forms were obtained from all participants prior to their interview.

**Consent for publication:** Not applicable.

**Availability of data and materials:** The datasets used during the current study are available from the corresponding author on reasonable request.

**Competing interests:** The authors declare that they have no competing interests.

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**Authors' contributions:** RH and SB conducted the interviews. RH transcribed all interviews and undertook initial coding. All authors contributed to ongoing data coding and analysis. RH drafted the initial manuscript, and ES and SB edited and further developed the manuscript. All authors read and approved the final manuscript.

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## CHAPTER FIVE:

Multimorbidity and its effect on perceived burden, capacity and the ability to self-manage in a low-income rural primary care population: a qualitative study.

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The published version and supplementary files for this paper are provided in Appendices E and F.

## 5.1 Abstract

### Introduction:

Multimorbidity is increasing in prevalence, especially in low-income settings. Despite this, chronic conditions are often managed in isolation, potentially leading to burden-capacity imbalance and reduced treatment adherence. We aimed to explore, in a low-income population with common comorbidities, how the specific demands of multimorbidity affect burden and capacity as defined by the Cumulative Complexity Model.

### Materials and methods:

Qualitative interviews with thirteen rural community health centre patients in Victoria, Australia. Participants were aged between 47-72 years and reported 3-10 chronic conditions. We asked about perceived capacity and burden in managing health. The Theory of Patient Capacity was used to analyse capacity and Normalisation Process Theory to analyse burden. All data specifically associated with the experience of multimorbidity was extracted from each burden and capacity domain.

### Results:

The capacity domains of biography, resource mobilisation and work realisation were important in relation to multimorbidity. Conditions causing functional impairment (e.g. chronic pain, depression) interacted with physical, psychological and financial capacity, leading to biographical disruption and an inability to realise treatment and life work. Despite this, few people had a treatment plan for these conditions. Participants reported that multimorbidity affected all burden domains. Coherence and appraisal were especially challenging due to condition interactions, with clinicians providing little guidance.

Discussion:

The capacity and burden deficits highlighted by participants were not associated with any specific diagnosis, but were due to condition interactions, coupled with the lack of health provider support to navigate interactions. Physical, psychological and financial capacities were inseparable, but rarely addressed or understood holistically. Understanding and managing condition and treatment interactions was a key burden task for patients but was often difficult, isolating and overwhelming. This suggests that clinicians should become more aware of linkages between conditions, and include generic, synergistic or cross-disciplinary approaches, to build capacity, reduce burden and encourage integrated chronic condition management.

## 5.2 Introduction

The shift from acute to chronic health conditions as the main driver for worldwide burden of disease has demanded alternative healthcare solutions (1). More recently, there has been a recognition that many chronic conditions do not exist in isolation, but as clusters of conditions(2). Multimorbidity, which is defined as the presence of two or more chronic health conditions(3), has become the rule rather than the exception(2, 4), especially with increasing age. In common with individual chronic conditions, multimorbidity is also more prevalent in vulnerable groups, including rural(5) and socially deprived populations(4).

This 'new normal' of multimorbidity is not reflected in our health systems, models of care or everyday clinical practice. Although the development of the Chronic Care Model(6) has enabled many healthcare systems and practitioners to transition from acute to chronic care, it remains limited by its single disease focus. Studies of clinical guidelines and qualitative studies with patients and healthcare providers (HCPs) note that multimorbidity is difficult to integrate into a chronic care model due to conflicting treatment recommendations, condition interactions and excessive treatment burden(7-10).

Traditionally, multimorbidity has been understood as a list of separate conditions which are prioritised according to mortality risk (11, 12). In clinical practice, this has led to each condition being managed as a separate entity(10), with precedence given to conditions with a higher risk of future adverse outcomes such as diabetes or cardiovascular disease(13, 14). Interviews with patients suggest that they approach multimorbidity differently, placing greater importance on symptomatic conditions affecting their quality of life(15-19). This preference has implications for health outcomes, with conditions that may have low symptom burden but high future risk being deprioritised or ignored by patients(16).

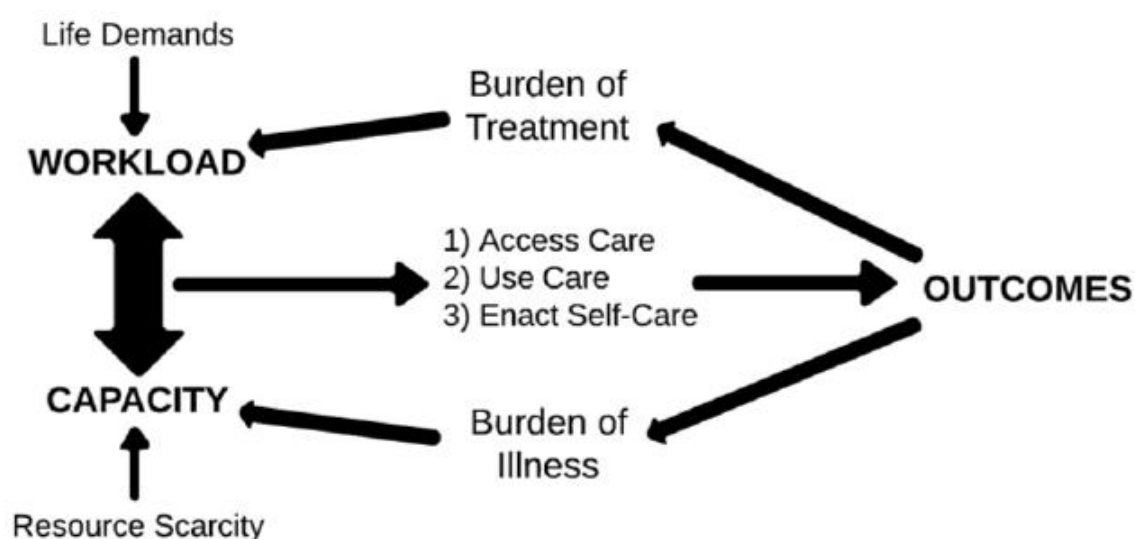
Recognising that for most people, multimorbidity is an experience they live with, rather than a condition(s) they die from, researchers have started to pay more attention to the patient experience(16, 20-22). This has drawn out the importance of interactions between the disease(s) and psychosocial factors. The risk of a co-occurring mental health condition (often excluded from morbidity counts)(11) increases with each additional physical condition (23), and socially disadvantaged populations report 10-15 years earlier onset of multimorbidity(4). Although disease count is important when measuring mortality, functional impairment, psychological distress and social context are more accurate predictors of quality of life(11, 24).

In acknowledgement of these social and contextual influences, Coventry (21) has characterised multimorbidity as an 'encounter with complexity', consisting of emotional, environmental and functional as well as medical components. Shippee's Cumulative Complexity Model (25), which defines complexity as the result of an imbalance between an individual's capacity and their workload, is a useful way to understand multimorbidity. This model conceptualises capacity as a persons' physical, cognitive and psychological functioning as well as their available resources. Workload comprises treatment and condition requirements plus the demands of everyday life (see fig. 5.1). Although Shippee's model(25) uses the term 'workload', to increase clarity and consistency with the wider literature we will be using the term 'burden' or 'treatment burden' instead, defined as both the healthcare tasks ('work') of managing chronic illness, and the impact on the patients' life roles and functioning ('life')(26).

Concepts of burden and capacity are important in multimorbidity, since the additional treatment tasks (e.g. medications, condition monitoring, appointments) associated with multiple conditions are likely to increase treatment burden. With sufficient capacity, the burden can be managed; but low capacity (e.g. inadequate income or social support) will reduce a persons' ability to manage their treatment burden (e.g. medication costs, accessing appointments). Burden-capacity imbalance can lead to reduced treatment adherence and

declining health outcomes (27). This model is particularly relevant to socially disadvantaged populations, because they experience higher levels of multimorbidity(4) (therefore greater treatment burden) whilst having fewer resources (lower capacity).

**Fig. 5.1. The Cumulative Complexity Model (25, 28).**



The cumulative complexity model has been explored in a range of populations, including people with diabetes (29), kidney disease(30), stroke(31) and in low-middle income countries(32). We wished to apply this model to a rural low-income multimorbid population, who were at risk of both high burden (from multiple health conditions) and low capacity (from resource constraints). The point of difference in this study was its focus on how the experiences that are specific to multimorbidity affect perceptions of burden and capacity.

To explore this we will use established taxonomies of workload and capacity, since this will enable us to see how each workload or capacity domain is differentially affected by the demands of multimorbidity. The Theory of Patient Capacity(33), which describes capacity as the interaction between Biographical adjustment, Resource mobilisation, Environmental fit,

Work realisation and Social functioning (abbreviated as 'BREWS') will structure our examination of capacity. To explore burden, we will use Normalisation Process Theory (NPT). This theory explains how new practices are integrated into everyday life (34), and has been applied previously in studies of treatment burden (27, 31, 35).

Our research question was: In low-income rural primary care patients, how does the experience of multimorbidity affect perceived burden and capacity to self-manage their health?

### **5.3 Materials and methods**

#### **Study design**

The study method was qualitative. We employed a phenomenological methodology, which is an approach focussed on the lived experience of participants (36). Research was conducted in accordance with national ethics guidelines, with approval granted by the La Trobe University Human Research Ethics Committee (HEC19387). The completed COREQ checklist for reporting of qualitative studies is available in file S1.

#### **Participant recruitment and setting**

Participants were clients of two regional community health centres in Victoria, Australia. Victorian community health centres provide primary care and chronic disease services to low-income and socially disadvantaged populations (37). People aged between 18-75 years who described themselves as having at least two chronic physical health conditions, such as diabetes, back pain, arthritis, heart or lung conditions were invited to participate. Our focus



was on conditions commonly managed in primary care. Since low-income groups are known to experience multimorbidity 10-15 years earlier (4), we looked for people who were middle-aged or early retirees (under 75 years). We were interested in exploring multimorbidity in an age group where there are still societal expectations of active and independent life roles.

Participants were recruited via posters in the waiting rooms of the health centres, as well as by direct invitation from their healthcare providers. Potential participants were provided with basic study information and their contact details were provided (with permission) to the researchers. Sixteen people expressed interest in the study, with three withdrawing prior to the interview. Recruitment was initially via snowball sampling, with the last four participants purposively selected to ensure gender balance.

### **Data collection**

Following completion of written consent, we conducted semi-structured interviews, each lasting for approximately one hour. All interviews were conducted by a single clinician-researcher (RH), either by phone or at a community health centre. The interview protocol was developed following review of the qualitative literature (31, 33, 38, 39), but was not trialled in patients. Interview topics explored all capacity and burden domains as outlined by BREWS and NPT. We asked people to describe their health conditions; how their daily life was affected; the treatments they needed to undertake and the difficulties they experienced in managing their healthcare. Interviews were audio recorded and continued until all researchers agreed that saturation had been reached. Interviews were transcribed verbatim by the interviewer (RH). Field notes detailing key issues and observations were made following each interview. The interview protocol is available in file S2.

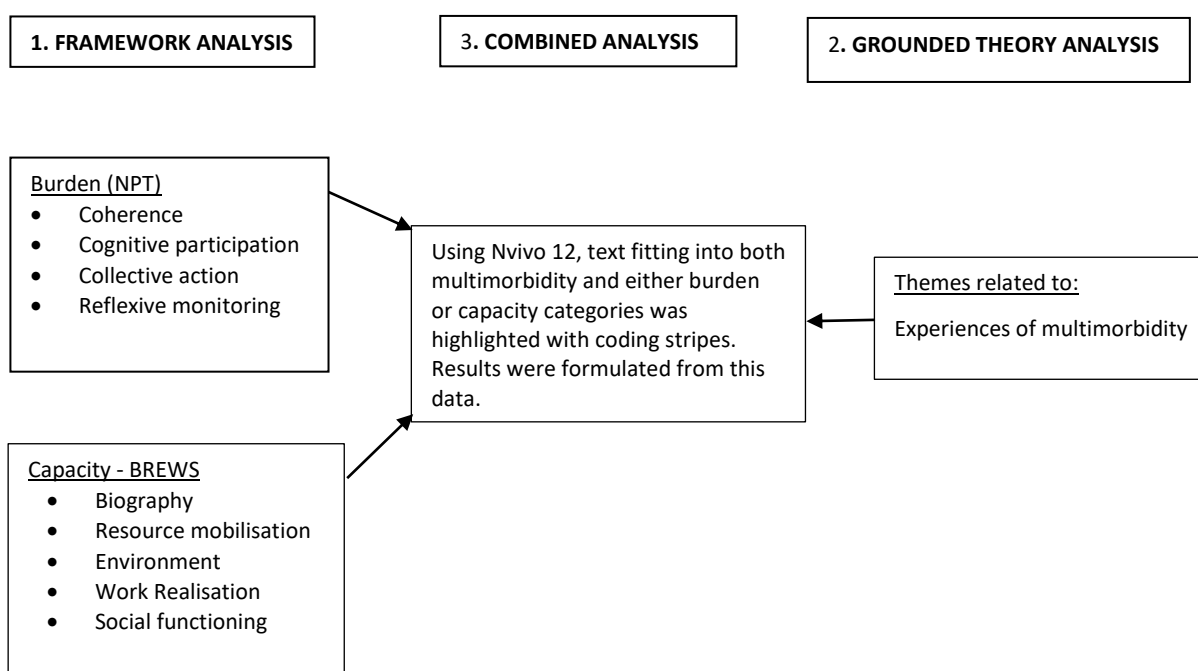
Participants also completed a series of self-report scales and sociodemographic details were recorded.

## Data analysis

We aimed to explore how the experience of multimorbidity, as distinct from that of having a single chronic condition, affected each aspect of capacity and burden. For this reason, we undertook analysis in several stages (fig 5.2). First, we explored capacity and burden by dividing the interview data into these two broad categories. We then applied framework analysis, which uses a pre-defined coding system (the framework) to structure the data (40). The coding systems used were the Theory of Patient Capacity to analyse capacity (33) and Normalisation Process Theory to analyse burden (27). Tables 5.1 and 5.2 describe each coding system in terms of its component domains; further details are available in file S3. Data was transcribed verbatim by RH and initially coded by hand, then imported into NVivo 12. Coding was evaluated and refined by SB and ES. Findings were reviewed and disagreements resolved in discussion with all three researchers.

**Fig. 5.2. Description of analysis process**

All data underwent initial framework analysis using the two categories of NPT and BREWS. We then returned to the raw data to record experiences of multimorbidity. Finally, analyses were combined to identify multimorbidity data that was relevant either to burden or capacity.



**Table 5.1: Coding domains for capacity (BREWS)**

CAPACITY DOMAINS		
<b>Biography</b>		Ability to maintain purpose and create a meaningful life while living with chronic conditions
<b>Resource mobilisation</b>	Physical	Symptom burden (pain, fatigue etc.), functional capacity (task performance, physical fitness, sensory abilities).
	Psychological	Personal traits (resilience, self-efficacy); mental health burden (anxiety, depression); cognitive capacity (memory, literacy).
	Practical	Financial, personal (e.g. access to transport) and organisational (e.g. aids/equipment, governmental services) resources.
<b>Environment</b>		Support available in healthcare and personal environments; whether treatment demands are a good 'fit' with daily life.
<b>Work realisation</b>		Ability to successfully achieve and normalise all aspects of treatment workload; ability to achieve expected life roles.
<b>Social functioning</b>		Ability to socialise; practical social supports, social acceptance or stigma, social relationships with HCPs.

**Table 5.2: Coding domains for burden (NPT)**

BURDEN DOMAINS		
<b>Coherence (Sense-Making)</b>		Learning about, understanding and making sense of the condition(s) and treatments, planning care, setting goals.
<b>Cognitive Participation (Relationship work)</b>		Engaging with others (HCPs, services, friends) for help, managing these relationships; individual organisational tasks to support healthcare (e.g. transport, arranging prescriptions).
<b>Collective Action (Enacting work)</b>		Specific treatment tasks (appointments, medication, self-care); integration of condition and treatment into daily life (adjusting to work, social or financial changes).
<b>Reflexive Monitoring (Appraisal)</b>		Reflecting on the condition(s) and treatment, reviewing and modifying management individually or in discussion with others.

Since our focus was on the relationship between capacity, burden and the experience of multimorbidity, we then returned to the original data and performed a second analysis, using a grounded theory approach to identify themes related to multimorbidity. Grounded theory is an inductive approach to qualitative research that focusses on the data alone, without an underlying theoretical perspective (36). We looked for any references to having more than one health condition, including how conditions were prioritised, interactions between conditions and any demands related to managing multiple health conditions. Following the second analysis, by using the coding stripes function on NVivo 12, we could then locate all data associated with both the burden/capacity and the multimorbidity codes. Thus, we could identify the burden and capacity domains perceived by the participants to relate most strongly to multimorbidity.

## **5.4 Results**

### **Participant and interview characteristics**

Eleven interviews were conducted with thirteen people (two interviews were with couples who both experienced multimorbidity). Nine interviews were conducted face-to-face at a community health centre, and two by phone, due to COVID-19 restrictions. Interview duration ranged from 31-71 minutes (mean 43 minutes). Participants were aged between 47 and 72 years (mean = 61 years) and reported between 3-10 health conditions each (mean=7) using the Disease Burden Impact Scale (24, 41) to report type and severity of condition. The most common conditions reported were musculoskeletal disorders (back pain, osteoarthritis and/or other chronic pain - reported by 100% of participants), followed by type 2 diabetes (n=10 people, 77%); cardiovascular conditions (heart disease, peripheral vascular disease and/or hypertension: n= 10, 77%); overweight/obesity (n=8, 62%); mental health conditions

(depression, anxiety and/or PTSD: n=8, 62%) and gut or bowel disorder (n=8, 62%). Other conditions reported by 3-6 participants were respiratory conditions (asthma and COPD), vision and hearing impairments. Table 5.3 records key characteristics of the participants.

**Table 5.3: Characteristics of study participants**

ID	Sex	Age	Living situation	Source of income	Health conditions
P1	M	57	With friend	Unemployment payment <sup>1</sup>	Back pain, OA, other chronic pain, depression, PTSD, liver disease, vision.
P2	F	50	Spouse and child	Unemployment payment <sup>1</sup>	T2DM, back pain, other chronic pain, obesity, depression, gut, bowel, vision, HT
P3	M	72	Spouse (P4)	Age pension <sup>2</sup>	RA, back pain, OA, CVD, HT, gut, vision, overweight
P4	F	71	Spouse (P3)	Age pension <sup>2</sup>	RA, T2DM, back pain, OA, overweight, gut, bowel, asthma
P5	M	70	Spouse	Age pension <sup>2</sup>	CVD, HT, T2DM, PVD, vision, hearing, OA, kidney disease
P6	M	54	Alone	Unemployment payment <sup>1</sup>	T2DM, OA, back pain, other chronic pain, PVD, HT, overweight, vision, depression, thyroid.
P7	M	65	Spouse, other family	Part time work <sup>3</sup>	T2DM, HT, back pain, other chronic pain, gut, depression/anxiety, sleep apnoea, obesity, hearing
P8	M	59	Alone	Unemployment payment <sup>1</sup>	T2DM, PVD, overweight, depression/anxiety, OA, back pain, other chronic pain.
P9	F	57	Children	Disability pension <sup>2</sup>	T2DM, OA, back pain, gut, COPD, asthma, depression/anxiety, incontinence, HT
P10	F	66	Spouse (P11)	Part time work <sup>3</sup>	OA, asthma, depression/anxiety
P11	M	68	Spouse (P10)	Age pension <sup>2</sup>	CVD, HT, T2DM, PVD, hearing, cancer, gut, asthma, depression/anxiety, COPD, chronic back pain, other chronic pain
P12	F	47	Other family	Carer pension <sup>2</sup>	T2DM, OA, other chronic pain, back pain, kidney disease, liver disease, cancer, obesity, gut, bowel, HT
P13	F	60	Alone	Disability pension <sup>2</sup>	T2DM, OA, back pain, other chronic pain, HT, obesity, COPD, gut, lymphoedema, sleep apnoea

CVD=cardiovascular disease; HT=hypertension; T2DM=type 2 diabetes; COPD=pulmonary disease; RA=rheumatoid arthritis; PVD=peripheral vascular disease; OA=osteoarthritis; PTSD= post-traumatic stress disorder.

1= income ≈ A\$15000 p/a – below poverty line; 2 = income ≈ A\$22000 p/a – equivalent to Australian poverty line; 3 = unskilled occupation, < 20hr/week.

### **Multimorbidity and capacity**

As illustrated in table 5.4, multimorbidity was related to biography, resource mobilisation and work realisation. People reported biographical challenges when a new condition emerged.

They had often managed a chronic condition for years without difficulty, but the impact of another condition could make all the difference. This was especially the case with conditions associated with functional impairment, which often placed greater demands on biographical reframing due to the loss of meaningful activities (especially if people had to stop work or lost other significant life roles).

*Participant 6: I've always been an outdoor labouring person working all my life you can't just flick the switch and sit in front of a computer I'd rather shoot myself to be honest [I feel] just not as happy...because you're not going forward...in life because you haven't got a job...it's like you're just stagnant*

For those people who were waiting (or hoping) for a definitive diagnosis, treatment or explanation of their condition, building biographical capacity was difficult. They felt that they were in limbo and unable to 'move on' with their lives.

**Table 5.4: The relationship of multimorbidity to capacity domains**

CAPACITY DOMAINS		THEMES RELATED TO BOTH CAPACITY AND MULTIMORBIDITY
<b>Biography</b>		Each new condition requires biography work. Certain conditions (e.g. undiagnosed, disabling) place greater demands on biography.
<b>Resources</b>	Physical	Conditions causing functional impairment are prioritised.
	Psychological	Poor mental health affects ability to look after other conditions.
	Financial	Multiplying healthcare costs. 'Tipping point' where increased number of conditions or disability results in loss of income.
<b>Environment</b>		No issues specific to multimorbidity
<b>Work</b>		Treatment workload is easier to achieve if conditions have low symptom burden or are perceived as interrelated; harder if mental health is poor.
<b>Social</b>		No issues specific to multimorbidity

Multimorbidity had a profound effect on resource mobilisation. Physical, psychological and financial capacity were all compromised. Eight of the thirteen participants reported chronic pain conditions (osteoarthritis (3), shoulder pain (1), back pain (2), leg/foot pain (2)) and two reported diabetic foot ulcers as their most important condition. All ten participants related condition priority to the associated loss of physical capacity, including the ability to work, exercise, undertake household tasks and leisure activities. Both couples prioritised their partner's chronic pain condition above their own chronic pain conditions because of the additional physical demands it placed on them as carers, further reducing their own (already restricted) physical capacity.

*Participant 11: [my biggest issue is] the shoulders more than diabetes...because if I do something I shouldn't do I pay for it...Participant 10 (spouse): and it impacts on sleep and me having to do things*

Psychological capacity was also essential. Although we selected participants based on their physical health conditions, eight people also reported a mental health diagnosis. The remaining five interviewees also described emotional difficulties, with several having undergone mental health treatment in the absence of a formal diagnosis. Two participants rated depression as their most important condition, and one prioritised obesity due to its impact on her mental health. Again, these conditions were prioritised because they prevented the attainment of desired goals including the ability to socialise, work, undertake study, and engage in family life. Participants also described how depression affected their adherence to, and motivation for, treatment of other health conditions. All those having trouble with their diabetes management reported moderate to severe depression.

*Participant 1: I get depressed because things don't seem to happen quickly enough for me and I get upset that I can't do things so I don't eat, I stop taking my meds, I self-harm ... things like that*

All participants noted that multiple chronic conditions led to increased healthcare expenditure, thus reducing financial capacity. All bar one interviewee stated that they had not undertaken recommended treatments or appointments at times due to cost.

*Participant 12: the psychologist that I'm seeing I... pay out-of-pocket to see her...I have to think about what don't I get done that week do I not pay my phone or power...*

Four participants paid for private health insurance. Although there was a recognition that this provided a better quality, faster service, participants felt that the cost could not be sustained into the future without additional funds provided by ongoing employment or other family members.

Increased healthcare costs were often complicated by loss of income. As multimorbidity increased, functional capacity declined, with ten of the thirteen participants reporting that their health conditions had forced them to stop work. Several people described a 'tipping



point' where they were no longer able to work due either to a gradual increase in disability or due to a new health condition which resulted in greater functional impairment. Most were unable to access the disability or aged pension (at least initially), which could provide a low but secure income, and were reliant on savings or financial support from their family.

*Participant 6: I've lost my house that was the main thing...I nearly had it paid off [but] I had no insurance because I had shoulder operations before and they wouldn't give me income insurance so I couldn't get that ...when this happened I was buggered couldn't work so I had to sell my house*

The ability to build capacity by work realisation depended on the nature of the condition. Conditions such as diabetes which had a low symptom burden, were reasonably predictable and had a clear management plan were cited as easier to successfully manage than more unpredictable or difficult to control conditions such as chronic pain, rheumatoid arthritis or depression.

*Participant 4: [managing condition workload] it depends on what sort of health conditions you've got because my diabetes is really just diet and of course medication but the rheumatoid arthritis is one that you need to keep in check ...if you have a flare-up*

If the person saw their conditions as interrelated in terms of cause or treatment, they were more able to manage it, compared to seeing it as a series of separate conditions. Those with the greatest difficulty in successfully accomplishing treatment work all reported mental health issues, associated with a sense of being overwhelmed and disorganised, rather than enormous treatment demands.

*Participant 2:... it'd be so much easier if I just had one health problem I could work on and not have multiple problems and you just think ...put your hands up...I got really bad a few months ago ....I just stopped taking everything ....I went into a really deep depression and couldn't be bothered doing a thing*

## Interacting capacities

Loss of capacity often snowballed. The interaction between mental and physical health conditions was a common theme. Some thought of depression as the trigger for all their health conditions, often related to past trauma. For others, depression developed after other health conditions, either directly (e.g. following heart surgery) or due to pain or functional incapacity.

*Participant 8: that's where depression comes in you're just sitting in the same house all day every day when I was working I would have holidays for 8-10 weeks a year*

Loss of physical capacity, in turn, provided multiple triggers for mental health decline. It had direct impacts on income (ability to work) and on biography (loss of life role, ability to engage in meaningful activity), as well as the symptom burden of pain or fatigue. Worsening depression, whether triggered by a physical health issue or not, affected work realisation, reducing adherence to treatment tasks, affecting motivation and problem-solving ability. It could thus exacerbate co-existing physical health conditions.

Financial resources could bolster capacity. Those who had a secure (if limited) income, compared to those receiving unemployment benefit or in an insecure work environment had fewer mental health difficulties and more effective strategies to manage their mental health. The two participants working part-time chose to continue because they recognised the mental health benefits (boosting psychological capacity) despite the fact that it exacerbated their chronic pain (reducing physical capacity).

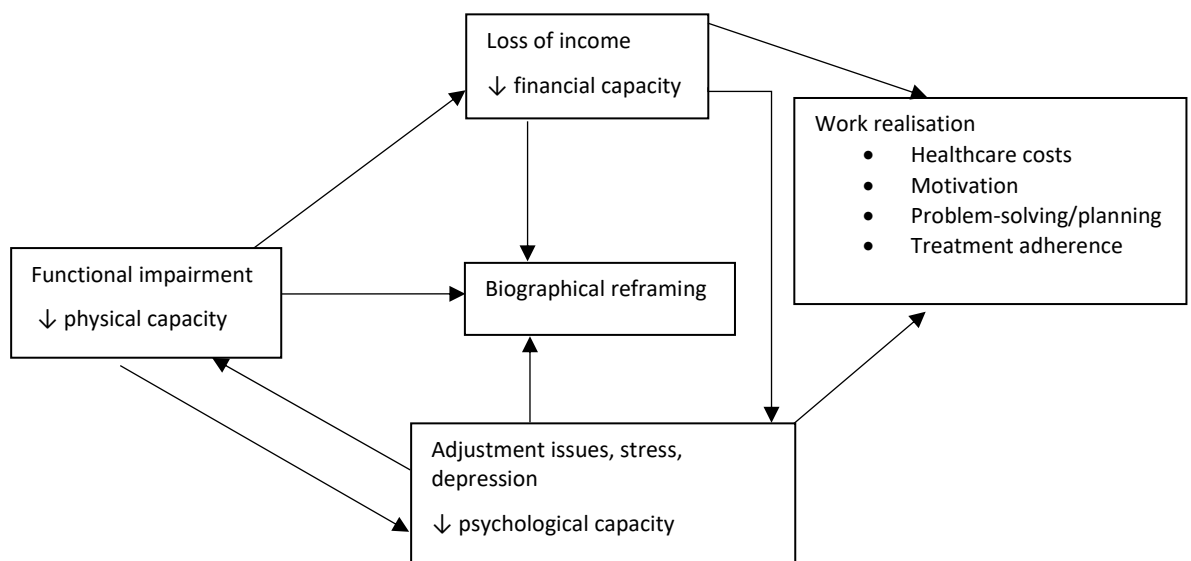
*Participant 7: with depression people handle it in different ways I keep busy I work I do things if I can't work what happens I go downhill...as soon as I stop doing things I go downhill*

All three resource mobilisation factors were closely related to biographical disruption (fig 5.3). Reduced physical capacity led to the loss of preferred and meaningful activities, including important life roles such as work. This could lead to depression (reduced psychological

capacity), which then affected motivation and future planning. Reduced financial capacity often resulted from the loss of physical capacity (inability to earn an income) but lack of income also limited people's access to meaningful or enjoyable activities, as well as access to healthcare (which could potentially improve physical and psychological capacity). Those with greater financial security (e.g. access to the pension) were more able to put their energies into meaningful activity which assisted with biographical reframing.

**Fig. 5.3. Interacting capacities**

Functional impairment leads to loss of income, biographical difficulties and psychological stress. Loss of income affects biography, psychology and work realisation. Psychological stress affects biography, physical capacity and work realisation.



## Multimorbidity and burden

The relationship between multimorbidity and the different aspects of burden, as described by NPT, is demonstrated in table 5.5.

**Table 5.5: The relationship of multimorbidity to burden domains**

BURDEN DOMAINS		THEMES RELATED TO BOTH BURDEN AND MULTIMORBIDITY
<b>Coherence</b>		Making sense of conditions is easier when they are interconnected but harder if depression dominates. HCPs help with diabetes understanding but less so with other conditions.
<b>Cognitive participation</b>	HCP relationships	Multiple HCP involvement, poor service co-ordination between conditions
	Individual	Mental health affects ability to organise healthcare
<b>Collective action</b>	Treatment tasks	More tasks to undertake (polypharmacy, appointments, self-care), but for many this becomes a routine not a burden.
	Contextual Integration	Greater healthcare costs, often combined with loss of income, are the main barrier
<b>Reflexive monitoring (Appraisal)</b>		Constant need to reassess due to interactions between conditions and treatments. Little guidance or assistance from HCPs.

The ability to form a coherent understanding of health problems was easier if the conditions were seen to be interconnected or to stem from the same cause. Disparate health issues often felt overwhelming and some people struggled to make sense of them. These participants often had depression as their primary (initial) health condition.

*Participant 5 [managing multiple health conditions is not a problem]...because I got them all together and they're sort of all related...I was diagnosed [with diabetes] in 89 and I had my first heart attack in 92 so it's the same period of time and there is no doubt about the fact that they were all related to my drinking...I see it as one big problem instead of separate things*

Many people reported that HCPs had provided them with information and education about diabetes, but few other conditions were addressed. Of note, HCPs were rarely seen as sources of information about conditions causing functional impairment (pain, mental health, fatigue). Learning about these conditions was either via trial and error or the internet.

*Participant 10 ...[learning about osteoarthritis] I've self-managed I've experimented with myself*

In the cognitive participation domain, interactions with HCPs multiplied as numbers of health conditions increased. All participants reported involvement with several providers, with most seeing 3-5 HCPs regularly. This could be challenging if HCPs were time-limited, unsympathetic or transient (common in rural areas). Some people found it hard to keep track of who they were seeing and for what condition. Multidisciplinary and co-located services were noted to be very helpful and the need for co-ordination was repeatedly discussed.

*Participant 11: every time you go there [to the GP clinic] they change the doctors around and the doctor changes the tablets Interviewer: seeing different doctors all the time? Participant 11: yeah*

Individual organisation was important in multimorbidity. Those who had a routine, or a system to manage medication coped better. Poor medication adherence was associated with a lack of routine and was frequently associated with mental health conditions.

The topic of collective action was explored in relation to the numbers of treatment tasks, and the ability to integrate the condition into daily life. All participants were asked which of their health condition(s) required the most treatment work. Four people selected diabetes as having the greatest workload and three nominated conditions related to wound healing and dressing. The remaining participants did not identify a specific condition. Six of those with diabetes felt that their diabetes management was normalised and fully integrated into their lives.

Despite this, all participants recognised that having multiple health conditions meant additional treatment tasks. Some incorporated it into their daily routine, with several people describing it as their 'job', but others found the workload too great. Everyone reported polypharmacy, and many had concerns about medication interactions and side-effects. Those living more remotely (6 hours travel from the state capital city) had significantly greater time and money costs associated with travelling to appointments, as well as fewer treatment choices, compared to those living in an inner regional area (2 hours from the capital). Some people managed their treatment load by recognising that the same treatment (e.g. exercise) could work for several conditions.

For most people, the additional costs of healthcare associated with multimorbidity was the main barrier to the integration of the conditions into their daily life, especially for those who were no longer able to work.

Finally, reflexive monitoring (appraisal) played an important role in the management of multimorbidity. People had to undertake more cognitive work to understand how treatments and conditions interacted, and needed to constantly reassess and reconsider one condition in the light of their other conditions. This ongoing instability could make normalising treatment workload more difficult. Participants reported undertaking appraisal in relation to both medication use and lifestyle recommendations. Most people had concerns about polypharmacy and were keen to minimise medication use, but struggled to unravel the interactions between conditions and medications.

*Participant13: because it's all combined as I said when I went for oncology there yesterday because I take a tablet that can cause hot flushes...they ask do you get hot flushes... I don't know I've got so many health problems...*

Lifestyle recommendations were often questioned because participants felt they were unrealistic (for diet), or because people did not know how to undertake exercise when they had coexisting chronic pain.

*Participant 3: everywhere we go it whether you go to see the GP or [the dietician] ...the physiotherapist or whatever they all say exercise and I said but it's just not possible we can't do it...because of the pain*

Those with diabetes frequently described the process of appraising and modifying treatment due to the impact of stress, pain or illness on their blood sugar levels. Some were confident in 'trouble shooting' their various health conditions and could monitor and adjust treatment as needed, while others found that additional health conditions 'muddled the waters' and made it harder to plan what to do.

*Participant 7 [managing diabetes when first diagnosed] because it was new it was a bit of a novelty and I knew what I had to do but as time goes on...I've had lots of other health issues...I have to think oh I've got to look after my shoulder I've got to be careful of my hernia and it takes you away from the diabetes*

Many participants engaged in individual appraisal and adjusted their treatments (including medication) without necessarily discussing the changes with a HCP.

*Participant 8: when I was going to [the hospital] they wanted four [blood sugar] readings a day but you run out of the strips after a while... I did that for about 4 or 5 weeks but it there wasn't really a great deal gained by it so I can't see the point.*

## 5.5 Discussion

### Main findings

This study aimed to investigate how the additional challenges of multimorbidity influence different aspects of capacity and burden, as described in the literature. For this rural, low-income population, the nature of the condition was of key importance. Conditions associated with functional impairment, especially chronic pain and mental health conditions, had the greatest influence on capacity. In our analysis of burden, multimorbidity was associated with a greater number of treatment tasks, costs, and appointments with HCPs, as has been well-documented previously (42, 43). The domains of coherence (sense-making) and reflexive monitoring (appraisal) were particularly important and this was related to the interactions between capacities, conditions and treatments that most participants dealt with.

### The nature of the condition

Several studies (15, 16, 18, 22), have reported that patients prioritise health conditions based on their functional impact, and this study reports similar findings. Analysis of specific capacity domains showed that pain and mental health conditions (as well as diabetic foot ulcers) had the greatest impact on capacity. In this low-income rural setting, most participants had been manual workers, and the biggest functional impact was the loss of employment. This had multiple impacts on other capacity domains including biographical, financial, psychological and work realisation, and could affect motivation for, and adherence to, self-management of other health conditions (21, 39).

The loss of capacity associated with functional and psychosocial conditions indicates the need for targeted treatment to bolster capacity. However, for many participants, treatment work



was focussed on conditions with few symptoms (e.g. diabetes), with limited formal treatment for their chronic pain or depression. In an ideal world, per the Cumulative Complexity Model, successfully managing treatment work should reduce illness burden and increase capacity, thus making it easier to normalise health conditions. In this population, effectively managing treatment work often had little impact on capacity, since loss of capacity was related to conditions which had few treatment demands. Without observed capacity benefits, this may discourage people from engaging in treatment work (44). Although the Cumulative Complexity Model and the associated burden and capacity frameworks fitted the data well, the issue of mismatch between treatment burden and capacity deficits has not been previously noted. This may be an important factor in multimorbidity self-management which deserves further attention.

While some participants had structured management approaches for their pain or mental health conditions, this was often developed without HCP input. Others did not see such conditions as having a treatment pathway at all, but just as symptoms to endure. However, these conditions are often responsive to generic interventions such as exercise or mindfulness, which means that their management need not increase treatment work: the use of synergistic treatments which work across a range of health conditions has been recommended for multimorbidity (10, 19, 22). The challenge may lie in convincing patients of treatment efficacy. Despite its known efficacy for chronic pain and depression (45), many participants believed that exercise was contra-indicated, or did not know how to approach it. This may be an important but neglected role for HCPs working in chronic disease management. Providing education about the relationships between pain, mental health and other chronic conditions, as well as synergistic treatments such as exercise and mindfulness could be helpful, although a low HCP knowledge base in these areas (46, 47) and insufficient funding of non-pharmacological interventions (noted by several participants) remains a barrier.

The role of mental health in treatment adherence makes it a particularly important area to be formally addressed in the chronic disease management environment. For all participants, their mental health was closely entwined with, and responsive to, their physical and financial capacity. Unfortunately, as a relic of dualism, mental health conditions are often dealt with and funded in isolation from other chronic diseases, and many mental health providers have limited knowledge of physical health conditions and limitations. This study emphasises the importance of ensuring that mental health interventions are integrated and tailored to people with co-existing physical health conditions, thus reflecting the reality of people's experience as unified beings, not as minds and bodies.

### **Interactions and integration**

The increase in treatment tasks and HCP interactions as a result of multimorbidity is widely recognised, and has led to the development of treatment burden assessment tools (26, 48, 49). There has been less attention paid to the importance of coherence and appraisal, which emerged as important in this study. Participants frequently engaged in coherence and appraisal work to help them understand and manage the interactions between capacities, conditions and treatments. Psychological, physical and social capacities were inextricably linked, and although stand-alone mental health treatment was important for some people, understanding the connections between, and integrating all three aspects of well-being was the key for those who were managing well.

In terms of individual conditions, people struggled more to make sense of conditions with functional impairment, but this may have been related to the lack of HCP input for these conditions. People reported a greater knowledge of diabetes, with most having received education, but few understood how it interacted with other conditions. Those who saw the

linkages between their conditions had a more integrated understanding of their health overall and reported greater confidence in self-management and lower perceived burden.

Although study participants regularly engaged in appraisal, reviewing, prioritising and adjusting their treatments, HCP input into these decisions was limited. Many participants considered that 'juggling' their different conditions was up to them and that the HCPs' role was to provide instruction or treatment on specific individual conditions. An important role for HCPs, which would potentially increase treatment adherence and complement the provision of 'synergistic' treatment interventions, might be to help patients explore the linkages between conditions (20, 22). Making treatment decisions based on a good understanding of how different conditions interact and affect capacity and workload is likely to be useful for both the patient and the HCP.

### **Limitations and strengths**

This was a small qualitative study of a low-income rural population, and therefore the observations may be less relevant to more advantaged urban groups or in countries with greater levels of social medicine than Australia. The fact that two interviews were conducted by phone (due to Covid-19) could be considered a limitation, although no difference was noted in the interview length or topics covered. The findings remain useful because the research participants came from the most relevant population, as distilled from the literature (4). Multimorbidity in younger (pre-retirement) age groups is becoming more common especially amongst low-income populations, and there is a need to explore more effective self-management interventions for this group. Our phenomenological focus of prioritising individual experience meant that we could explore a wide and varied range of responses from people facing similar life challenges. The use of existing taxonomies, allowing us to explore different aspects of capacity and burden, was a further strength of this study.

## **Conclusion**

Our exploration of burden and capacity in this qualitative study confirmed the importance of understanding multimorbidity in its broadest sense. Multimorbidity consists of far more than a list of diagnoses, and to manage multimorbid chronic conditions effectively, HCPs must address the crucial and interacting role of functional and psychosocial factors. Additionally, understanding the links between conditions is important to help patients to integrate and normalise their conditions into their daily life. Patients need support from HCPs to build bridges between conditions and make choices that best fit their needs and preferences. Finally, this study also highlighted the overwhelmingly negative effect of financial insecurity on burden and capacity. Financial hardship associated with chronic illness is well-known (50). The additional impact experienced by those who are already disadvantaged underlines the importance of health and social policies to address the challenges faced by this population.

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## CHAPTER SIX:

# Self-efficacy in disadvantaged communities: Perspectives of healthcare providers and clients

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The published version and supplementary files for this paper are provided in Appendices G and H.

## 6.1 Abstract

**Objective:** Most chronic disease self-management interventions emphasise the integral role of self-efficacy in achieving behaviour change. We explored the applicability of this model in a low-income setting, from the perspective of both patients and clinicians.

**Methods:** Interviews with multimorbid patients and their health providers at two rural community health centres in Victoria, Australia. We used a phenomenological methodology, exploring themes of confidence to manage health, outcome expectations and goals.

**Results:** Many assumptions in which the self-efficacy model is grounded did not apply to this population. Past experiences and resource constraints, especially poverty and healthcare access, influenced confidence, expectations and the ability to achieve desired outcomes.

**Discussion:** The focus of traditional self-management support on individual behaviour change disadvantages rural low-income patients, who face barriers related to life experience and resource constraints. For this group, self-management support needs to return to its roots, moving away from a narrow conception of behaviour change and reinstating the role of 'support' into 'self-management support' interventions. Health providers working in rural low-income settings should recognise the limits inherent in self-efficacy focussed interventions and think broadly about engaging with their clients in whatever way supports them to find a life with meaning and purpose.

## 6.2 Introduction

Chronic health conditions (CHCs) such as diabetes, arthritis, cardiovascular disease and depression are common and frequently comorbid. Effective management of these conditions requires long-term commitment to treatment adherence and lifestyle modifications, and thus is often reliant on the quality of an individual's self-management skills(1, 2). Self-management encompasses everything that a person with a CHC needs to do to manage their condition(s) and its impact, including condition management (appointments, treatment adherence, lifestyle changes) and adjustment to changes in life roles, emotions and social relationships(1, 3). To assist in this process, self-management support (SMS) interventions have been developed to help people learn about their CHCs and use generic skills such as problem solving, decision making and resource utilisation to take control of their conditions, optimise health and create a purposeful life(1, 2, 4).

SMS interventions, whether individual, group, peer or professional-led, are usually grounded in Bandura's theory of self-efficacy(1-4), defined as confidence in one's ability to perform actions required to produce a given outcome(5). Knowledge of a CHC and its treatment must be supplemented with adequate self-efficacy for behaviour change to occur. This should in turn lead to better control over the condition(s) and reduce their impact on peoples' lives. Most providers of SMS embed self-efficacy enhancing techniques such as performance mastery, symptom interpretation and modelling into the knowledge and skills training they provide(1-3).

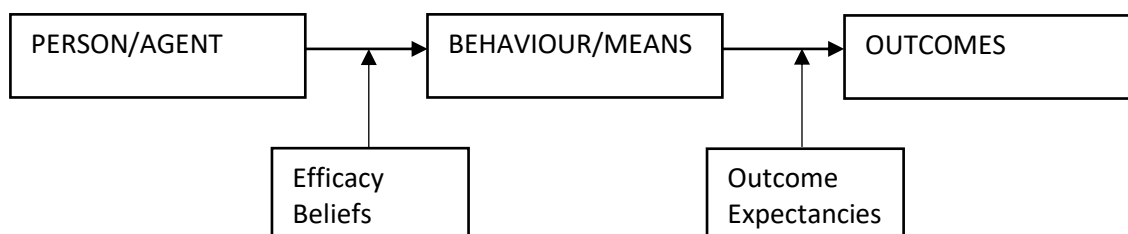
Although SMS interventions are consistently associated with increased self-efficacy, this has not necessarily translated into improved clinical and behavioural outcomes(2, 3, 6). A common criticism is that positive findings are often limited to a narrow patient cohort, usually socioeconomically advantaged volunteers(2, 7), with lower participation and higher attrition

rates seen in lower socioeconomic status (SES) groups(8). Whether these positive outcomes, and the proposed behaviour change processes driving them, are relevant in other contexts has been questioned. The behaviour change pathway described by Bandura (see fig 6.1)(5) has several components: in addition to self-efficacy, there must be a sense of individual agency; a belief that self-management actions will lead to beneficial outcomes (outcome expectations); and outcomes (goals, priorities) that are agreed between patients and health providers and relate to improved health or function(5). The fact that most participants in SMS intervention research are volunteers means that they are already likely to have a sense of individual agency; a belief that their actions will achieve desired goals; and goals related to improved health. Self-efficacy is the missing link, but this may differ in low SES settings.

Low SES groups are known to have both lower baseline self-efficacy,(9, 10) more negative outcome expectations,(9, 11, 12) and priorities that differ from higher SES groups(9, 11). Explanations for these findings include fewer experiences of control in peoples' daily lives(9, 13), limited exposure to modelling of self-efficacy, greater vicarious experiences of poor health outcomes(11-13), lower education levels, greater practical or resource barriers to achieving desired outcomes(14) and fewer social supports(6, 11). If the components of the behaviour change pathway (fig 6.1) are operating differently in low SES settings, this may explain why self-efficacy approaches are more effective in higher SES groups(10, 15). We wished to investigate this further in the current study.

**Figure 6.1**

(adapted from Bandura's description of the relationship between self-efficacy and outcome expectations(5, 16) and Skinner's taxonomy of control terminology(16)).



This study is part of a wider qualitative project exploring the challenges of chronic disease self-management (CDSM) in rural low-income settings. Rural populations experience limited healthcare access in addition to high levels of social disadvantage and disease burden(17). Using the same interview data, we have explored three key barriers to self-management: health providers and systems(18); health demands (multimorbidity); and (in this study) self-efficacy. The new element to this research is that we are investigating the relationship between self-efficacy, SMS and social disadvantage from the perspective of Bandura's pathway between person and outcomes (see fig 6.1). By basing our analysis on the theory that most commonly informs SMS interventions, we hope to clarify or identify the different approaches needed for SMS in this context. Therefore, our research question is: What is the place of self-efficacy in self-management interventions for low-income rural populations?

## 6.3 Methods

### Overall study design

The study design was qualitative. We first interviewed thirteen people living with multimorbidity, using a phenomenological methodology, then undertook a pragmatic study with twelve healthcare providers (HCPs). Sample size was determined by data saturation. Research was conducted in accordance with national ethics guidelines, and approval was granted by the La Trobe University Human Research Ethics Committee (HEC19387; HEC19363). The completed COREQ checklist for qualitative studies is available in appendix A.

### Participant recruitment and setting

Participants were recipients or providers of chronic disease SMS services in two community health centres in Victoria, Australia. Community health centres provide primary care services, including chronic disease SMS, for low-income and socially disadvantaged populations. The health centres were based in towns with 118,000/56,000 inhabitants, 150km/540 km away from the state capital and servicing the surrounding regions.

Client participants met study inclusion if they were aged between 18-75 years, with at least two chronic health conditions and in receipt of government income support or a healthcare card (signifying low income). Clients were recruited directly by their HCPs or via posters displayed in the health centre waiting areas, directing them to discuss the study with their HCPs if they wished to participate. HCP participants were all nurses and allied health professionals who worked in chronic disease management and who described SMS as an integral part of their job. We did not include GPs (physicians) since our focus was on clinicians who exclusively provided chronic disease SMS. Potential HCP participants were identified via

the community health employee database, then emailed directly with information about the study and invited to participate. Selection was purposive to ensure a range of disciplines and years of experience.

### **Data collection**

Following completion of informed consent and collection of sociodemographic variables, we conducted individual semi-structured interviews from December 2019 to June 2020. Clients were asked to describe their health conditions, the healthcare tasks they needed to undertake and difficulties or barriers they encountered. Healthcare professionals were presented with two vignettes which had been modelled on the patient participants, and asked to reflect on self-management capacity, treatment burden and perceived barriers to self-management. The interview protocols, which are available in appendix B and C, were trialled and modified in response to feedback. Interviews were conducted by RH and SB and continued until all authors agreed that saturation had been reached. Six HCP interviewees were known to RH, who worked at one health centre, but none had a supervisory or subordinate relationship with her. Interviews were audio recorded, transcribed verbatim by RH and imported into NVivo 12. Field notes detailing key issues and observations were made following each interview.

### **Data Analysis**

Following importation of the interviews and field notes into the NVivo12 programme, all authors read through the data independently several times. We undertook a deductive approach to our thematic analysis, using self-efficacy theory as our guide. During data familiarisation, we used NVivo coding stripes to highlight text related to self-efficacy, such as confidence in undertaking self-management tasks; reported psychological/cognitive barriers to

self-management; references to outcome expectations; descriptions of goals, priorities, expected outcomes and future hopes.

After data familiarisation and group discussion, we decided to use the behaviour change pathway described in figure 6.1 as an initial coding structure. We used Skinner's(16) headings of: Agency (the individual person); Agent-means (the connection between the person and their actions, including self-efficacy); Means-outcomes (connection between actions and outcomes) and Outcomes (goals) as the four main coding categories in nVivo12. Data coding into these categories was first undertaken by RH, then reviewed and revised by ES and SB. Following initial data categorisation, we used an iterative approach, triangulating between interview data, discussion amongst the authors, review of the literature, then back to the data. This evolved into a shared understanding of the important themes and sub-themes.

## **6.4 Results**

### **Participant and interview characteristics**

We conducted eleven interviews with thirteen community health clients (two interviews were with couples who both had multiple CHCs). Two interviews were by phone due to COVID-19 restrictions and all others were conducted face-to-face in a community health centre interview room. Interview duration ranged from 31-71 minutes (mean 43 minutes). Twelve health providers were interviewed, all by phone or video link (determined by individual preference and technology capacity) due to the COVID-19 pandemic. Interview duration ranged from 38 to 60 minutes (mean 45'). Table 6.1 and 6.2 record key participant characteristics.



**Table 6.1: Characteristics of client participants**

ID	Sex	Age	Living situation	Source of income	Health conditions (as reported using the Disease Burden Impact Scale).
P1	M	57	With friend	Unemployment payment <sup>1</sup>	Back pain, osteoarthritis (OA), other chronic pain, depression, PTSD, liver disease, vision problems.
P2	F	50	Spouse and child	Unemployment payment <sup>1</sup>	Type 2 diabetes (T2DM), back pain, other chronic pain, obesity, depression, gut problems, bowel problems, vision, hypertension (HT)
P3	M	72	Spouse (P4)	Age pension <sup>2</sup>	Rheumatoid arthritis, OA, HT, back pain, cardiovascular disease (CVD), gut, vision, overweight
P4	F	71	Spouse (P3)	Age pension <sup>2</sup>	Rheumatoid arthritis, OA, T2DM, back pain, overweight, gut, bowel, asthma
P5	M	70	Spouse	Age pension <sup>2</sup>	CVD, HT, T2DM, OA, peripheral vascular disease (PVD), vision, hearing, kidney disease
P6	M	54	Alone	Unemployment payment <sup>1</sup>	T2DM, OA, HT, PVD, back pain, other chronic pain, overweight, vision, depression, thyroid.
P7	M	65	Spouse, other family	Part time work <sup>3</sup>	T2DM, HT, back pain, other chronic pain, gut, depression/anxiety, sleep apnoea, obesity, hearing
P8	M	59	Alone	Unemployment payment <sup>1</sup>	T2DM, OA, PVD, overweight, depression/anxiety, back pain, other chronic pain.
P9	F	57	Children	Disability pension <sup>2</sup>	T2DM, OA, HT, back pain, gut, COPD, asthma, depression/anxiety, incontinence.
P10	F	66	Spouse (P11)	Part time work <sup>3</sup>	OA, asthma, depression/anxiety
P11	M	68	Spouse (P10)	Age pension <sup>2</sup>	CVD, HT, T2DM, PVD, hearing, cancer, gut, asthma, depression/anxiety, COPD, chronic back pain, other chronic pain
P12	F	47	Other family	Carer pension <sup>2</sup>	T2DM, HT, OA, other chronic pain, back pain, kidney disease, liver disease, cancer, obesity, gut, bowel.
P13	F	60	Alone	Disability pension <sup>2</sup>	Diabetes, osteoarthritis, hypertension, back pain, other chronic pain, obesity, COPD, gut, lymphoedema, sleep apnoea

Income categories: 1= income  $\approx$  A\$15000 p/a – below poverty line; 2 = income  $\approx$  A\$22000 p/a – equivalent to Australian poverty line; 3 = unskilled occupation, < 20hr/week, supplemented by income support payment.

**Table 6.2: Characteristics of HCP participants**

		Number/range	%/Mean (SD)
Female gender		12	100
Age in years		24-56	41 (12.3)
Profession	Nurse	2	16.7
	Diabetes educator	4	33.3
	Occupational therapist	3	25
	Physiotherapist	1	8.3
	Exercise Physiologist	1	8.3
	Podiatrist	1	8.3
Years since graduation		1-34	14.9 (10.8)
Years worked in chronic disease SMS		1-18	9 (5.2)
Number reported postgraduate training in SMS		7	58

## Main themes

As described earlier, our initial coding categories were informed by self-efficacy theory(5, 16).

These categories: agency; agent-means; means-outcomes; and outcomes, fitted the interview data well.

### Agency

Self-management and self-efficacy are premised on a concept of the 'self'(6). This theme explored ownership and responsibility for self-management tasks and healthcare generally.

Both clients and HCPs discussed the need for acceptance of CHCs as a prerequisite for taking action. ... *There's no good whinging about it or carrying on it's just the way it is I've got a heart problem... (Client 5)*

Some clients described the transition from denial to 'facing up' to their CHCs. HCPs discussed how fear, mental health, cultural and health system barriers could lead to denial.

*...he may be in denial that he has diabetes and that he has got other health issues... but he doesn't want to change anything... (HCP 4)*

Most clients endorsed a sense of responsibility for their healthcare, even if they recognised that they were not managing it well. Some expressed a strong sense of ownership, describing self-management tasks as something they did for their own benefit – 'for me',

*... I'm losing weight I'm monitoring my blood and I'm actually doing that as something for myself... (Client 13)*

whilst others viewed these tasks as things required by HCPs and done 'for them'.

*...I've made a lot of changes but it's still not enough for what they want...it's very rare I get it [blood sugar] as low as they want - they want it under 7... (Client 8).*

The 'me-them' distinction was echoed by HCPs when describing the contrast between people who self-referred for SMS and those who had been referred by their GP.

*...the client turns up and they are not exactly sure why they are here they say I don't know my doctor sent me here ... (HCP 2)*

The self-referred clients had usually done so because they wished to improve their health ('for me'), but the latter group often had little idea of self-management and (apart from medication prescription) rarely discussed their condition with their doctor.

*...I would want to look at what her goals are - she has presented to me – has that been self-motivated or was it directed for her... (HCP 9)*

All participants were asked to reflect on the division of labour between clients and HCPs. Some clients retained a highly passive view and were looking for a 'fix',

*[in reference to visiting the GP] ... if she couldn't say I know how to fix it she would know where to send you... (Client 7)*

but most agreed that engagement with self-management was needed. For the majority, their responsibility was limited to following (or trying to follow) the instructions of their HCPs (compliance), with some reports of shared decision-making over how best to integrate self-management tasks into their life.

*... our GP did uni for so many years to do all this sort of thing...I trust him what he says...as far as anything medical goes that's the professionals job not Mr Google... (Client 3)*

A few clients reported that they made decisions about their health without seeking HCP input. Sometimes this was a choice based on knowledge of their CHC, but it could also be driven by poor relationships with HCPs or lack of agreed goals.

*...when you've been treated the way we have [by doctors] you tend to shut them out and try and do things yourself because you think well are they going to tell me the truth are they going to be honest... (Client 10)*

Some HCPs experienced frustration over passive clients who wanted to 'get something for free' from the service. Others emphasised the use of strategies such as motivational interviewing to promote a sense of agency. Most HCPs reported that increased complexity and resource constraints in rural low-income settings made this more difficult.

#### Agent-means:

This theme described peoples' ability and confidence to carry out self-management tasks, as well as HCP's understanding of self-efficacy and the methods they employed to enhance this.

Almost all HCPs considered that the development of self-efficacy was crucial for effective self-management, and described techniques such as building rapport, gauging confidence, client-directed goals, using feedback and grading tasks to promote performance mastery. HCPs stressed that a key feature of self-efficacy was having the confidence not just to undertake tasks, but to troubleshoot when circumstances changed or conditions were exacerbated.

*...a lot of people that we see ...pretty much hand their health over to the doctor so that when there are changes to [their] conditions [they] don't have an understanding of what's important or how to put strategies in place to make sure that those conditions don't worsen... (HCP 11).*

They also discussed how lower education levels and higher life demands (e.g. caring responsibilities, financial constraints) in low-income populations influenced self-efficacy.

*...when you have low education too you often lack confidence...you perhaps feel less confidence that you can manage those things... (HCP 11)*

*... the specialists they talk about what's wrong...half the time you don't understand what they're saying and you're trying to google it to work it out... (Client 2)*

Practical ways of modifying SMS for these populations, such as addressing literacy, were discussed but there was also widespread recognition that building self-efficacy could only occur if the person's environment was sufficiently resourced.

Client accounts also highlighted the importance of problem-solving and adjusting to changing circumstances, not just performing treatment tasks. Those who were skilled at this had greater knowledge of their health conditions and long-term relationships with their HCPs.

*...one of my readings was 3.5 which is technically a hyper...I actually took myself off it [the insulin] which the doctor was right behind me with... (Client 13)*

About half the participants reported established self-management routines, and described how they had integrated this into their lives. This included making lifestyle changes and finding

new ways to engage in preferred activities. These clients described themselves as mostly adherent rather than rigidly compliant, deviating at times from 'ideal' self-management according to their priorities.

*...we do eat a bit of stuff we're not supposed to eat ...oh god we're 71 for god's sake can't we have a chip now and then... but we're pretty good... (Client 4)*

Self-efficacy to exercise was an outlier, in that several people who were self-efficacious in other areas reported low confidence in this area, usually related to chronic pain conditions.

The remaining clients were not confident to undertake self-management tasks. This included those who saw self-management as something required by HCPs rather than for their own benefit, as well as those who felt responsible for their self-management, but experienced mental health barriers.

*...I get depressed because things don't seem to happen quickly enough for me and I get upset that I can't do things so I don't eat I stop taking my meds... (Client 1)*

*[the diabetes educator said] you aren't doing many blood sugars... I said yes I should have been doing it but everything was getting on top of me... (Client 7)*

#### Means-outcome:

This theme explored the connections between specific actions or behaviours, including self-management tasks, and expected or desired outcomes.

Virtually all HCPs stressed the need to understand one's CHCs, to make sense of the connection between self-management behaviours (e.g. diet, medication adherence) and outcomes.

*...you get told what you should be doing for your own health but if you don't understand why then you are less likely to take those things on board... (HCP 8)*

Some clients also recognised that limited understanding of their CHC had contributed to condition exacerbation,

*...I [thought] well I take my medications I'll be fine until they told me that I had kidney problems...so I thought maybe I should find out more... (Client 12)*

and both groups agreed that poorly delivered healthcare information was often to blame.

Most HCPs believed that greater knowledge would promote engagement in self-management by explicating the behaviour-outcome connection. Some clients also reported this, either because they had been 'scared' into action by the threat of negative outcomes

*...my blood sugar was at the point of massive organ failure and it freaked me out and that was like a little slap in the face... this is a reality check... (Client 13)*

or because they had seen their actions lead directly to positive outcomes. These views were espoused by those with higher levels of self-efficacy; in less confident clients, fear led to paralysis rather than action.

*...since I've known about this kidney disease I think oh my god when am I going to die... (Client 12)*

Participants also discussed negative expectations and uncertain health outcomes. Some clients viewed their conditions fatalistically, believing there was little they could do to change the situation or slow their decline.

*... it's just constant it won't change it's something I have to put up with... (Client 6)*

This was often related to wider social or environmental factors such as the experiences of family or friends (e.g. relatively early deaths), or loss of income resulting from their inability to work.

*...living those last 3 years before I turned 66 I was thinking oh my god I'm going to be just like her [my mother] I'm going to die of cancer... now I'm worried because I'm thinking maybe that's what's wrong... (Client 4)*

HCPs noted how disability and poor health was often considered a part of normal aging amongst their clients.

*...they tend to get used to the condition and used to how it impacts and then it is really hard to get back function ...so acceptance of disability... (HCP 7)*

In contrast to their advocacy of condition knowledge as a driver for self-management, HCPs also reflected on the reality that many CHCs do have uncertain outcomes despite good self-management, *...they're living with the underlying knowledge that this causes severe morbidity and mortality ...these are overwhelming issues... (HCP 10)*

or require significant effort to achieve only modest outcomes.

*... [does he] believe that with assistance he can slightly improve his quality of life without giving him the impression [he can] be completely pain-free... (HCP 6)*

Maintaining hope in these circumstances was a challenge, possibly for both HCPs and clients. Some clients maintained a phlegmatic outlook and for these individuals, social connections (including hobby clubs, peer support groups and time with grandchildren) were often of great importance. Having a degree of income security (i.e. receiving a pension) was a consistent feature for these individuals.

### Outcomes:

The final theme explored the desired outcomes (goals, priorities) reported by each group, where they differed, and how they aligned with the agent-means-outcome pathway.



For most clients, looking after their health was a high priority. Some felt that they had integrated their health conditions into their lives while still retaining purpose and meaning, in line with the outcomes expected for successful self-management.

*...even though it's [our health is] ruling our lives we try not to let it rule our lives if that makes sense... (Client 3)*

For others, their CHCs had become incorporated into their lives, but had essentially taken over their lives:

*...I look after it [my health] as best I can ...it's a full-time job but [it] never goes away... (Client 6)*

and a third group were overwhelmed by their health conditions and managing poorly.

*... [taking medication] I just seem to miss a couple of days...I get too mixed up in everything else ...on one of my visits to hospital they put me in for 3 days and the girl from pharmacy came in and she was horrified because I had big gaps in it... (Client 7).*

Both clients and HCPs noted that caring responsibilities, employment and complex life stresses (often interacting environmental and mental health factors) could detract from one's healthcare, and this was common in clients overwhelmed by their CHCs.

*...I have my family that are constantly needing help or ringing so I'm always trying to fix things for them and I just get put on the backburner... (Client 2).*

HCPs reported that in these situations, they focussed on addressing environmental factors rather than SMS, but resource constraints often limited their effectiveness.

Virtually all HCPs stressed the importance of identifying the goals and concerns of clients when engaging with SMS, with several also acknowledging that goals may differ between HCPs and clients. *... [I try to] ensure that the goals that the client has are very specific to themselves and is relevant for what they want to do so the client cares about it... (HCP 12)*

As expected, given their roles as providers of SMS for chronic health conditions, most HCPs focussed on health-related outcomes and linked these directly to self-management behaviours, for example, improving fitness (behaviour) to maintain independence and reduce pain (outcomes), modifying diet to stabilise diabetes and establishing routines to reduce treatment burden.

Client goals were often less specific, but still focussed on maintaining activity and independence, as well as spending time with friends or family. Several clients wanted to be employed in the future, but few believed this was likely. Although these goals appear amenable to SMS interventions, a different story emerged when clients talked about how they expected to achieve their goals. In contrast to the HCPs, who linked goal achievement to effective self-management, the pathways to clients' desired outcomes rarely prioritised self-management. Some clients were already self-managing effectively, but important goals remained out of reach, and could not be attained (at least in their view) via self-management, instead requiring some external support. Of the thirteen interviewees, seven reported that lack of access to surgery or specialist medical services was the key barrier to achieving their goals. Those living more remotely (540km from the state capital) reported greater difficulty accessing specialist appointments and additional transport and accommodation costs.

*...every time you've got to do something you've got to go away to Melbourne or Bendigo or Adelaide there's just not enough professionals here which is a pain... (Client 6)*

Access to social welfare services, and provision of aids, equipment and home care services (which were either unaffordable or had long waiting times) were also seen by several participants as the most effective way to increase independence and achieve their desired outcomes.

*... there's probably a lot more services out there than people realise you just don't know how to access them... (Client 5)*

*... I often ... think of having one person that can like I can call and say look this and that and then they can chase it up... (Client 1)*

*... we are registered with My Aged Care but you can't get the services...you're on the waiting list... (Client 12)*

Only two participants believed that working on self-management tasks with their HCP was the main pathway to their goals.

## 6.5 Discussion

### Summary of findings

Our aim was to explore the place of self-efficacy in self-management interventions for low-income rural populations. We looked at how community health clients and their HCPs negotiated the behaviour change pathway from agent, via self-efficacy beliefs and outcome expectations, to outcome.

All HCPs, and most clients, recognised the initial importance of taking responsibility (owning) their CHCs. For most HCPs, building self-efficacy was an important focus for SMS. However, clients and HCPs both identified psychological and environmental barriers to self-efficacy development, and some felt that positive outcome expectations were unrealistic given their life situation. For many clients, resource constraints formed barriers to their desired outcomes that could not be overcome by behaviour change. Both clients and HCPs felt that the task of building confidence (self-efficacy) and optimism (outcome expectations) was at times misplaced, given the past experiences and present realities faced by many clients. For this population, the concept of 'self-management support' needs revisiting, to emphasise 'support', rather than focussing only on 'self-management'.

### Confidence, optimism and life experience

In common with other studies, past experiences and current life demands were associated with lower self-efficacy(9, 10). People who have had limited success with education or employment, or have few healthy role-models will struggle more with self-efficacy boosting techniques such as performance mastery and vicarious learning(5). Since social support is known to bolster self-efficacy, peer support may be especially important in this population(19), given that there are likely to be greater cultural differences (therefore less opportunity for vicarious learning) between clients and their HCPs. Online peer support could provide a wider range of role models and maintain privacy (important in smaller rural communities), if barriers relating to technology literacy (common in low-income settings) and rural internet connectivity are addressed.

Lower outcome expectations have been observed previously in socioeconomically disadvantaged groups(9, 11) and in this study, the influence of both rurality and income was clear. Negative expectations were commonly related to people's experience of additional losses in consequence of their health conditions, including loss of employment (for ten of the thirteen clients), housing, social and leisure pursuits. A history of manual work, lack of financial cushioning and living in regions with few employment opportunities was common, thus the ability for participants to recoup their losses was limited. Experiences of early death or disability amongst family and friends appeared to influence future outlooks and this has also been reported elsewhere in similar contexts(11, 12). Unfortunately, such negative expectations also reflect the reality of health outcomes in rural low-income populations, who experience both poorer health and poorer healthcare(17). HCPs recognised this tension between promoting positive expectations and the reality of uncertain health outcomes. Both groups stressed the importance of meaningful goals, to enable hope in the face of uncertainty.

### Revisiting the meaning of 'self-management support'

Other studies have reported discordance between HCPs and patients over expected outcomes from self-management, with HCPs focussed on compliance and healthcare utilisation and patients seeking improvements in quality of life(20, 21). In the current study, the two groups agreed over desired outcomes, with both prioritising increased control over CHCs and better quality of life. However, opinions differed over how these goals could be achieved. Whilst HCPs saw the solution in behaviour change, clients (even those who were self-managing well) identified external (resource) rather than individual (belief/behaviour) barriers to achieving desired outcomes, with income and rurality acting as resource constraints. This reiterates the importance of context and suggests that a broader conception of SMS is needed for this population.

Chronic disease self-management should encompass three aspects: medical management, role management and emotional management(1, 22). Most HCPs providing SMS focus on medical management: skill-building and behaviour change(20, 23), but the aspects of role and emotional management are critical in (re)creating a life with purpose and meaning(24). For many people, the process of developing confidence and learning self-management skills will facilitate and enable emotional and life role adjustment. For others, having insufficient income or transport may present a barrier to living a meaningful life that cannot be overcome by any amount of confidence or lifestyle change(25). Therefore, HCPs working in these settings may need to view SMS more broadly, moving beyond traditional behaviour change interventions to explore other ways to support their clients and facilitate outcomes that provide purpose and hope.

This approach is not without its own set of challenges. Firstly, how to have this conversation. HCPs typically focus on a single condition at a time and may feel that exploring meaning and purpose is outside their discipline boundaries and comfort zone. Decision-making tools such as

ICAN(26) or PPC(27) are potentially useful to initiate such discussions, if coupled with clear pathways to resources and supports. Second, the health system often dictates the HCP role (to provide health-focussed self-management 'education') and requires time-limited measurable outcomes which may not fit the client's needs and preferences. The mantra of 'patient centred care' rarely allows for interventions that are primarily social, environmental or involve advocacy, even though these factors may form the greatest barriers(28). Community health centres, which often bring together social and health perspectives, may be best placed to take on this challenge.

### Strengths and limitations

The study focus on a multimorbid low-income population in rural Australia prevents generalisation to other settings. However, the need to analyse and modify self-management approaches in different contexts remains relevant, especially since the chronic disease burden is far higher in disadvantaged populations.

The strengths of this study lie in the consistency of the data obtained from both HCPs and their clients, who were based in the same rural communities. By grounding the study in self-management and self-efficacy theory, we could explore these topics in terms of what they were originally designed to do and consider their fit in a different context.

Study limitations include the necessity of conducting some interviews by phone due to Covid-19 and the small sample size, although the same topics were canvassed in both interview settings and data saturation was achieved, with no new themes identified in later interviews. A further limitation is the lack of inclusion of GP interviewees. This was deliberate, since the focus was on HCPs whose primary role was provision of SMS. However, a GP perspective would have been useful especially since both HCPs and clients appeared to view them as relatively peripheral to the SMS landscape, possibly related to rural GP workforce scarcity.

### Conclusion and Practice Implications

As Kendall(25) has noted, privileging self-efficacy as the foundation for SMS puts the onus on the individual and ignores the social context that each of us inhabits. This disadvantages rural low-income populations, who face barriers related to life experience and resource constraints. HCPs working in these settings should redefine and rediscover self-management support, moving beyond a narrow conception of behaviour change to encompass whatever is needed to support a life with meaning. If we are to truly aspire to patient-centred care, we must take a much wider view on what gives people hope and purpose (and how to help them achieve it) whilst living with long-term conditions.

**List of Abbreviations**

CHC: chronic health condition; SES: socioeconomic status; HCP: healthcare provider; SMS: self-management support; GP: general practitioner.

**Availability of data and materials**

Restrictions have been placed on our dataset by the La Trobe University Human Ethics board. The decision was based on the fact that this was a qualitative study of a small rural sample, involving sensitive health information that was potentially identifiable. The data may be obtained through the corresponding author or the La Trobe University Human Ethics board who may be contacted via email: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) or phone +61 3 9479 1443. The approval reference numbers are HEC19387 and HEC19363.



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## CHAPTER SEVEN:

Exploring the ability of self-report measures to identify risk of high treatment burden in chronic disease patients: a cross-sectional study

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This paper has been submitted for publication to the BMC Public Health Journal and is currently under review.

The supplementary files for this paper are provided in Appendix I.

## 7.1 Abstract

Background: Effective self-management of chronic health conditions is key to avoiding disease escalation and poor health outcomes, but self-management abilities vary. Adequate patient capacity, in terms of abilities and resources, is needed to effectively manage the treatment burden associated with chronic health conditions. The ability to measure different elements of capacity, as well as treatment burden, may assist to identify those at risk of poor self-management. Our aims were to: 1. Investigate correlations between established self-report tools measuring aspects of patient capacity, and treatment burden; and 2. Explore whether individual questions from the self-report tools will correlate to perceived treatment burden without loss of explanation. This may assist in the development of a clinical screening tool to identify people at risk of high treatment burden.

Methods: A cross-sectional survey in both a postal and online format. Patients reporting one or more chronic diseases completed validated self-report scales assessing social, financial, physical and emotional capacity; quality of life; and perceived treatment burden. Logistic regression analysis was used to explore relationships between different capacity variables, and perceived high treatment burden.

Results: Respondents (n=183) were mostly female (78%) with a mean age of 60 years. Most participants were multimorbid (94%), with 45% reporting more than five conditions. 51% reported a high treatment burden. Following logistic regression analyses, high perceived treatment burden was correlated with younger age, material deprivation, low self-efficacy and usual activity limitation. These factors accounted for 50.7% of the variance in high perceived treatment burden. Neither disease burden nor specific diagnosis was correlated with treatment burden.

Conclusions: This study supports previous observations that psychosocial factors may be more influential than specific diagnoses for multimorbid patients in managing their treatment workload. A simple capacity measure may be useful to identify those who are likely to struggle with healthcare demands.

Keywords: Chronic diseases, multimorbidity, patient capacity, treatment burden, deprivation.

## 7.2 Background

Living successfully with chronic health conditions (CHCs) requires effective self-management, including completing specific treatment tasks, lifestyle modifications and managing the physical, social and emotional impacts on one's daily life(1, 2). Self-management abilities vary, and people who struggle with self-management are at greater risk of disease escalation, preventable hospitalisation, and mortality. Earlier identification of those at risk of poor self-management could enable targeted support to circumvent such outcomes.

Most risk prediction in chronic disease has focussed on quantifiable late-stage outcomes such as hospitalisation or mortality, using disease counts and biomarkers(3-6). Although measures of self-management ability and patient engagement exist(7, 8), clinically usable measures to identify those likely to struggle with self-management have not been well-explored. This is despite copious literature describing the barriers to self-management(9-13).

Health professionals' assessments of self-management ability, patient capacity and treatment burden can be at odds with the patient experience(14, 15). Clinicians focus on biomedical status(15, 16) and perceived motivation(17) when assessing patient capacity, whereas patients consider resource constraints and social support levels to be more important(14, 18, 19).

Underestimation of treatment burden by health professionals has also been reported(19), who often focus only on adherence to specific treatment tasks. Treatment burden is a broader concept which is dependent on individual perception. It includes social, emotional, and financial aspects, as well as the difficulty in task management when one is ill, fatigued or in pain(14, 16, 20).

An assessment of self-management barriers informed by the patient, rather than the clinician perspective may better identify those people likely to struggle with self-management.

Structuring a risk assessment tool is challenging given the multiple factors associated with poor self-management but using a capacity-burden model such as the Cumulative Complexity Model(21) can provide direction. In this model, successful CHC management relies on a balance between capacity and burden(21). Capacity describes internal and external resources such as physical functioning, income, and social support. Burden, or workload, includes accessing healthcare, adhering to treatment recommendations, and maintaining a purposeful life. The perception of treatment burden will depend on individual capacity. A modest number of treatment tasks can be experienced as an overwhelming burden if capacity is insufficient, whilst patients with high levels of capacity may be able to cope with significant healthcare demands(22). If there is inadequate capacity to service the burden, the patient may struggle with self-management. This can lead to condition deterioration (further reducing capacity) and treatment escalation (increasing treatment burden) – hence cumulative complexity(20, 21, 23).

Measuring capacity and burden has been recommended in order to discover those at risk of cumulative complexity(20, 23-25). Self-report treatment burden tools have been developed(26-28), as well as assessments of capacity such as illness burden, financial and social capacity scales(29-31). For patients with established multimorbidity, direct measurement of treatment burden has been recommended(32). In our study, we have instead chosen to focus on capacity measurement for two reasons: first, it could be undertaken early, at the point of patient assessment or diagnosis, prior to treatment provision or self-management recommendations. Alerting the clinician to capacity constraints (thus limited ability to manage treatment burden) would direct them to simplify treatment demands and/or provide additional support. Secondly, measuring different elements of capacity could enable the clinician to pinpoint the specific barriers for that patient.

Our aim was to investigate the ability of different capacity domains to act as a 'flag' to identify those more likely to report high treatment burden. We intended to combine already validated self-report scales to see if they could provide an overall picture of capacity, and potentially act as a short screening measure usable in the clinic environment.

The aims of this study are:

1. To explore the correlations between established self-report tools that measure aspects of capacity, and treatment burden.
2. To discover whether selected individual questions from the self-report tools will correlate to treatment burden without loss of explanation.

We hope that this analysis may support the development of a clinically useful tool to identify people at risk of high perceived treatment burden.

## **7.3 Methods**

### **Study design**

This was a cross-sectional design involving the analysis of data from a survey undertaken both online and in a clinic population. Research was conducted in accordance with national ethics guidelines and approval was granted by the La Trobe University Human Research Ethics Committee (HEC number 19517).

The choice of screening tools was informed by the Cumulative Complexity Model(21) and other studies influenced by this model(22, 33-35).



## **Recruitment and participants**

Adults over the age of 18 with at least one chronic health condition were eligible to participate in the survey. The survey invited “anyone who has one or more chronic health conditions (e.g., arthritis, diabetes, chronic pain, heart or lung disease) that affect their daily life” to participate. Although the overall focus was on multimorbidity, with one tool developed specifically for multimorbid populations, a decision was made not to specify a certain number of health conditions since complexity may still occur when someone has only one health condition but a complex psychosocial environment(4, 5).

The onset of COVID-19 required a pivot from the original recruitment plan, which involved direct enrolment of participants from community health waiting rooms and activity groups using paper and ipad-based surveys. With services in lockdown and the switch to telehealth, we instead moved to conducting the survey both online and via post. The online survey was available from March to December 2020. It was placed on two patient advocate websites – Arthritis Australia and Diabetes Australia – as well as the website of the community health centre where the postal survey was run. The postal survey was sent in March 2020 to 400 clients who were registered with the chronic disease service of a large regional community health service in Victoria, Australia. Due to resource constraints related to COVID, we were unable to follow up non-respondents. Both paper and online surveys stated that the researchers were investigating ways to help health professionals support people with CHCs, that the survey was anonymous and voluntary and would take 15-20 minutes to complete. Consent was inferred based on completion of the survey.

## Survey Measures

The focus in this study was to choose already validated generic (not disease-specific) tools which were short and simple enough to be used in a clinical setting. If the self-report tools proved useful, our intention was to eventually modify the survey to screen for risk in a chronic disease population. The survey was trialled with a convenience sample of researchers and their acquaintances, but since all self-report scales had been previously validated, further pilot testing was not undertaken.

### Dependent variable

The primary dependent variable was perceived treatment burden, measured using the Multimorbidity Treatment Burden Questionnaire (MTBQ)(28). This is a 10-item (plus three optional items) Likert scale measure which ranks the difficulty of healthcare tasks. We used all thirteen items since all were considered relevant in the Australian healthcare environment. The MTBQ has good internal consistency and was validated in a large multimorbid primary care population. It was chosen because it was a shorter and more simply worded tool than the other available treatment burden measures(26, 27), and our focus was on clinical usability. We calculated both a global MTBQ score as well as treatment burden ranking (none, low, medium, or high burden), following the scoring process described by Duncan et al (28, 36).

### Independent variables

The independent variables were chosen to cover key capacity domains. There are currently no validated tools to assess capacity in its entirety. Capacity describes the ability for a person to manage their treatment load in terms of their abilities and resources. It includes social support, socioeconomic resources, literacy, attitudes/beliefs, and level of mental/physical functioning(33, 35). Since the aim was to trial established, clinically usable tools, we decided to include the following aspects of capacity: economic, social, personal, and physical.

To assess economic and social capacity, we used the Deprivation in Primary Care Questionnaire (DiPCare-Q) which consists of 16 yes/no questions assessing individual social, financial and health disadvantage(30). This has good psychometric properties (ICC=0.847); has been validated in a primary care chronic disease population(30, 37) and is correlated with treatment burden and quality of life(38). Although this is a Swiss scale not previously used in Australia, the DiPCare-Q has been professionally translated into several languages including English. We were unable to find any other measures of individual deprivation(31, 39, 40) that had been validated in a primary care population. Following the instructions of Leiser et al(37) we generated an overall DiPCare-Q index (ranging from 0-5.4), as well as a material (MatDCQ) and social (SocDCQ) deprivation score to use in analysis.

Personal capacity includes attitudes, beliefs, resilience, and self-efficacy. We chose to focus on self-efficacy for several reasons. Of the wide range of health attitudes and beliefs, self-efficacy stands out as a well-defined and strong psychological predictor across multiple outcomes associated with chronic health conditions(1, 2). Whilst resilience is important, the concept is poorly defined, and current measures cross into several different capacity domains. Therefore, we used the short form Perceived Medical Condition Self-Management Scale (PMCSMS-4)(41) to assess personal capacity. This is a validated 4-item Likert scale (scored from 4 to 20), assessing self-efficacy for self-management of CHCs. The measure was chosen because it is not disease-specific, very short and judged to be more simply worded than comparable generic self-efficacy measures.

To assess physical capacity, we used the Disease Burden Impact Scale (DBIS)(29, 42). This consists of a list of 25 possible medical conditions (plus the ability to report 'other' conditions). For each reported condition, the respondent uses a 5-point Likert scale to rate the interference in daily life caused by that condition. This has been found to be more predictive of quality of life than a disease count(42), and has been validated in a large multimorbid primary care

population(29, 43). It has also been correlated with the MTBQ(28) and the EQ-5D5L(42). We followed Peters et al(42) in modifying the original DBIS to include mental health and additional neurological diagnoses, and slightly reworded some terminology to increase understanding for the Australian audience. Although we recorded condition count, we did not analyse it as a separate variable, since the DBIS encompasses both CHC count and impact.

We also included the EQ-5D5L, a 5-item Likert scale plus VAS score (the VAS component was not used in the analysis). This is a widely used quality-of-life measure with good psychometric properties(44) which has previously been correlated with three of our chosen independent variables: the MTBQ(28), the DBIS(42) and the DiPCare-Q(38). Because the Australian population norms for the EQ-5D5L have not been reported, we used the UK scoring algorithm to calculate a single index score. This process has been successfully applied in other Australian studies(45).

Finally, we included the presence of diabetes or a mental health diagnosis (as reported in the DBIS) as dichotomous variables, since they are the only specific conditions that have previously been associated with increased treatment burden(28, 38, 46).

### Covariates

Our covariates were age and gender. Higher reported treatment burden has previously been correlated with younger age(28, 38, 46) and female gender(28). Since one aim of this study was to identify the smallest number of variables needed to correlate with treatment burden, we only included covariates that have previously been associated with treatment burden and excluded those that might overlap with other capacity measures.

## **Analysis**

Scores for each of the self-report tools were calculated according to the instructions provided by the developer of each measure. All data was entered into SPSS version 25.0 for analysis. In our descriptive analysis, we aimed to compare our survey population to those populations in whom the self-report measures were initially validated. We also calculated Cronbach's alpha for three of the self-report measures used to confirm reliability. We then undertook bivariate analysis across all variables of interest.

Our approach to multivariate analysis was informed by our aim to develop a simple screening tool. We therefore undertook logistic regression analysis, comparing high treatment burden to no/low/medium burden, since this would be easier to interpret in a time-poor clinical environment. Independent variables were selected based on whether they were significantly correlated with the dichotomous treatment burden variable in bivariate analysis, and we built a series of models to identify the best fit. Our plan was for each model to include a measure of physical, personal, economic, and social capacity, but, with a potential screening tool in mind, we wanted to minimise the number of self-report items that would be needed. Missing data was addressed by imputation using median score or commonest category, and sensitivity analysis was conducted to confirm that this did not influence the results.

## **7.4 Results**

### **Descriptive analysis**

#### Participant characteristics

183 surveys were returned – 80 postal (20% return rate) and 103 online. The population was 78% female with a mean age of 60.1 years. The online and postal populations differed, with the online respondents more likely to be younger (mean 53yrs compared to mean 68yrs), female (91%) and living in a capital city. This reflects the fact that the postal survey was conducted in a rural setting amongst an older community health population. Only 30.4% of respondents were employed either full- or part-time, with the majority either retired from or unable to work due to health.

94% of participants reported more than two CHCs, with 45% reporting more than five. Recoding for some DBIS scores was required due to double scoring (when a condition was selected and then listed again under 'other condition') or when the condition was selected but the impact not rated. For double scoring, the higher score was included and the lower excluded and when the impact was not rated, a score of 1 ('does not interfere') was allocated. The median DBIS score was 15 (scores were positively skewed); this was comparable to Peters(42). The most common condition grouping was musculoskeletal disorders (91.2% of respondents), followed by cardiovascular (56%) and mental health conditions (50%). Although these CHCs are all prevalent in the Australian population(47), the very high number of people reporting musculoskeletal conditions likely reflects the fact that online participation was largely via the Arthritis Australia portal.

Since neither the DiPCare-Q nor the MTBQ had been previously used in an Australian population, we confirmed acceptable reliability for both these scales (DiPCare-Q: KR-20 = 0.782; MTBQ: Cronbach's  $\alpha$  = 0.913) and for the EQ-5D5L (Cronbach's  $\alpha$  = 0.773) in our population. All scales had non-normal distributions, therefore we included median/IQR as well as mean/SD values for each variable. Demographic and descriptive data are presented in table 7.1.

**Table 7.1: Descriptive Characteristics**

Description	Value	Freq/mean/median	Percent/SD/IQR	Missing values
Age	Mean/SD	mean=60.1	SD=16.5	n=3
Gender	Female	n=143	78.1%	n=3
Employment	Working (full/part)	n=55	30.4%	n=2
	Retired	n=74	40.9%	
	Not working due to health	n=34	18.8%	
	Other	n=18	9.8%	
Number of conditions reported*	1	n=11	6.0%	n=1
	2-5	n=89	48.6%	
	More than 5	n=82	45.0%	
Condition type**	Musculoskeletal <sup>1</sup>	n=166	91.2%	n=1
	Cardiovascular <sup>2</sup>	n=102	56%	
	Mental health <sup>3</sup>	n=91	50%	
	Respiratory <sup>4</sup>	n=55	30.2%	
	Diabetes	n=36	19.8%	
DBIS score	Mean/SD	mean=18.04	SD=12.96	n=1
	Median/IQR	median=15	IQR=17	
PMCSMS-4 score	Mean/SD	mean=12.15	SD=3.44	n=2
	Median/IQR	median=12.00	IQR=5	
EQ-5D5L	Mean/SD	mean=0.575	SD=0.246	n=5
	Median/IQR	median=0.626	IQR=0.341	
DiPCare-Q	Mean/SD	mean=1.96	SD=1.30	n=5
	Median/IQR	median=2.00	IQR=2.00	
	MatDCQ: Mean/SD	mean=0.89	SD=0.965	
	MatDCQ: Median/IQR	median=1	IQR=2	
	SocDCQ: Mean/SD	mean=2.36	SD=1.17	
	SocDCQ: Median/IQR	median=2	IQR=1	
MTBQ	Median/IQR	median=23.08	IQR=35.58	n=14
	MTBQ rank: none	n=20	11.8%	
	MTBQ rank: low	n=31	18.3%	
	MTBQ rank: medium	n=31	18.3%	
	MTBQ rank: high	n=87	51.5%	

\*Based on the number of conditions selected on the DBIS. This may include several conditions of the same type, as listed below.

\*\*Number of people who reported one or more conditions under the following DBIS headings: 1 (Musculoskeletal): Back pain/sciatica; Osteoarthritis; Osteoporosis; Rheumatoid arthritis; Other muscle/joint pain condition (e.g. fibromyalgia). 2 (Cardiovascular): High blood pressure; High cholesterol; Angina/heart disease; Heart failure. 3 (Mental health): Anxiety/depression; Other mental health (e.g. bipolar). 4 (Respiratory): Bronchitis/COPD; Asthma.

## **Bivariate analysis**

Univariate analysis confirmed that all scales had non-normal distribution, therefore non-parametric tests were employed for bivariate analysis. We conducted bivariate analysis on both the global MTBQ score (GMTBQ) and the dichotomous treatment burden variable (MTBQ-2) used in regression, but include only results for the categorical variable. Results are summarised in table 7.2.

Previously observed relationships between the DiPCare-Q (SR= -0.229,  $p=0.002$ ) and MTBQ-2 (MW= -0.362,  $p=0.000$ ) and younger age were confirmed, and between the DBIS and older age (SR= 0.158,  $p=0.035$ ). Female gender was significantly correlated to treatment burden ( $p=0.005$ ,  $\Phi=0.216$ ). Contrary to expectation, living in a capital city (based on postcode data) was associated with higher treatment burden ( $p=0.000$ ), but this was not significant after controlling for age, with younger participants (who reported higher treatment burden) overrepresented in the urban setting.

We explored the influence of condition type on treatment burden. The presence of diabetes(19, 46) or a mental health condition(28) have been previously associated with treatment burden and although we noted significant correlations with the GMTBQ (diabetes  $p=0.005$ ; mental health  $p=0.001$ ), only mental health conditions remained significant when treatment burden was dichotomised (mental health  $p=0.000$ , diabetes  $p=0.057$ ). We were unable to analyse musculoskeletal conditions because almost all participants reported this, but



neither cardiovascular ( $p=0.557$ ) nor respiratory ( $p=0.737$ ) conditions were significantly correlated to treatment burden.

Low to moderate correlations ( $MW = 0.299$  to  $-0.515$ ,  $p=0.000$ ) were observed between MTBQ-2 and the four self-report scales (DiPCare-Q, DBIS, PMCSMS-4 and EQ-5D5L). Since one aim was to reduce the number of questions asked, we also conducted bivariate analysis on individual EQ-5D5L questions, selecting the two questions with the greatest effect size (Q3: Activity and 5: Mood) to use in regression (Q2; Personal care was excluded because of its high floor effect). We also analysed the material and social components of the DiPCare-Q separately, which had moderate (MatDCQ:  $p=0.000$ ,  $MW=0.422$ ) and weak (SocDCQ:  $p=0.033$ ,  $MW=0.156$ ) correlations with treatment burden, as well as analysing Q1 (difficulty paying bills) and Q3 (forgoing healthcare due to cost) of the DiPCare-Q in isolation. These two questions were selected because they were the most frequently endorsed, and question one alone has previously been found to predict the risk of forgoing healthcare due to cost(48).

**Table 7.2: Bivariate correlations**

	Age	DBIS	PMCSMS-4	DiPCare-Q	EQ-5D5L	MTBQ-2 (Dependent)
Age	X	SR= 0.158*	SR= 0.267***	SR= -0.229**	n.s. p=0.079	MW= -0.362***
Gender	MW= -0.255**	n.s. p=0.765	n.s. p=0.279	n.s. p=0.924	n.s. p=0.711	Phi=0.216**
<b>Disease burden measures (Physical capacity)</b>						
DBIS score	X	X	SR= -0.318***	SR=0.313***	SR= -0.534***	MW=0.299***
Has diabetes	MW= 0.307***	MW= 0.208**	n.s. p=0.497	n.s. p=0.691	n.s. p=0.606	n.s. p=0.057
Has mental health condition	MW= -0.196**	MW=0.420***	MW= -0.305***	MW=0.361***	MW= -0.277***	Phi=0.337***
<b>Self-efficacy measures (Personal capacity)</b>						
PMCSMS-4 score	X	X	X	SR= -0.432***	SR= 0.481***	MW= -0.515***
<b>Deprivation measures (Economic and social capacity)</b>						
DiPCare-Q index	X	X	X	X	SR= -0.442***	MW=0.389***
MatDCQ (material)	SR= -0.322***	SR= 0.236**	SR= -0.376***	X	SR= -0.323***	MW=0.422***
SocDCQ (social)	n.s. p=0.718	SR= 0.221**	SR= -0.204**	X	SR= -0.306***	MW=0.156*
Q1 DiPCare	X	MW=0.287***	MW= -0.361***	X	MW= -0.317***	Phi=0.325***
Q3 DiPCare	X	MW=0.262***	MW= -0.323***	X	MW= -0.276***	Phi=0.389***
<b>Quality of life measures</b>						
EQ index score	X	X	X	X	X	MW=0.343***
EQ mobility	X	X	X	X	X	n.s. p=0.136
EQ pers care	X	X	X	X	X	MW=0.347***
EQ activity	X	SR=0.358***	SR= -0.389***	SR= 0.328***	X	MW=0.350***
EQ pain	X	X	X	X	X	MW= 0.181*
EQ mood	X	SR= 0.419***	SR= -0.487***	SR= 0.469***	X	MW=0.404***

SR= Spearman's rank effect size; MW = Mann-Whitney U effect size; Phi = Chi-square effect size; n.s. = non-significant.

All results to 3 s.f. \*p<0.05 \*\*p<0.01 \*\*\*p<0.001

## Multivariate analysis

### Missing data

We undertook imputation using median score or commonest category for eleven surveys that were missing data from a single independent variable. Since the MTBQ-2 variable had almost

equal numbers in each category, imputation was not undertaken for the fourteen surveys (8%) with greater than 50% of their MTBQ responses missing. These surveys were excluded from the regression analysis.

### Multivariate modelling

We trialled several multivariate models, using the MTBQ-2 as the dependent variable, aiming to find the most parsimonious model with the best fit. All models included sex, age and one or more variables from each capacity category and the EQ questions. All variables selected were those which correlated significantly to MTBQ-2 in bivariate analysis, with the exception of the presence of diabetes, which was included because of its known association with treatment burden in other studies. First, we entered the following variables using the Forward Stepwise Wald method: sex; mental health; age; DBIS; PMCSMS-4; EQ activity; EQ mood; MatDCQ; SocDCQ. We then trialled a series of models entering the variables manually, starting with sex, age, DBIS and PMCSMS-4 and sequentially adding in different deprivation and EQ-5D5L variables to identify suitable models. Age, self-efficacy and material deprivation remained significant in every model. Hosmer-Lemeshow testing was non-significant for all models. Nagelkerke  $r^2$ , % correct classification, sensitivity and specificity varied 2% or less between models. Models were compared using the Akaike information criterion (AIC) and Bayesian information criterion (BIC), with the final model selected having the lowest AIC and BIC scores, indicating the best fit of all models trialled. This model consisted of the following covariates: age, sex, PMCSMS-4, EQ activity and MatDCQ. Logistic regression results for this model are displayed in table 7.3.

In the final model, age ( $p=0.042$ ), PMCSMS-4 ( $p=0.000$ ), EQ activity ( $p=0.032$ ) and MatDCQ ( $p=0.005$ ) remained significant. The model correctly classified 80.5% of cases, with sensitivity of 79.1% and specificity of 81.9%. It explained 50.7% of the variance in treatment burden (Nagelkerke  $r^2= 0.507$ ). The factors having the greatest impact on treatment burden were

material deprivation, EQ activity score, and self-efficacy. Odds ratios indicated that each unit increase in the 4-level MatDCQ doubled the risk of high treatment burden (92% increase) and each unit increase in the 5-level EQ activity led to a 59% increase in the risk of high treatment burden. Conversely, each point increase in PMCSMS (scored in 16 increments) was associated with a 28% reduction in the risk of high treatment burden. Examination of residuals identified only 4 outliers, most of whom had borderline GMTBQ scores just above or below the dichotomous cut-off between high and 'other' treatment burden.

**Table 7.3: logistic regression**

Variable	S.E.	2-tailed sig.	Odds ratio	95% CI lower	95% CI upper
Age	.014	0.042	0.973	0.947	0.999
Sex	.578	0.053	0.326	0.105	1.013
PMCSMS	.078	0.000	0.720	0.618	0.839
Mat DCQ	.233	0.005	1.920	1.215	3.032
EQ activity	.217	0.032	1.591	1.040	2.433

Nagelkerke  $r^2=0.507$

AIC=164.079

BIC=182.858

## 7.5 Discussion

This study aimed to explore the correlations between established self-report tools that measure aspects of capacity, and perceived treatment burden. We found that material deprivation, self-efficacy, usual activity level and younger age remained significant in multivariate analysis and accounted for more than half the variation in the risk of having high treatment burden.

## Relationship to other research

In our survey, both deprivation and treatment burden scores differed from previous population studies. Our DiPCare-Q index score mean was higher than previously reported (1.96 compared to 1.2)(37). We questioned whether the impact of Covid-19 on social isolation might be contributing to this difference. However, after comparing our participant responses to previous studies, we found triple the number of positive responses to material deprivation questions in our population, but little difference in social deprivation responses. This may relate to the younger mean age of the population (with material deprivation known to be higher in younger age groups)(37), differing social welfare systems between countries, and/or sampling bias.

High treatment burden scores were also reported by 51.5% of our sample, compared to 27% in a previous study(28). Again, the younger mean age may partially explain this, given the consistent association between younger age and higher burden(28, 38, 46). To reflect the Australian healthcare environment, we included the financial burden question (excluded by Duncan et al), which was endorsed as at least 'somewhat difficult' by 54% of our population and may have resulted in a higher overall score. The MTBQ section of the survey was also not completed by 8% of participants, and these participants reported fewer mental health conditions, lower scores on the DipCare-Q and DBIS and higher EQ-5D5L scores than the rest of the population. These participants may have considered the MTBQ to be irrelevant, potentially increasing the representation of people experiencing high treatment burden.

Consistent with other literature (28, 37, 42), we also found that the MTBQ, DBIS, DiPCare-Q were all correlated with the EQ-5D5L with moderate effect sizes. Previous relationships between deprivation, treatment burden and younger age, and with the DBIS and older age, were also confirmed.

### **Key findings in this study**

Low self-efficacy and material deprivation were strongly associated with high perceived treatment burden, regardless of the model trialled. Both these factors have been previously correlated with high treatment burden(19, 22, 46, 49, 50) although the relationship with deprivation appears to depend on whether subjective or objective (e.g. income, area data) measures are used(28). Since the MTBQ measures patient perceptions of treatment burden, a subjective report of deprivation (such as the DiPCare-Q) may be more sensitive than traditional measures of socioeconomic status(30). The significance of self-efficacy and material deprivation is unsurprising since both factors are known to be strong predictors of self-management ability, treatment engagement and adherence(1, 9, 51). Importantly, they are also closely related to each other, with financial strain and low socioeconomic status consistently associated with low self-efficacy across a range of health behaviours(52, 53). This relationship may make it more difficult to reduce treatment burden if both low self-efficacy and material deprivation are present.

Even though disease count or severity are often used by clinicians to estimate treatment burden, we found that neither disease burden (as measured by DBIS) nor specific conditions (presence of mental health diagnosis or diabetes) remained significant after multivariate modelling. In other studies, disease burden has been associated with treatment burden(28), but relationships between treatment burden and specific conditions have been much less consistent(28, 38, 46, 54). This again highlights how patient perception of non-medical factors (e.g., confidence in one's abilities, available resources) may be more important than a specific diagnosis in assessing treatment burden.

In our study, age and/or EQ activity score may have moderated the influence of the DBIS in multivariate analysis. Despite older people reporting a higher DBIS score and higher disease count, treatment burden declined with age. The inverse relationship between age and

treatment burden is consistent across several studies(19, 28, 46). Younger people are likely to have greater demands on their time (work, caring responsibilities), different expectations regarding health, fewer governmental social/health provisions, and greater financial insecurity (19, 28, 55), all of which may contribute to increased treatment burden.

EQ activity (which rates perceived ability to undertake ‘work, study, housework, family or leisure activities’) was the only physical capacity measure that remained significant, suggesting that the impact of CHCs on function may be more important in terms of perceived treatment burden than the conditions themselves. This makes sense since loss of function is likely to make many treatment tasks (e.g., attending appointments, lifestyle changes, relying on family) more difficult, and may particularly relate to non-life threatening conditions that impair function such as musculoskeletal disorders, reported by 91% of our sample.

### **Identifying risk of high treatment burden**

The secondary aim of our study was to make progress toward developing a tool to identify those at risk of high treatment burden. Our results showed that a small number of variables, taken from three established and validated self-report scales, can explain a considerable proportion of perceived treatment burden. The results also suggest that (perceived) material deprivation, self-efficacy and usual activity levels may be more important than diagnosis or condition count. The self-report measures we used are simple and quick to use and could be easily incorporated into a clinic environment. We expect that additional capacity measures, not explored in this study, will provide further explanation for perceived treatment burden. For example, we did not assess life workload since we were unable to identify any validated self-report measures; nor did we assess resilience due to debate over whether the available measures adequately capture the concept(56). Since our self-complete survey assumed

reading skills, we were unable to include a literacy or health literacy measure despite health literacy being a known contributor to treatment burden(54, 57).

Our current results have provided us with an initial foundation. The intent is to further develop the screening tool in a larger population using additional capacity measures, including a format (e.g. phone or face-face) that allows individual literacy/health literacy to be explored.

### **Strengths and limitations**

Since this was a cross-sectional study, we were unable to infer causal relationships. The study did suffer from sampling bias, and the multiple modes of data collection may have resulted in two different populations. Using the internet across patient self-help groups provided a convenience sample that overrepresented women, people with musculoskeletal conditions, and possibly those who had greater health concerns. The survey was undertaken during the height of the COVID pandemic which compromised our recruitment strategy and may have impacted the low response rate (20%) for our postal survey, since we were unable to follow up non-respondents. It is also possible that the unique pressures associated with the COVID pandemic influenced participant survey responses, especially in relation to perceived treatment burden, deprivation, and quality of life. However, although the population may have been non-representative, it did report high levels of deprivation. The strong association of deprivation with multimorbidity, poorer condition trajectory and lower quality of life(58-60) means that this is an important group to study.

The use of the DiPCare-Q may be a limitation since it has not been validated in an Australian population and has previously been conducted as a phone questionnaire, although the low level of non-completion suggests that it was acceptable to participants who may be more comfortable answering questions about deprivation anonymously.



The key strengths of this study were in using already validated scales and running several models to explore how they could be combined to create a capacity measure.

## **7.6 Conclusions**

The ability to identify those at risk of high treatment burden may help to target support where it is most needed. Our study suggests that having a specific health condition is less important than younger age, material deprivation, low self-efficacy, and functional limitations.

Recognising those who are struggling most with treatment burden is important because effective management may reduce future condition escalation and overall burden of disease.

### **List of abbreviations**

CHC: Chronic health condition

MTBQ: Multimorbidity Treatment Burden Questionnaire

DiPCare-Q: Deprivation in Primary Care Questionnaire

MatDCQ: Material deprivation index

SocDCQ: Social deprivation index

PMCSMS-4: Short-form Perceived Medical Condition Self-Management Scale

DBIS: Disease Burden Impact Scale

SR: Spearman's rank effect size

MW: Mann-Whitney U effect size

AIC: Akaike Information Criterion

BIC: Bayesian Information Criterion

### **Declarations**

**Ethics approval and consent to participate:** Research was conducted in accordance with national ethics guidelines and approval was granted by the La Trobe University Human Research Ethics Committee (HEC number 19517). Consent was inferred based on completion of the survey.

**Consent for publication:** Not applicable

**Availability of data and materials:** The datasets generated and analysed during the current study are available via figshare at: <https://doi.org/10.26181/615cdea12551c>

**Competing interests:** The authors declare that they have no competing interests.

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**Authors' contributions:** RH designed the survey with assistance from ES and SB. All authors planned the analysis and RH conducted the regression. RH drafted the initial manuscript, and ES and SB edited and further developed the manuscript. All authors read and approved the final manuscript.

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## CHAPTER EIGHT:

Care for Complexity in Community Health (the 3C trial):

Protocol for a feasibility study.

This paper will be submitted for publication in 2022 following ethics approval.

The supplementary files for this paper are provided in Appendix J.



## 8.1 Abstract

**Background:** Socially disadvantaged populations are at risk of multimorbid chronic disease, but can struggle to engage with self-management. Approaches that assess and target overall patient capacity and treatment burden, such as those informed by the Cumulative Complexity Model, may promote more achievable, patient-centred care. However, many chronic disease management services operate in a single-disease framework. Alternative service delivery options are needed for people experiencing disadvantage and multimorbidity.

**Methods/Design:** This is a protocol for a pilot study, assessing the feasibility and acceptability of a model of care for multimorbid community health clients in rural Victoria. The study consists of two stages. First, community health clinicians will undergo training in the Cumulative Complexity Model, and chronic disease care provision will be restructured to include care co-ordinators and support clinicians. In stage two, care co-ordinators will use a capacity-burden model to engage with 45 low-income multimorbid clients, assisted by support clinicians and additional resources in the wider organisation. The main outcomes will be the acceptability of the intervention to clients and health providers; ability to implement the intervention as planned; modifications needed; and demand for the service. Qualitative interviews will be conducted with community health employees and patient participants, and process data obtained from the medical records. Data will be analysed thematically using NVivo. In addition, patient quantitative data, including demographics, measures of treatment burden, individual capacity, and quality of life, will be collected at baseline, 3 months, and 6 months into the intervention.

**Discussion:** If feasibility is demonstrated, a cluster trial across the Victorian rural community health network is planned in the future to investigate efficacy and cost-effectiveness.

**Ethics and Dissemination:** Approval will be obtained from the La Trobe University Human Research Ethics Board and the trial will be registered through the Australia New Zealand Clinical Trials Registry (ANZCTR). Findings will be disseminated to consumers, community health and primary care networks in Australia; and via peer-reviewed publications and conferences.

## 8.2 Background

Effective management of chronic health conditions (CHCs) requires long-term commitment to self-management, but disadvantaged and low-income populations face many barriers to engagement(1-3). Traditional self-management approaches, which focus on building individual capacity and self-efficacy to manage ones' health(4, 5) can be overwhelming for those with few resources(6, 7).

The role of burden and capacity, as outlined in Shippee et al.'s Cumulative Complexity Model(8), can help to explicate the challenges faced by this population. People need sufficient capacity, including social support, socioeconomic resources, and adequate mental/physical functioning, to cope with the workload (burden) associated with living with a CHC, such as self-management tasks, health system interactions and other life demands. Limited capacity (e.g. poverty, social isolation) or overwhelming burden (e.g. multimorbidity) may reduce adherence and lead to disease escalation. Healthcare systems respond by intensifying treatment, increasing burden further and resulting in 'cumulative complexity'(8).

An alternative approach is needed for such individuals, especially when multimorbidity is involved. Minimally-disruptive medicine (MDM) is a practical model of care that builds on the concepts described in the Cumulative Complexity Model(9, 10). The key elements of MDM are first, to assess burden and capacity levels; and second, to undertake practical actions designed to reduce burden and/or increase capacity. Such interventions might include medication deprescribing, shared decision-making, and teaming with social welfare agencies. Although many of these strategies are recommended when managing multimorbidity(11, 12), incorporating them into a systematic approach which targets burden-capacity deficits is less common.

Integration of MDM into primary care settings is still in its early days(13-15). However, interventions that focus on burden and/or capacity in disadvantaged or multimorbid patients have reported improvements in adherence and quality of life, with reductions in hospitalisation and treatment burden(16-18). For healthcare providers (HCPs), managing complex multimorbid clients in socially deprived circumstances is a well-known stressor and can contribute to burnout(19, 20). Interventions designed specifically for these settings, rather than current single disease models which ignore burden and capacity(21, 22), may reduce HCP burden and promote truly client-centred care(19, 20, 23).

This paper presents a protocol for a pilot trial, running from January 2022 – Dec 2024, of an MDM-based intervention for multimorbid community health clients living in rural Australia. Community health centres are important providers of chronic disease management services for low-income and disadvantaged populations(24). Our intervention consists of two stages. Stage one is to provide additional training to healthcare providers working in chronic disease management (CDM). We aim to expand the existing CDM expertise of these providers to include skills that are central to an MDM approach. These are:

1. Assessment of burden and capacity:
  - a. Structured assessment and measurement of burden and capacity(10, 25, 26).
  - b. Use of shared decision-making tools to prioritise based on client preferences and values(27-29).
2. Practical interventions to reduce burden and increase capacity:
  - a. Direct provision of synergistic treatments(30, 31) known to be effective across multiple conditions, with a particular focus on mental health, functional impairment and social needs(32, 33).
  - b. Care co-ordination and effective use of established referral pathways designed to minimise patient burden.

The second stage of our intervention will be with the community health clients who undertake CDM with the upskilled HCPs. In line with recommendations for undertaking complex interventions(34, 35), our initial study focus is on feasibility and acceptability rather than efficacy. This will enable us to test and modify aspects of the recruitment and intervention process and determine the likely benefits of progressing to a cluster randomised trial(36-38). Bowen(36) has identified a number of potential outcomes for a feasibility trial, and we intend to focus on the following:

- Acceptability: Reactions of the participants to the training (HCPs) and intervention (clients and HCPs).
- Demand: Numbers of clients eligible; numbers who engage; attrition rates.
- Implementation: Ability to implement the intervention as planned and any modifications that are required.
- Practicality: Resource constraints (time, workforce, funding) that may impact on the ability to deliver the intervention.
- Integration: Organisational changes required to integrate the intervention into the existing CDM service.

Although intervention efficacy cannot be determined from a feasibility trial, we will also collect efficacy outcome measures in preparation for a future larger trial, and to provide some preliminary outcome data.

### **Objectives**

This study aims to discover:

1. The feasibility and acceptability of a training programme for health providers working in CDM, based on the principles of MDM.

2. The feasibility and acceptability of a MDM approach to chronic disease management for rural community health clients with multimorbidity and social complexity.

## **8.3 Methods**

### **Study design**

This is a mixed methods study. The primary outcome will be the feasibility of the recruitment process, HCP training, and intervention delivery, especially its integration within the existing chronic disease service. We will also investigate the acceptability of the intervention to client participants, HCPs who deliver the service, and other employees of the community health centre. Qualitative interviews (1-1 and focus groups) will be undertaken to explore the views and experiences of all stakeholders. Patient quantitative data will include demographic information and measures of treatment burden, individual capacity, and quality of life, measured at baseline, 3 months, and 6 months into the intervention. We used the SPIRIT checklist for clinical trial protocols to guide our trial reporting and this is available in Supplementary File 1.

### **Participant involvement**

This study is the next stage of a programme of research into chronic disease self-management in rural community health settings. In line with NHMRC recommendations regarding consumer and community engagement(39), we are using the consumer experience to inform our research. We have already undertaken qualitative research with community health centre clients and HCPs. In that study, we explored the barriers and facilitators to engagement and analysed them in relation to burden and capacity(40-42). The intervention described in this

protocol has been shaped by the specific difficulties encountered by both groups and their suggestions for improvement(40, 41), as well as by the literature and research conducted elsewhere with patient groups facing similar challenges(43-46). At the commencement of the intervention we will establish an advisory group, including consumer, HCP and organisational representatives, to provide input into the direction of the trial(47). Throughout the duration of the intervention, we plan to continue our collaborative approach with clients and HCPs across the whole organisation by running interactive sessions to discuss the proposal, incorporate suggestions, and address concerns. Further interviews and focus groups will be conducted at the trial's conclusion so that we can modify our approach based on feedback.

### **Setting**

The trial setting is a large, publicly funded community health centre located in the regional town of Mildura (population 57,000), in Victoria, Australia. Mildura is relatively isolated (400km from the next large town) and experiences social and health challenges common to many Australian rural settings, including high rates of chronic disease, social disadvantage, and limited healthcare access(48-50).

The community health centre participating in the trial provides a wide range of services, including CDM, to low-income and otherwise vulnerable clients. CDM, which includes self-management support and care co-ordination, is provided by nurses and allied health professionals and operates largely on single-disease models. Siloing of care, especially for clients with complex multimorbidity, is widely acknowledged as an issue and was specifically identified in our qualitative research as contributing to the clients' treatment burden(40).

## **Recruitment Process**

This intervention focusses on upskilling HCPs to support clients with complex multimorbidity. Recruitment will occur in 2 stages: first, recruitment of HCPs who will be providing care; and secondly, client participants.

### **Recruitment of HCPs**

#### **Initial information sessions**

Information sessions describing the proposed intervention will be presented to multiple teams across the organisation, including clinicians, client-facing employees, management, and consumer representative groups. The aim will be to engage interest and commitment throughout the organisation and to address concerns at an early date. Given the disruption experienced across health services following COVID-19, it was considered very important to maximise buy-in and ownership of the intervention. Topics discussed will include:

- Findings from research already conducted within the organisation.
- Challenges associated with multimorbidity, social disadvantage, and treatment burden.
- The Cumulative Complexity Model and principles of MDM.
- Proposed pilot trial and invitation to employees to participate at different levels.

Attendees will be encouraged to question and discuss the proposed intervention, and their views will be recorded by the researchers. We will undertake an iterative process, which will allow for participant insights related to the context and environment to be incorporated into the intervention. Potential trial participants may be identified by their team manager or self-identify during the information sessions. A follow-up time will be arranged to discuss the project in more detail with the research co-ordinator.



### Healthcare Provider and Community Health employee roles

Although the focus is on individual care coordination, we recognise the importance of integrating the intervention across the organisation. Therefore, community health centre staff will be encouraged to participate with the intervention in a variety of ways. The key roles are:

Care co-ordinators: Care co-ordinators are nurses or allied health providers who have pre-existing experience and training in self-management support for clients with CHCs. This intervention targets non-medical HCPs, rather than GPs, because they are more likely to be the direct providers of self-management interventions. We expect to recruit 3 care co-ordinators, and that the client participants in this intervention will equate to approximately 20 – 25% of their full-time chronic disease client load.

Support clinicians: Named clinicians with specific skills who are available to provide additional support or secondary consults to the care co-ordinators. Based on the patient population and needs identified in previous research, we expect to include a social worker/mental health clinician (to provide direction on social and mental health needs); a physiotherapist/occupational therapist (to address functional concerns and pain/fatigue management) and a GP/nurse (support for diabetes and medication management). These support clinicians will act as points of contact and providers of specific advice and referral options to the care co-ordinators. They will also be involved in the initial care co-ordinator training. Following initial training, support clinicians will be available via phone, email, or face-face as needed. Although cross-disciplinary management of clients already occurs to some extent in the organisation, the aim is to formalise this process by utilising identified people who are familiar with the intervention and who can provide specific support.

Other community health employees: We plan to familiarise all staff members with the intervention via our introductory meetings and discussion sessions, especially those who provide services to clients with CHCs. We will provide ongoing updates to employees

throughout the trial period, informing them of the care co-ordinator role; client eligibility criteria; referral processes; and progress of the trial.

## **Recruitment of community health clients**

### Recruitment process

For existing community health clients, recruitment will be via their current clinicians, or via the intake clinician if clients are new to the health service. All community health clients undergo a telephone intake assessment with a nurse when first referred, which documents client health status (conditions, medications) and social situation (family, income, housing). The intake assessment covers all inclusion/exclusion criteria and will determine initial client eligibility.

Once care co-ordinators have been identified and trained, clinicians across the organisation will be informed of the client inclusion criteria and encouraged to discuss the intervention with potential participants, aided by information brochures. Interested clients will have their name and contact details forwarded (with permission) either to the research co-ordinator or a care co-ordinator. The client will be contacted to confirm eligibility, and to complete informed consent and baseline measures. If the client has a regular treating GP external to the organisation, the care co-ordinator will contact (with permission) the relevant GP or practice nurse, by phone or email. The aim will be to provide information about the trial, obtain consent to exchange information and ensure that other providers understand the role of the care co-ordinator and agree to their clients' participation in the trial. The client will also be informed of their right to withdraw from the trial at any point without consequences.

### Inclusion criteria:

- Over 18 years
- At least 2 CHCs

- Low-income or in receipt of government income support (based on organisational income determination scale)
- Additional psychosocial complexity, such as a mental health diagnosis, major social stressor (e.g. social isolation, complex family situation, housing insecurity) or low literacy
- Clients without additional psychosocial complexity, but with four or more CHCs, are also eligible since this level of multimorbidity is associated with increased healthcare utilisation and poor outcomes(30).

Exclusion criteria:

- Palliative patients
- Those in residential care, dependent on a full-time carer, or already in receipt of case management
- Unable to consent (e.g., dementia, psychosis, significant learning disability)
- Medical conditions preventing engagement in self-management (e.g., unstable angina)
- Unable to understand spoken English.

Sample size consideration

The intervention will involve the entire organisation, with all client-facing staff provided with some training in MDM. We expect all clients, not just those with multimorbidity and complexity, to gain from increased organisational awareness of burden and capacity.

Therefore, we will not have a ‘treatment as usual’ client group or undertake a sample size calculation. Based on current staffing and client numbers we expect to train three HCPs as care co-ordinators and for each to engage with approximately fifteen clients. If the intervention

proves feasible, we will proceed in a separate study to a randomised cluster trial across other sites to explore power and efficacy.

### **Description of intervention**

#### **Intervention stage 1: Training of HCPs**

Since the care co-ordinators will be clinicians who already work in CDM, they will be expected to already have experience in self-management support, including skills in behaviour change and care planning. Additional training will focus on expanding those skills to address treatment burden and multimorbidity.

#### **Care co-ordinators will undergo training in the following areas:**

- MDM theory, measuring burden and capacity, and the practical application of MDM. Training will be provided by the research co-ordinator. The Knowledge Education and Research (KER) team at the Mayo Clinic, USA, who first developed the Cumulative Complexity Model, will provide additional supervision.
- How to use the shared decision-making tool (ICAN) in care planning. Training will be provided by the research co-ordinator.
- Building skills in generic/synergistic treatments that apply across multiple conditions, such as sleep hygiene, stress management, establishing daily routines and behavioural activation. Training will be provided by support clinicians, focussing on simple strategies and useful resources to support these interventions, as well as clear guidance on when the client may need onward referral. It is recognised that some of the care co-ordinators may already have skills in these areas, and this will allow for peer-to-peer teaching. Utilising existing skills amongst care co-ordinators and support clinicians will complement one of the organisational goals for this intervention:

namely, to increase collaboration, reduce siloing and improve awareness of expertise within the organisation.

- The above components will be manualised and documented to enable replication.

Additional supports provided for care co-ordinators:

- Resource registry for social support services, with clear referral pathways and contact information. The current resource registry will be reviewed and updated as necessary to ensure the least possible treatment burden on clients.
- Internal resources: Current self-management resources (e.g., educational materials) across the organisation will be reviewed with the aim of ensuring consistency, readability (for low literacy levels), availability of multiple formats (e.g. paper, online, DVD/apps) and greater awareness of resources amongst clinicians.
- Use of a formal template for the ICAN tool in the electronic medical record (EMR). This will both document the client's status at each contact and ensure fidelity to the study protocol.
- Support clinicians will be available to contact for advice, secondary consults, or onward referrals.
- Clear referral pathways internally to different disciplines, which can bypass waitlists.
- Fortnightly supervision sessions once the trial begins. The study co-ordinator, who is an experienced clinician and educator in chronic disease management as well as a researcher, will facilitate the sessions, which will:
  - Address treatment fidelity by reviewing the EMR and revisiting key aspects of training.
  - Review clients, troubleshoot barriers, and monitor HCP burden.

## **Intervention stage 2: Care co-ordination of complex multimorbid clients**

Currently, patients engaging with CDM at the community health centre receive 1-1 tailored support or group sessions and are engaged with one or more clinicians. The key differences with this intervention are as follows:

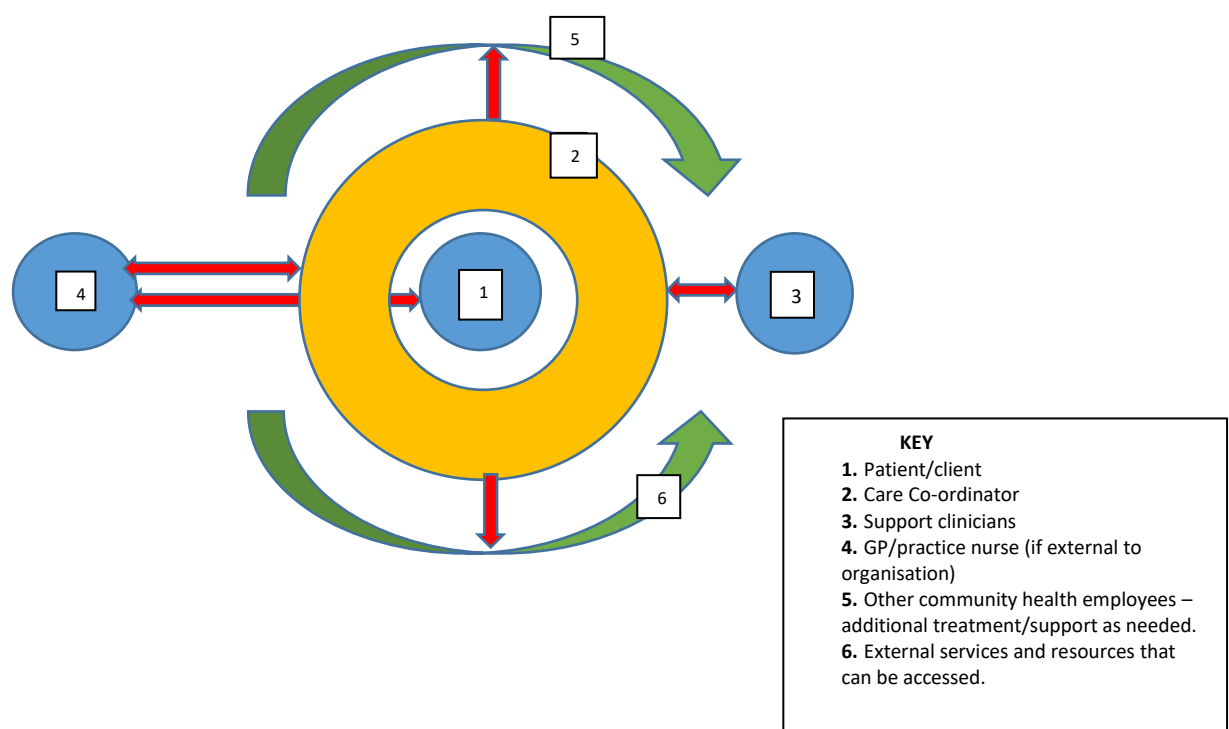
- Care co-ordinators will not be limited to or expected to focus on a single condition, but on holistic management of multimorbidity, based on prioritisation of the clients' concerns.
- The ICAN discussion aid will be used at the beginning of each session to enable HCPs and clients to systematically explore burden and capacity issues. This will be recorded in the electronic medical record (EMR) using a template.
- Care planning will be informed by the values and preferences expressed when using the ICAN tool and directed toward the dual aims of reducing burden and maximising capacity.
- Care co-ordinators will be encouraged to directly provide generic treatments and mental health support to their clients initially, rather than immediately referring them to another provider. Support clinicians will provide advice as needed, including pathways for onward referral when necessary.
- Care co-ordination will include indirect client time to liaise with other providers and arrange external service provision for health and social needs as required.
- Clients will continue to engage with any existing external health service provision, but for clients engaged with multiple community health services, their clinicians will liaise directly with the care co-ordinator to improve integration and reduce treatment burden.

Appointment frequency and location (in clinic, at home or by phone) will be based on preference and need, and informed by the ICAN discussion aid. The trial will be conducted over

a period of nine months, to allow for rolling recruitment. Clients will complete self-report measures at baseline, 3 months, and 6 months, and will be invited to participate in a qualitative interview six months after their engagement with the programme. Due to varying levels of complexity, clients may still be engaged with the community health service after this time, but no further data will be collected. Discharge from the programme, either before or after the 6-month period, will be based on client-identified needs and measured capacity/burden level.

Figure 8.1 describes the relationships between clients and clinicians engaged in the intervention, and Table 8.1 outlines the intervention timeline.

**Figure 8.1: Intervention linkages**



**Table 8.1: Proposed timeline for the intervention**

Year 1: 1 <sup>st</sup> quarter	Year 1: 2 <sup>nd</sup> quarter	Year 1: 3 <sup>rd</sup> quarter	Year 1: 4 <sup>th</sup> quarter
Ethics approval	Deliver HCP training	Recruit client participants	Intervention period
Set up advisory group	Recruit client participants	Baseline measures	3-month measures
Organisational co-design	Baseline measures	Intervention period	(clients)
Develop HCP training		Supervision sessions for	Supervision sessions
Recruit HCP participants		care co-ordinators	
Year 2: 1 <sup>st</sup> quarter	Year 2: 2 <sup>nd</sup> quarter	Year 2: 3 <sup>rd</sup> quarter	Year 2: 4 <sup>th</sup> quarter
Intervention period	Qualitative data	Data analysis	Dissemination
Supervision sessions	collection (clients and		
6-month measures	HCPs)		
(clients)			
9-month measures (HCPs)			

### **Measures used and data collection**

For a feasibility study, using a mixture of quantitative and qualitative methods will enable us to understand barriers to participation and implementation, as well as to estimate response and recruitment rates.

### **Primary outcome: feasibility**

This will be measured under the following categories(36):

- Acceptability of the intervention: assessed via 1-1 qualitative interviews with patients and focus groups for care co-ordinators and support clinicians. Clients will also complete the short-form Patient Assessment of Chronic Illness Care (PACIC-11) at baseline and 6 months.
- Demand: Recorded quantitatively: numbers of clients eligible; numbers who initially engage/are referred; numbers who refuse; attrition rates; numbers of clinicians



involved in intervention; numbers of clinicians who refer into the programme. Data will be obtained from the EMR, along with client demographics (age, gender, living situation, education level, employment status and income). To ascertain the level of complexity in the trial population, clients will also complete self-report tools recording illness burden (Disease Burden Impact Scale, DBIS) and deprivation level (Deprivation in Primary Care Questionnaire, DiP-CareQ) at baseline and at six months.

- *Implementation*: Qualitative interviews with HCPs and patients will be conducted to explore barriers, facilitators, and suggestions for improvement. Fortnightly supervisions with HCPs, to discuss issues raised during the intervention, will be documented and reports generated.
- *Practicality*: Time spent on intervention (direct and indirect) by HCPs, time for training and supervision and time needed for administrative support will be recorded from the EMR. Difficulties associated with completing self-report measures or documenting the intervention will be explored during qualitative interviews.
- *Integration*: Focus groups will be undertaken with chronic disease clinicians and management staff who are not directly involved with the intervention, to explore the impact on other community health services and on the organisation as a whole.

### **Secondary outcome: Efficacy**

Although this study is not powered to assess efficacy, we will be using the following outcome measures in preparation for a powered efficacy trial in the future. Self-report data will be collected at baseline, 3 months and 6 months into the intervention. We will be recording quality of life, treatment burden and self-efficacy.

- *Quality of life* is a key outcome measurement for multimorbidity(30) and we will be using the EQ-5D5L, a widely used 5-item Likert scale plus VAS score with good

psychometric properties (51) and strong correlations to longer-term outcomes including cost-effectiveness(52).

- *Treatment Burden*: Since this is an intended target for our intervention, we will record this using the Multimorbidity Treatment Burden Questionnaire (MTBQ)(53), which is a thirteen-item Likert scale measure ranking the difficulty of healthcare tasks.
- *Self-efficacy* will be assessed using the short form Perceived Medical Condition Self-management scale (PMCSMS-4)(54), which is a 4-item Likert scale measuring self-efficacy in management of CHCs. We included a self-efficacy measure since it is a well-established and researched concept known to be important in chronic disease self-management and responsive to change(4, 5).
- *Hospital Data*: We will document hospital admissions and emergency presentations from the participating clients' medical records for 12 months prior to, and 12 months following the intervention.

Table 8.2 summarises the outcomes and methods of data collection.

**Table 8.2: Outcomes and methods of data collection**

What is being measured	How will it be assessed	When will data be collected
Acceptability	Qualitative: 1-1 interviews with clients, care co-ordinators, support clinicians	Clients: 6 months after recruitment HCPs: At trial conclusion
	Quantitative: PACIC-11 (clients)	Clients: at recruitment and 6 months
Demand	Clients: numbers eligible; numbers referred, number who engage; attrition rates.  HCPs: numbers involved in intervention, numbers who refer into the programme.	EMR – gathered over the course of the intervention
	Demographic characteristics and level of multimorbidity/psychosocial complexity in clients	Self-report measures gathered at baseline or intake (DBIS, DiP-CareQ, demographics)  DBIS and DiP-CareQ repeated at 6 months
Implementation	Interviews with HCPs and patients, focus groups amongst wider staff groups.	Clients: 6 months after recruitment HCPs: At trial conclusion
	Explore in fortnightly supervisions, review of EMR	Throughout intervention
Practicality	Time spent on intervention (direct and indirect) by HCPs, time for training and supervision; time for admin support.	EMR, during and after intervention.
Integration	Focus groups across organisation	End of intervention
Efficacy	Quality of life, treatment burden, self-efficacy – client self-report (EQ5D5L; MTBQ; PMCSMS-4)	Baseline, 3 months, 6 months

## Data analysis

Qualitative data will be analysed thematically and imported into NVivo. In view of the small sample size and lack of control group, quantitative analysis will be mostly descriptive with limited exploration of data trends.

## Ethics

Ethics approval will be sought from the La Trobe University Human Research Ethics Board. The trial will be registered through the Australia New Zealand Clinical Trials Registry (ANZCTR). All

participants will complete written informed consent forms. Any identifiable data generated from this trial will be anonymised prior to publication or dissemination. Data will be securely stored at a password-protected site and managed in accordance with the La Trobe University Research Data Management Policy.

## **8.4 Discussion**

There is a great need to find ways of managing multimorbidity without increasing treatment burden, especially for populations experiencing social disadvantage. This pilot trial aims to translate the concepts and practical techniques of minimally-disruptive medicine into an Australian rural community health setting. Community health centres are committed to addressing the social determinants of health in practice, and their typical client population faces 1.5–2 times the risk of CHC prevalence, hospitalisation and death(55) compared to Australians in the highest socioeconomic quintile. Our outer regional setting experiences high CHC prevalence and risky health behaviours in the context of limited healthcare access, especially to GPs and medical specialists(48, 50). The intervention we propose will support these vulnerable clients by utilising and building on skills already present in the local workforce, which may increase sustainability. If our pilot intervention is judged to be feasible and acceptable by community health staff and clients, and there are indications that it may be effective, we plan to progress to a cluster RCT with other Victorian rural community health centres facing similar challenges. Findings from this study will be disseminated to regional consumers and health organisations; across community health and primary care networks in Australia; and via peer-reviewed publications and conferences.

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## CHAPTER NINE:

### Discussion and Conclusions

#### **9.1 Summary of thesis objectives**

This project was undertaken as an industry PhD, in partnership with a community health centre. Therefore, I needed to explore a topic of significance to my industry partner, that would also contribute to the research base in chronic disease management. The defining feature of the community health movement is a commitment to the social model of health and to socially disadvantaged clients. The greater health risk factors and poorer health outcomes associated with this population means they are a group of key importance both to my industry partner, and to public health research more generally. The broad aim of my thesis, and the knowledge gap I intended to address, was to explore the barriers to managing chronic disease effectively in rural community health settings, and to consider alternative models of care.

#### **9.2 Summary of thesis findings**

In **chapter one**, I reviewed the literature on chronic disease epidemiology and the role of the social determinants of health in prevalence and health outcomes. I discussed the current approach to chronic disease management — the Chronic Care Model — and the place of self-

management in this model. I described four known barriers to chronic disease self-management (CDSM): social disadvantage, multimorbidity, beliefs and health systems. I noted that very little research into CDSM had taken an equity perspective, despite consistent evidence that social disadvantage was associated with poorer outcomes. Finally, I identified eight key research questions that I planned to answer in my thesis. Table 9.1 lists each question and the relevant thesis chapter. The key findings from each chapter, in answer to the research questions, are detailed below.

**Table 9.1: Research questions and chapters**

Research question	Chapter
1. Are there differences in participation in, or outcomes from SMS interventions based on socioeconomic status?	2
2. Do SMS interventions increase inequity between low and high SES groups?	2
3. How do multimorbid patients in rural low-income settings manage their health workload and self-manage their CHCs? Is this different from more advantaged populations?	5
4. Is the emphasis on building self-efficacy through SMS appropriate in low-income or resource-constrained settings?	6
5. What is the impact of health system and organisational factors on the self-management capacity of rural low-income patients with CHCs?	4
6. Are health providers working in SMS in these settings aware of the social and contextual factors facing their clients and how do they address them?	4
7. Is it possible to identify people who are likely to struggle with self-management?	7
8. What Model of Care is most appropriate to assist multimorbid patients in rural low-income settings in managing their CHCs?	8

Questions one and two were answered in my systematic review (**chapter two**), which aimed to discover whether socioeconomic status (SES) affected outcomes or engagement from CDSM interventions. If interventions worked differently in low SES groups, this would argue the case for alternative models of care. Although findings were inconclusive, the systematic review did suggest that without careful tailoring, CDSM had the potential to increase health inequity.

However, more importantly, what emerged was that 'SES' was a far too wide-ranging concept, and that risk of poor outcome was associated with sub-groups within this population, for example those with poor literacy or high workload.

This prompted me to explore these sub-groups in greater detail. It is neither feasible nor appropriate to provide tailored CDSM to all comers, but if it were possible to identify the groups who were most at risk, they could be targeted for specific interventions. Those at lower risk could access less intensive, generic interventions. I found that the concepts of burden and capacity, as described in the Cumulative Complexity Model (CuCoM), provided a framework enabling me to explore potential at-risk groups and in **chapter three** I outlined this model and how it was integrated with my overall thesis.

Since this PhD was embedded within a rural community health environment, I wanted to explore how the CuCoM fitted with my client and healthcare provider (HCP) population. As a patient-centred model, most of the research using this model had involved patients rather than HCPs. It was important to also explore the HCP perspective since their views and opinions would be crucial if a change in service delivery was needed. I also focussed on non-medical (nursing and allied health) providers since they were much more directly involved in self-management support (SMS) provision than doctors, and (in a low-income rural setting) were also more accessible for clients. This consideration was important if I were to look at a future intervention. Therefore, I undertook qualitative interviews with both community health staff who provided SMS, and their multimorbid patients. My focus was on the understanding (for HCPs) and experience (for clients) of burden, capacity, and barriers to self-management.

I chose to organise my qualitative data in two ways. Firstly, I used already-established frameworks to analyse burden and capacity, using Normalisation Process Theory (NPT) to analyse burden and the Theory of Patient Capacity (BREWS) for capacity. This enabled me to

match the data with both CuCoM theory and the patient qualitative literature, as well as allowing for direct comparison between my client and HCP participants.

Secondly, in writing up my findings I returned to the four broad headings identified in the introduction as barriers to CDSM: social disadvantage, multimorbidity, beliefs and health systems. Taking social disadvantage as 'read' (since the entire patient population experienced social disadvantage), my qualitative papers addressed each of the other headings, with **chapter four** focussing on health systems, **chapter five** on multimorbidity, and **chapter six** on beliefs. By systematically exploring these impediments to self-management in the overall context of social disadvantage, I could look at the intersection of these factors rather than simply compiling a list of barriers.

**Chapter four** focussed solely on health provider perspectives. This chapter addressed questions 5 and 6, using the Framework Method (NPT and BREWS) to analyse the data. Whilst I found that HCPs did have a good understanding of burden and capacity, multiple health system barriers prevented them from acting on this. Although some barriers (e.g., lack of funding) were beyond the capacity of the HCPs to address, other barriers were to some extent created and reinforced by the HCPs. The key challenge was that most HCPs worked in a single disease model. This meant that multimorbid clients were often referred to numerous, poorly integrated services, increasing treatment burden. This was especially common for clients experiencing comorbid depression or other psychological conditions. Although all HCPs recognised the mental health impact of chronic health conditions (CHCs), there was a tendency to refer people on to address this, rather than incorporating it into SMS. This could be related to lack of HCP confidence, professional role delineation or lack of alternative models of care.

**Chapter five** consisted only of client interview data and used the same analysis approach as chapter four to address question three. The focus in this paper was on the effect of managing more than one health condition (multimorbidity) on perceived burden and capacity. Data

analysis revealed that the nature of the CHC was important. Conditions associated with functional impairment, particularly chronic pain and mental health conditions, had the greatest impact on capacity; whereas treatment burden was mostly related to conditions that had few functional impacts, such as diabetes. This means that for multimorbid patients, effective management of treatment burden may not lead to increased capacity, potentially discouraging engagement in treatment work. A second key finding was the significant treatment work involved in managing condition interactions, and this was mostly managed by patients with little support from HCPs. These findings suggested several important roles for HCPs, as well as reiterating the limitations associated with a single disease approach to chronic disease management. Greater emphasis on interventions which address a range of different CHCs (e.g., exercise, stress management) could help to build capacity and address functional impairment as well as improving low-symptom conditions like diabetes and hypertension. Both HCPs and patients need a greater awareness of the connections between conditions, symptoms and treatments, and assisting patients to negotiate this is another potentially useful role for HCPs.

**Chapter six** included interview data from both clients and HCPs and focussed on the role of beliefs on self-management in this population to answer question four. For this study I moved away from the capacity-burden framework, instead re-analysing the interview data using Bandura's self-efficacy theory. The reason for this was that self-efficacy theory provides the theoretical underpinning for most SMS interventions. A critique of SMS in this population would be much stronger if it were grounded in a theory that is widely accepted as the basis for SMS. This analysis found that self-efficacy theory contained assumptions that were not consistent with the experience of either clients or HCPs in the community health environment. Achieving desired health outcomes relies not only on building confidence and mastery (self-efficacy), but also on both the belief and the reality that individual actions will lead to beneficial outcomes. Outcome expectations of both clients and HCPs were strongly shaped by

past negative experiences, as well as by the reality that resources (such as money) rather than behaviours, were often key to beneficial and desired outcomes. This suggested that the traditional self-efficacy approach to SMS may not be appropriate for clients with resource constraints or social complexity, and further supports the need to focus on capacity and context.

Between them, chapters four to six explored the key barriers to self-management in the community health setting, using a burden and capacity lens. The papers identified some common themes. This included the limitations of a single disease model; the importance of addressing mental health conditions together with physical health conditions; the need to identify and address where possible specific resource constraints; and the need for broader skillsets and flexible professional boundaries for HCPs. These findings point to a possible alternative model of care for this population which is developed in **chapter eight**.

**Chapter seven** returns to the theme of burden and capacity but looks at whether it is possible to identify sub-groups at higher risk of poor outcomes, as discussed in chapter two and formulated in question seven. The Cumulative Complexity Model proposes that individuals require a sufficient level of capacity to service their treatment burden. Even a modest number of treatment tasks can be perceived as an overwhelming burden if capacity is inadequate. In this study, I undertook a cross sectional survey that explored the correlations between different capacity domains - social, economic, personal, and physical – with treatment burden and quality of life. I found that high perceived treatment burden was associated with younger age, material deprivation, low self-efficacy and usual activity limitation, accounting for 50.7% of the variance in high perceived treatment burden. Although there were limitations to this study, due to its small size and possible sampling bias, it suggested that perceived treatment burden was associated with psychological and social factors rather than disease burden or specific diagnosis, consistent with my qualitative findings. Progress was made toward the

creation of a formal risk-screening tool, and recommendations to further develop this were proposed. The fact that the capacity and burden measures I used were already validated means that it would be relatively simple to scale up the study for a more definitive outcome.

**Chapter eight** answers question eight by synthesising the findings of my research into a feasibility trial. The overall aim of my thesis was to explore a better way to manage CHCs in the community health population. This has eventuated in the proposed model of care outlined in my protocol study. This model is grounded in the Cumulative Complexity Model and incorporates findings from my previous studies. The intervention will include:

- Supporting the community health centre to move from a disease-specific model to a capacity-burden model for chronic disease management (chapter 4).
- Formal measurement of burden and capacity using self-report scales (chapter 7).
- Care co-ordination by HCPs (chapters 4-5).
- Additional training and support for HCPs in the areas of mental health strategies, managing interactions in multimorbidity, integrating social services, and the use of synergistic interventions (chapters 4-6).

### 9.3 Limitations and Future Research Directions

#### Limitations

The limitations specific to each study are detailed in the relevant chapters. However, it is also important to note the overall limitations of this thesis. Since this PhD has been undertaken in a specific setting, the results may not be generalizable. The qualitative research took place over

only two community health centres, and the sample sizes were relatively small. The quantitative component was also small and not amenable to causal analysis. Despite this, findings were very consistent. More generally, Australian rural community health centres have many relevant similarities in terms of client needs and workforce distribution. This argues for wider applicability across the community health network. Additionally, few of the findings were specific to the rural setting, suggesting that the results may apply to urban settings as well. The similarity of my results to the international literature on multimorbidity in socially disadvantaged populations also supports this.

### **Future Research Directions**

The overall message of my thesis is that the traditional approach to chronic disease self-management, as informed by self-efficacy theory, is not fit for purpose in rural community health settings and potentially, in similar settings with high levels of multimorbidity and social disadvantage. Instead, I argue that a minimally disruptive medicine approach, which focusses on individual capacity and burden, is more appropriate and is more likely to lead to improved outcomes in this population. My protocol study in chapter eight describes this alternative model of care in detail.

The most important and immediate practice implication that has emerged from my thesis is the alternative model of care that is planned for a feasibility trial in 2022. If successful, the objective would be to expand this into a cluster trial across other rural community health centres, which have similar client and HCP populations. The HCP training that will be developed during the pilot trial may also lead to further research, in different HCP populations. Exploration of the role of GPs in the self-management space, and their relationship with other HCPs providing SMS, may also lead to useful insights in relation to service delivery. Additionally, a larger cross-sectional or potentially longitudinal study could allow further



investigation of capacity and burden domains and the development of a validated screening tool for treatment burden risk.

## 9.4 Reflections and Conclusion

My thesis question emerged from the observation that patients and HCPs in socially disadvantaged settings often struggled with chronic condition self-management. Many clinicians, including myself, felt that self-management support was at times a Sisyphean task.

The issue we all faced was the gap between efficacy and effectiveness. Efficacy can be determined in a controlled environment with scientific rigour, but patients and their social environments are messy and complex. For treatment efficacy, the ideal patient is selected to fit the intervention. Real-world effectiveness is more elusive since ideal patients can be hard to find.

Although the efficacy/effectiveness gap is widely recognised, too often it results in clinicians simply dismissing research as impractical, or irrelevant to their patient population. In my PhD, I have aimed to bridge this gap by systematically exploring the challenges of CDSM within the community health setting. As a practising clinician throughout the length of this PhD, there has been a continual process of dialogue between my research and my clinical work. This has grounded and enriched both spheres of practice and helped to maintain my focus on the central importance of the patient-HCP relationship.

Amidst the many findings and recommendations in this thesis, the single constant theme has been the importance of fit. Instead of the patient being selected to fit the intervention (as in *efficacy* studies), to be *effective* the intervention needs to fit the patient. How do we do this? It's profoundly simple. By listening to the patient and respecting their values and priorities. By

remembering that chronic disease management is not a goal in itself, but is always 'in order to'...keep working, spend time with family, continue to enjoy hobbies, provide care for another, pursue meaningful goals. Using the approaches outlined in this thesis and starting with the individual's experience of burden, capacity and complexity, patient-HCP interactions could be truly centred around the person rather than the intervention.

## APPENDICES

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**Appendix A: Chapter 2 Publication**

RESEARCH ARTICLE

Open Access

# What impact do chronic disease self-management support interventions have on health inequity gaps related to socioeconomic status: a systematic review

Ruth Hardman<sup>1,2\*</sup>  Stephen Begg<sup>3</sup> and Evelien Spelten<sup>1</sup>



## Abstract

**Background:** The social gradient in chronic disease (CD) is well-documented, and the ability to effectively self-manage is crucial to reducing morbidity and mortality from CD. This systematic review aimed to assess the moderating effect of socioeconomic status on self-management support (SMS) interventions in relation to participation, retention and post-intervention outcomes.

**Methods:** Six databases were searched for studies of any design published until December 2018. Eligible studies reported on outcomes from SMS interventions for adults with chronic disease, where socioeconomic status was recorded and a between-groups comparison on SES was made. Possible outcomes were participation rates, retention rates and clinical or behavioural post-intervention results.

**Results:** Nineteen studies were retrieved, including five studies on participation, five on attrition and nine studies reporting on outcomes following SMS intervention. All participation studies reported reduced engagement in low SES cohorts. Studies assessing retention and post-intervention outcomes had variable results, related to the diversity of interventions. A reduction in health disparity was seen in longer interventions that were individually tailored. Most studies did not provide a theoretical justification for the intervention being investigated, although four studies referred to Bandura's concept of self-efficacy.

**Conclusions:** The limited research suggests that socioeconomic status does moderate the efficacy of SMS interventions, such that without careful tailoring and direct targeting of barriers to self-management, SMS may exacerbate the social gradient in chronic disease outcomes. Screening for patient disadvantage or workload, rather than simply recording SES, may increase the chances of tailored interventions being directed to those most likely to benefit from them. Future interventions for low SES populations should consider focussing more on treatment burden and patient capacity.

**Trial registration:** PROSPERO registration [CRD42019124760](https://doi.org/10.1186/1745-6215-191-24760). Registration date 17/4/19.

**Keywords:** Self-management, Socioeconomic status, Health inequity, Patient capacity, Chronic disease

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## Background

Chronic health conditions are increasingly common, with some population groups, such as those of lower socioeconomic status (SES) having both a greater incidence of chronic disease and a poorer prognosis [1–3]. The long-term nature of these conditions means that the patient is largely responsible for day-to-day disease management [4, 5] and since many chronic conditions are lifestyle-related [6], the quality of patient self-management is important. Self-management support (SMS) approaches have been developed to give people the skills to more effectively manage their health. These interventions involve both education and behaviour change strategies to address the medical, physical, emotional and social challenges associated with CD, aiming to help the person adapt to their changed circumstances whilst still leading a meaningful life [4, 5, 7].

Although SMS interventions are now widespread, outcomes have been mixed, with the benefits being limited to short-term improvements in psychological variables such as self-efficacy, rather than sustained clinical or behavioural changes [4, 6, 8, 9]. Most SMS interventions are theoretically grounded in Bandura's concept of self-efficacy [5] and utilise specific techniques to enhance self-efficacy [5–7, 10, 11]. Self-efficacy theory refers to an individual's belief or confidence in their capacity to undertake tasks or achieve goals, which can translate into health behaviour change and by implication, improved health status [4, 5].

Persisting questions remain, however, about the effectiveness of SMS in low SES and other disadvantaged groups. The original SMS trials were conducted in self-selected, higher SES populations [4, 6, 10] and studies in disadvantaged populations have reported poorer outcomes and lower levels of adherence [12, 13]. Several writers have theorised that the individual patient focus of SMS limits its effectiveness in these groups. By prioritising individual self-efficacy and activation, the potential barriers to self-management within the patient's wider social context (e.g. literacy, resources, social supports) are ignored [6, 10, 11, 14, 15]. Although the dominant role of the social determinants of health is acknowledged in CD epidemiology, their influence on treatment engagement is rarely addressed [15].

Effective chronic disease (CD) management should include both an improvement in overall population health and a reduction in health inequities [16–18]. An intervention that appears more effective in a better-off population may widen the disparity gap, and there are strong suggestions that individually-focussed 'downstream' interventions, such as SMS, can increase disparity [17, 19, 20]. Specific targeting of disadvantaged groups is one way to deal with inequity, and tailored SMS approaches for these groups have been trialled, but systematic reviews have

shown inconsistent and dose-dependent benefits [13, 21]. In addition, such interventions may have positive outcomes, but still not address the disparity gap [18].

Although there are suggestions that SMS interventions may be less effective in low SES groups, this can only be determined by comparing SMS outcomes between more and less advantaged groups. There have been no previous reviews on this topic, despite many researchers stressing the importance of addressing and quantifying the equity gap in CD [18–20, 22, 23]. This is partly due to statistical challenges, since the evidence will emerge from subgroup analyses [19, 24, 25]. However, given the strong connection between the social determinants of health and health outcomes, subgroup analyses need not be post-hoc data dredging but can be planned and valid approaches to answering these questions [26–28].

This review aims to examine studies that have looked at differences between socioeconomic groups undergoing SMS interventions, in order to answer the following questions: 1. Is there evidence that SES influences participation rates in SMS interventions? 2. Is there evidence that SES influences rates of retention or dropout from SMS interventions? 3. Is there evidence that SES affects clinical, behavioural or other specified outcomes following SMS interventions?

## Methods

### Search strategy and data abstraction

We conducted a systematic review of the literature using the PRISMA reporting guidelines [29] to structure the report. We searched for full-text articles in English to December 2018 in the following databases: Cochrane database; PubMed; CINAHL; Embase; Proquest and Psycinfo. The search terms covered the following areas, using MeSH terms and synonyms: [1] Chronic condition, including diabetes, cardiovascular disease, musculoskeletal conditions and chronic pulmonary disease [2]; Self-management [3]; Socio-economic status, including associated terms such as inequity, disparity, 'vulnerable groups'; and [4] Terms related to outcomes, efficacy, retention or participation. The PubMed search strategy is available in Additional file 1. No date filter was employed in order to obtain the widest possible search. In the course of the search thirteen related systematic reviews were located and their references were screened resulting in seven additional papers.

### Inclusion criteria

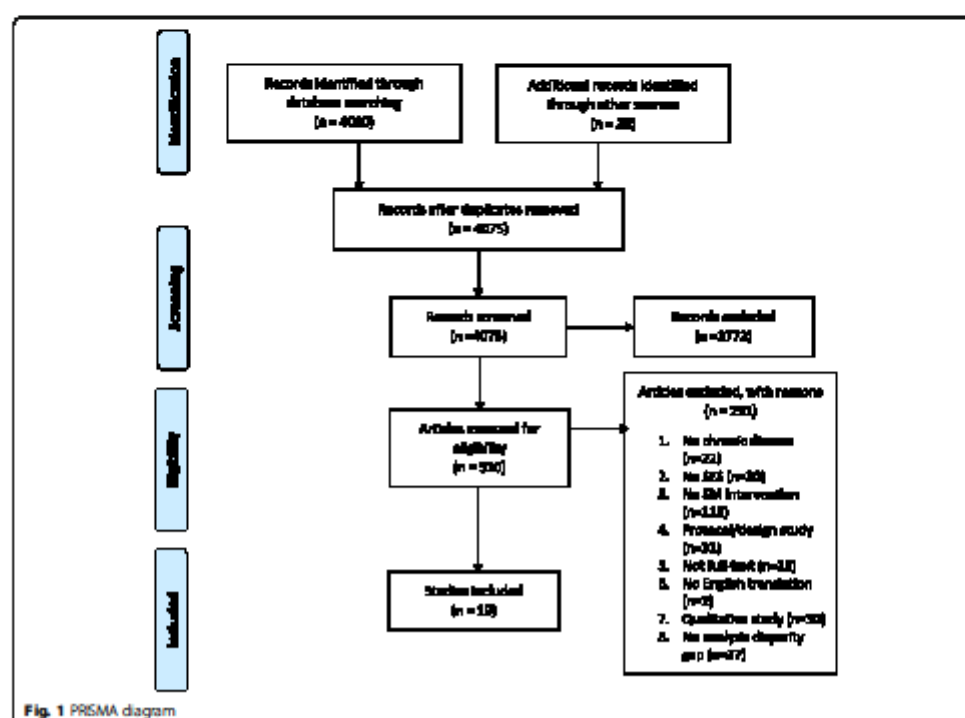
Inclusion and exclusion criteria are outlined in Table 1. We looked for four main chronic conditions: cardiovascular disease (CVD), musculoskeletal conditions (MSK), pulmonary disease (COPD) and diabetes. All these conditions contribute significantly to the burden of disease and share many common risk factors. We included

**Table 1** Inclusion/exclusion criteria

PICO	Inclusion Criteria	Exclusion Criteria
Population	Over 18 years Diagnosed with diabetes, COPD, cardiovascular disease, chronic musculoskeletal pain and any additional comorbidities SES described in terms of education, income, area or occupation.	At-risk patients (e.g. prediabetes) Disadvantaged (e.g. ethnic minority) population without quantifiable reference to SES.
Intervention	Includes a self-management support intervention incorporating at least 3 recognised elements of SM [7]	Single-component SMS intervention (e.g. education, medication adherence only).
Comparison	Includes analysis of whether the response to the intervention differs according to SES.	No measurement of SES disparity in reporting of outcomes.
Outcome	Reporting of outcomes which may be clinical, behavioural, psychosocial or related to participation/adherence.	

studies of co/multimorbidity since this is representative of the CD population. A decision was made to focus only on socio-economic status (SES), which has well-documented and consistent effects on chronic disease, rather than on other WHO PROGRESS+ factors such as gender and ethnicity, which can vary between countries [19]. All studies needed to provide a comparison between a less and more advantaged group, based on income, education or socioeconomic area. Comparisons

based on literacy or ethnicity were only included if there was a quantifiable relationship between these variables and other SES measures. As well as post-intervention outcomes such as behavioural or clinical changes, outcomes related to participation and dropout were included to fully capture potential areas of disparity. Study designs could include randomised controlled trials with subgroup analyses, pre-post designs, cross-sectional or longitudinal data analyses.

**Fig. 1** PRISMA diagram



### Search outcomes

Title and abstract screening reduced the number of papers to 310. Articles were excluded according to the criteria outlined in Table 1. Common reasons for exclusion were no SMS intervention (e.g. studies of self-care or adherence behaviours); SES not quantified, and no measurement of SES disparity. A full list of reasons for exclusion of the 291 full-text articles is available in Additional file 2. Figure 1 illustrates the search process undertaken. One reviewer (RH) completed the initial search and a second reviewer (ES) independently assessed the final papers to ensure agreement on inclusion criteria. Nineteen studies were included in the review.

### Data abstraction

The data was summarised on the setting, study design, type of CD, sample size, description of intervention and control, outcomes or variables measured, follow-up time, results and study quality (Table 2 and Table 3). Table 4 and Table 5 summarises data related specifically to SES and disparity, including the theory behind the SM intervention (or study question for participation/attrition studies), intervention description, SES adaptations made, SES status of population, results in relation to SES, drop-out rates and overall impact on SES disparity. Related papers were retrieved to provide additional data about the population or intervention as needed [31–38].

Quality analysis was undertaken using the Joanna Briggs Institute checklists [30] for randomised controlled trials (RCTs) and observational studies, and the Sun/Oxman criteria [27, 28] for subgroup analyses.

### Data synthesis

No meta-analysis was possible due to the diversity of study designs, interventions and outcome variables.

## Results

### Key study characteristics

Nineteen studies were identified, all published in English. Five studies looked at participation in SMS; five studied attrition from SMS programmes and nine assessed outcomes from SMS interventions. Interventions were very diverse, ranging from studies of the group-based Stanford Chronic Disease Self-Management Programme (CDSMP – 4 studies) to highly tailored 1–1 interventions. Table 2 and Table 3 details the main features of all studies.

### Methodological quality

Most studies were of moderate to good quality although two RCTs [39, 40] and three subgroup analyses [39–41] rated poorly. A summary of quality ratings is included in

Table 2 and Table 3 and a detailed table describing how each study was assessed is available in Additional file 3.

### Responses to study questions

#### 1. Is there evidence that SES influences participation rates in SMS interventions?

Four cross-sectional studies and one cohort study looked at initial participation in SMS programmes. All were large population surveys ranging from 2600 to 80,000 people. There were three reports on diabetes SMS education programmes [42–44], one on the Stanford CDSMP [45] and the final study examined recruitment to an internet diabetes SMS programme [46]. In all studies, low SES (as measured by education, income or location) was significantly and consistently associated with lower levels of participation, suggesting that disparity in CDSMP starts here. Some studies [43, 45] suggested that this imbalance was related to course availability, cost or marketing strategies. However, the studies which did match attendance to course availability and cost [42, 44] found that this did not influence participation in the low SES population. Glasgow [46] also compared participation rates in a self-selected (via media advertising) population to a referred population and found even greater disparity. As well as being of higher SES, the self-selected participants were those at lowest risk and least in need of the intervention.

There is consistent evidence that low SES is associated with lower levels of participation in SMS interventions, and some evidence that this is unrelated to access to SMS interventions.

#### 2. Is there evidence that SES influences rates of retention or dropout from SMS interventions?

Five studies examined attrition: two cross-sectional studies and three RCTs with subgroup analysis, with sample sizes from 100 to 300. Two RCTs [41, 47] were of more advantaged populations. Of these, one reported low (22.8%) completion rates of the Stanford CDSMP [41], but predictors were related to poor physical health rather than SES. Since this was a high-risk multimorbid rather than a low SES population, dropout likely reflects increased treatment burden, as noted in other multimorbid populations [48]. The second study [47], of a diverse urban population, reported no difference in use of a supported internet programme in terms of SES (education). This intervention had been carefully tailored to maximise engagement across population groups and included extensive community involvement in the design process. Three studies [49–51] focussed on low SES populations. Two cross-sectional studies [49, 50] reported that dropout rates correlated to social stressors and lack of job

**Table 2** Studies examining disparities in outcomes following SM interventions, stratified by quality<sup>1</sup>

Author <sup>1</sup>	Country and setting	Study design	Chronic Disease	Sample size	Intervention description, healthcare providers (HCPs), SM Components	Control	Outcomes measured	Follow up	Results	Quality rating
Rothman 2004 (Rothman 2005)	USA Public primary care clinics	RCT with subgroup analysis	Diabetes	217	Individual Phone and face-to-face SMS over 12/12 Pharmacist and nurse 1,2,3,5,6,7	Single 1-1 session with pharmacist	Hb A1c and blood pressure	12/12	HbA1c improved significantly from baseline for both IC. For higher literacy participants group there was no difference between IC but those with low literacy had a HbA1c change of -1.4% (adjusted), CI -2.3 to -0.6%, $p < 0.001$ , favouring intervention. BP improved in intervention group regardless of literacy, $p = 0.006$ .	JBI 11/12 SVO 11/11
DeWalt 2012 (DeWalt 2006)	USA Hospital clinics	RCT with subgroup analysis	Chronic heart failure (HF)	605	Individual Education session then phone support for 12/12 Health educators 1,2,3,5,7,8	Single 1-1 education session	All-cause hospitalisation, death, HF hospital admission, HFQOL	12/12	In low-literacy participants adjusted incident rate ratio (IRR) was 0.73 for all-cause hospitalisation and death and 0.48 for HF hospitalisation, favouring intervention; RR for high literacy was 1.16 for all-cause and 1.34 for HF hospitalisation, favouring control.	JBI 10/12 SVO 11/11
Booma 2011 (Jarnes 2010)	Netherlands Public primary care clinics	RCT with subgroup analysis	Diabetes or COPD with mild to moderate depression	361	Individual Home based CBT and SMS for 6/52 Nurses 1,3,4,6,7,8	Usual GP care	Depression primary outcome (Beck Depression Inventory); also health-related quality of life (QOL); control beliefs (mastery); self-efficacy.	9/12	Interaction between education level was significant ( $p < 0.05$ ) or nearing significance ( $p < 0.10$ ) at 3 and 9 months for all outcomes with no benefit for low educated. Clinically significant (> 50% improvement) in depression at 9 months for high educated only.	JBI 11/12 SVO 9/11
Moskowitz 2013 (Thom 2013)	USA Public primary care clinics	RCT with subgroup analysis	Diabetes	299	Individual Phone and face-to-face peer support over 6/12 Peer health coaches 1,3,4,5,6,8	Usual GP care	HbA1c	6/12	HbA1c reduced by 1.07% (intervention) vs 0.3% (control), $p = 0.01$ . HbA1c decrease was predicted by SM ability and medication adherence. Those with low SM ability benefited most; ethnicity and education did not differentially affect the outcome.	JBI 10/12 SVO 9/11
Powell 2010	USA Hospital clinics	RCT with subgroup analysis	Heart failure	902	Group SMS classes over 12/12 Health professionals 1,2,3, 4,5,6	Education sheets plus phone follow-up	Death/HF hospitalisation, medication adherence, salt intake, SM ability, cardiac QOL, SF 36, depression.	2.5 years	Depression, self-efficacy and salt intake improved in both intervention and control groups. Low income participants in the control group had a non-significant ( $p = 0.066$ ) trend to earlier cardiac event (death/hospitalisation).	JBI 11/12 SVO 6/11
Smeulders 2010 (Smeulders 2006)	Netherlands Hospital clinics	RCT with subgroup analysis	Chronic heart failure	317	Group Stanford CDSMP for 6/52 Nurse and peer leader 1,2,3,4,5,6,7, 8	Usual care	Cardiac QOL (Kansas City Cardiomyopathy Questionnaire)	12/12	Short-term improvement in cardiac QOL in intervention group but not at 6 or 12/12. Lower educated patients improved more than higher educated ( $p = 0.018$ ) throughout the follow-up period.	JBI 10/12 SVO 7/10
Jonker 2012	Netherlands Elderly	RCT with subgroup analysis	Frail elderly; unspecified	63 (intervention)	Group Stanford CDSMP for 6/52	Waitlist	Depression, valuation of life, control beliefs (mastery)	6/12	Mastery ( $p = 0.01$ ) and Depression ( $p = 0.01$ ) scores improved from baseline in	JBI 6/12 SVO 9/11

**Table 2** Studies examining disparities in outcomes following SM interventions, stratified by quality<sup>1</sup> (Continued)

Author <sup>1</sup>	Country and setting	Study design	Chronic Disease	Sample size	Intervention description, healthcare providers (HCPs), SM Components <sup>2</sup>	Control	Outcomes measured	Follow up	Results	Quality rating
	daycare facility	analysis	chronic disease (mean of 2 CDs)	group)	Nurses 123,4,5,6,7, 8		self-efficacy, cognitive function		the intervention group at 6/12 (small effect size); subgroup analysis showed improvements in mastery ( $p < 0.05$ ) were limited to the lower educated and those with better cognitive function.	
Nour 2006	Canada Public community health centres	RCT with subgroup analysis	Arthritis and household	58 (intervention group)	Individual Home based CBT and SMS for 6/52 At- risk HCPs 1,3,4,5,6, 8	Waitlist	Health behaviour changes, arthritis score, pain/fatigue scores, mastery, depression, self-efficacy	6/52	Increased frequency of exercise ( $p < 0.001$ ) and relaxation ( $p = 0.05$ ) in intervention group but not for those with depression or perceived low SES.	JB 5/12 SJO 5/11
Gavil 2009	USA Insurance funded clinics	Cohort study	Cardiovascular disease	785	Individual and group 3/12 lifestyle programme Range of HCPs 1, 3,4,5,6,7,8	None	Blood pressure, lipids, exercise tolerance, BMI, depression, adherence	3/12	Outcomes improved significantly $p < 0.05$ across all education and income levels. Adherence and attendance similar across all groups. Baseline measures were significantly lower in low educated.	JB 9/11

<sup>1</sup>Studies listed in order of quality as measured by Joanna Briggs Institute (JBI) criteria [27, 28] and SunnyOman (SO) subgroup analysis (for RCTs) criteria [27, 28]. RCTs listed first, followed by cohort studies. Includes additional studies from the same research group where supplementary information was obtained. Numbers correspond to the key components of self-management interventions as listed by Barlow et al. (Barlow): 1. Information 2. Drug management 3. Symptom management 4. Psychological management 5. Lifestyle management 6. Social support 7. Communication 8. Other (action planning, goal setting, decision making, problem solving, spirituality).

**Table 3** Studies examining disparities in participation or attrition from SM interventions, stratified by quality<sup>†</sup>

Author <sup>‡</sup>	Country and setting	Study Design	Chronic Disease	Sample size (Intervention group)	Intervention	Variables measured	Results	Quality rating
Rodwin et al. 2018 (Murray 2017)	UK Urban public primary care practices	Subgroup analysis of RCT	Diabetes	299 (Intervention group)	Comparing 2 Internet SM programmes +/- support Predictors of use	Gender, age, ethnicity, education	No difference in frequency of programme use or registration according to any demographic predictors. User characteristics were reflective of the overall target population of the area.	JBI 12/12 SJO 10/11
Thorn et al. 2011 (Day 2010)	USA Rural public primary care practices	Subgroup analysis of RCT	Chronic pain	109	Low-literacy pain SM (education and CBT) groups Drop-out predictors	Demographics, literacy, pain catastrophizing, disability, depression, ODI, pain intensity interference	Dropout before programme started was associated with low education ( $p < 0.02$ ), low literacy ( $p < 0.05$ ) and catastrophizing ( $p < 0.01$ ), failure to complete programme associated with income (under \$13,000 - $p < 0.01$ ) and low education ( $p < 0.02$ ).	JBI 12/12 SJO 9/11
Duhaldo et al. 2012 (Beault 2011)	USA Primary care (both insured and public patients)	Subgroup analysis of RCT	Multimorbid chronic disease	241	Stanford CDSMP Completion predictors	Demographics, health status, health activities, patient activation, patient-rated quality of care	22.8% of eligible adults completed (attended at least 5 of 6 sessions). Attendance was associated with satisfaction with GP ( $OR = 2.8$ ) and having higher SF-36 physical health scores ( $OR = 2.3$ ). Age, sex, education, race and SES were not significant.	JBI 11/12 SJO 5/11
Cauch-Dudek 2014	Canada National database analysis	Cohort	Diabetes - first 8/12 post diagnosis	46553	Any type of DSME Participation predictors	Age, sex, immigrant status, comorbidity, mental illness, rural residence, SES	21% of people attended DSME within 8/12 of diagnosis. Non-attendance was associated with older age, lower SES, recent immigration or physical/mental health comorbidity (all $p < 0.001$ ).	JBI 10/11
Adjei-Boafoe 2018	USA National telephone survey	Cross-sectional	Diabetes	84179	Any type of diabetes SM education (DSME) Participation predictors	Race, education, marital status, income, sex, health insurance, BMI, insulin use, self-care behaviour	53.7% reported attending DSME, with attendance less likely amongst men (adjusted $OR = 0.85$ ), Hispanics ( $OR = 0.81$ ), high school only ( $OR = 0.71$ ) or less than high school educated ( $OR = 0.51$ ), income $< \$10,000$ ( $OR = 0.70$ ) or $< \$25,000$ ( $OR = 0.81$ ) and the uninsured ( $OR = 0.87$ ). Attending DSME was significantly associated with adherence to SM behaviours.	JBI 8/8
Glasgow 2018	USA Database analysis (Health Insurance organisation)	Cross-sectional	Diabetes	2603	Internet SM programme Participation predictors	Sociodemographics, reason for declining service, HbA1c, BP, BMI, LDL, SF36, AQL, number of comorbidities	Participants were likely to be younger ( $p = 0.041$ ), not Latino ( $p = 0.022$ ), earning $> \$10,000$ ( $p < 0.0001$ ), greater than high school educated ( $p < 0.0001$ ), non-smokers ( $p < 0.0001$ ) with lower blood pressure ( $p = 0.028$ ). Self-selected participants were the most likely to be white, better educated and healthier.	JBI 8/8
Hornell 2017	USA National database analysis	Cross-sectional	Multimorbid chronic disease	19365	Stanford CDSMP Participation and completion predictors	Enrolment and completion of CDSMP compared to high/low SES area	81.6% of participants lived in the least impoverished areas ( $< 25\%$ of population below poverty line) and 0.3% of participants lived in the most impoverished areas ( $> 50\%$ below poverty line). SE area was significantly correlated with ethnicity and education level. Course completion was not associated with SES - poorer people had a higher (but non-significant) completion rate.	JBI 8/8
Hardman 2018	Australia Rural community health centre	Cross-sectional	Chronic pain	186	Tailored pain SM Drop-out predictors	Demographics, self-efficacy, pain catastrophizing, opioid dose, comorbidities	Early dropout associated with social stressors ( $p = 0.003$ ), $OR = 0.08$ for pain catastrophizing ( $p = 0.008$ , $OR = 1.03$ ) and pain catastrophizing ( $p = 0.048$ , $OR = 1.03$ ). Low income significant in bivariate analysis ( $p = 0.011$ ) only.	JBI 8/8
Nure-Belgel 2016	Denmark Urban community health centre	Mixed Cross-sectional + qualitative	Diabetes, COPD or CVD	104	Tailored SMS Drop-out predictors	Education, age, gender, comorbidity, whether 1st meeting cancelled	Non-completion associated with younger age (below 60) ( $p = 0.03$ , $OR = 3.8$ ). Non-significant trend of lower education associated with lack of completion. Qualitative study suggested comorbidity and low job control in low educated were factors.	JBI 8/8
Santorelli 2017	USA State-wide telephone survey (New Jersey)	Cross-sectional	Diabetes	4358	Any type of DSME Participation predictors	Age, sex, race, income	40% reported attending DSME, with attendance less likely amongst lower educated (high school or less), Hispanic or other ethnicity, those diagnosed under 2 years ago (all $p < 0.001$ ); the uninsured ( $p < 0.006$ ) and those without a HCP visit for diabetes in the past year ( $p < 0.002$ ). DSME attendance was not correlated to the number of certified DSME courses available in the area.	JBI 6/8

<sup>†</sup>Studies listed in order of quality as measured by Joanna Briggs Institute (JBI) criteria [30] and Sun/Om an (SJO) subgroup analysis (for RCTs) criteria [27, 28]. RCTs listed first, followed by cohort and cross-sectional studies. Includes additional studies from the same research group where supplementary information was obtained.



**Table 4** Effects on socioeconomic disparities: Studies examining outcomes from SM interventions, stratified by quality

Study	Theory behind intervention	Individual or group?	Intensity and duration	SES adaptations made (if any)	Demographics and SES status of population <sup>1</sup>	SES subgroup comparison	Results (in terms of SES only)	Dropout by group and SES	Impact on disparity
Rothman 2004	CD SM in low SES groups is best managed by a multidisciplinary approach that is tailored to the patient's needs and barriers.	Individual	2–4 phone or direct contacts a month (mean 38 min) over 12/12	Literacy adaptations, practical help to address barriers	Age: 36y mean Sex: 49% M Race: 69% EM Edu: 62% < 12 yrs Income: 74% < \$20,000 Literacy: 38% ≤ 6th grade <sup>2</sup>	Literacy – above/below 6th grade Correlated to education, income and insurance status.	Significant HbA1c improvement with intervention for low literacy group only; high literacy group did not differ between I/C.	Dropout low both before (study refusal) and during intervention; no difference for I/C or SES.	Reduced
De Walt 2012	People with low literacy have knowledge deficits. SMS should be adapted for their needs and provide ongoing support until mastery is achieved.	Individual	Education session + ongoing phone support for varied 12/12 depending on need (mean 14 calls)	Literacy adapted, intervention length varied	Age: 60y mean Sex: 52% M Race: 61% EM <sup>3</sup> Edu: 26% < 12 yr Income: 68% < \$25,000 Literacy: 41% <sup>3</sup> low	Literacy (\$ TO-HLA) Education and subjective SES also assessed in subgroups but were weaker predictors than literacy.	Phone support more effective in low literacy group; control intervention (education session) favoured high literacy. Literacy was a stronger predictor than education/income.	Dropout equal for I/C groups and did not differ by literacy.	Reduced
Bozma 2010	SMS is focused on increasing control and returning responsibility to the patient	Individual	2–100/hr face-to-face sessions (mean 4) for 6/52	Extra sessions if needed	Age: 30y mean Sex: 49% M Edu: 33% primary only	Education level (primary, some high school; completed high school).	No benefit for low educated. Gains only in higher educated groups.	Increased dropout from intervention in low educated.	Increased
Moskowitz 2013	Low SES patients have more challenges with SM and need assistance with literacy, depression and social support.	Individual	0–29 phone or direct contacts (median 5) over 6/12	Patients choose own coach, language and ethnicity catered for	Age: 36y mean Sex: 49% M Race: 55% EM Edu: 36% < 12 yr	Education (less than high school; high school; some college; college degree).	Benefit for those with low medication adherence and SM ability. Education level did not affect outcome.	Dropout low both before (study refusal) and during intervention; no difference for I/C or SES.	No change
Powell 2010	SMS groups aim to motivate people to participate in their care by teaching SM skills.	Group	18–2hr over 12/12	No	Age: 60y mean Sex: 53% M Race: 40% EM Edu: 44% ≤ 12 yr Income: 52% < \$30,000	Education (high school or less; above high school) and income (above/below \$30,000)	No improvement overall but low-income patients in intervention group had non-significant improvement on one outcome.	Dropout high both before and during intervention (in intervention group only); not reported by SES.	No change (vs. reduction)
Smeulders 2010	The CDMP aims to increase patient responsibility for SM by increasing self-efficacy.	Group	6 × 25h over 6/52	No	Age: 67y mean Sex: 72% M Edu: 44% < 12 yr	Education (under or over 12 yr education)	Low educated improved more than high educated in cardiac QOL outcomes.	Dropout high before intervention (study refusal) but no difference during intervention between I/C.	Reduced
Jonker 2012	SMS works by increasing self-efficacy and improving one's control over life and health.	Group	6 × 25h over 6/52	No	Age: 68y mean Sex: 50% M Edu: 50% ≤ 9 yr	Education (over/under 9 years)	Lower educated improved on mastery (p < 0.05) but no other benefits from multiple	Low dropout rate (but programme part of day care centre activities).	Reduced (one outcome)

**Table 4** Effects on socioeconomic disparities: Studies examining outcomes from SM interventions, stratified by quality (Continued)

Study	Theory behind intervention	Individual or group?	Intensity and duration	SES adaptations made (if any)	Demographics and SES status of population <sup>1</sup>	SES subgroup Comparison	Results (in terms of SES only)	Dropout by group and SES	Impact on disparity
Nour 2006	Arthritis SM is achieved by increasing knowledge and adopting health behaviours	Individual	6-7x/yr over 8/52	No	Age: 77y mean Sex: 50%MM Edu: 47% < 9 yr Perceived SES: 12% financially insecure	Education (lower/under 9 years) and perceived SES	Overall minor gains, but not for those with depression or perceived low SES	Low dropout rate	Increased
Gavil 2009	SMS aims to make lifestyle changes and improve health habits	Both	104 h over 3/12 (4 h, 2x/week)	No	Age: 60y mean Sex: 67%MM Race: 9% BM Edu: 48% < 12 yr Income: 22% < \$25,000	Education (high school or less, some college, college degree, postgrad degree)	All benefited equally – no difference across education levels, although lower educated had lower baseline measures	High attendance, low dropout, unrelated to SES	No change

<sup>1</sup>Population SES status terms have been structured to maximise comparability between papers.

<sup>2</sup>MM ethnic minority

<sup>3</sup>Literacy was used as an SES measure where it was clearly correlated with education and income.

**Table 5** Effects on socioeconomic disparities: Studies examining participation and attrition, stratified by quality

Study	Study question	Outcome	Intervention Description	SES adaptations made (if any)	SES status of population	Results (in terms of SES)	Impact on disparity
Podaval 2018	Can a DSME internet intervention engage people of differing demographics without increasing health inequity?	Use (more than 2 log-in post registration)	Internet SM programme + email/text support and assistance to register and access site	Low literacy developed with input from target population	Age 58y mean Sex: 55%MM Race: 55%BM Edu: 30% < 12yr	No difference in use according to education. Users were effective of the target population (inner London).	No change
Thorn 2011	Is pain SMS (CBT or education) effective in low SES groups and what are the predictors of engagement?	Initial participation and dropout over 10/52	SMS groups CBT and education for 10x 15h over 10/52	Literacy adaptations and teaching	Age 53y mean Sex: 20%MM Race: 79%BM Income: 68% < \$30,000 Literacy score: mean 21% (50% is population mean)	Non-attendance associated with low education, literacy and income dropout associated with low income.	Increased
Darabo 2012	Which subgroups of multimorbid older adults are most likely to attend CDMPs?	Completion (attend 5 or more sessions)	Sanford CDMP 6x 25h	None	Age 67-95 yf Sex: 43%MM Race: 51%BM Edu: 24% < 12yr Other SES: 42% financial strain <sup>1</sup>	No effect of SES variables on course completion	No change
Gauch-Dubek 2014	Are there disparities in utilisation of DSME soon after diagnosis?	Initial participation	Certified public health DSME programmes	Unspecified (multiple programmes)	All diabetes in Ontario, Canada diagnosed from Jan-June 2006 and followed up for 8/72.	Low SES area associated with increase in non-attendance, $p < 0.001$ .	Increased
Adjei-Boakye 2018	Are there are subgroups who do not participate in diabetes SM education (DSME)?	Initial participation	Diabetes SM education (DSME) - unspecified	Unspecified (multiple programmes)	Cross section of US population with diabetes	Non-participation associated with low education and low income association stronger as education/income reduced.	Increased
Gaugaw 2018	How representative of the diabetes population are those who participate or volunteer for an internet DSME study?	Initial participation	Internet DSME programme +/- support (phone calls and groups)	Available in 2 languages, no specific SES adaptation	Age 58y mean Sex: 50%MM Race: 31%BM Edu: 34% < 12 yrs Income: 25% < \$30,000	Higher income and education increased chance of participation, especially for self-selected people	Increased
Horell 2017	Do those in low income areas attend CDMPs and how can we promote higher enrolment?	Initial participation and completion	Sanford CDMP 6x 25h	None	USA attendees of CDMP courses Age 58y mean 63.6% of attendees lived in the least impoverished area.	Lowest SE area was associated with low participation (0.3% of participants) but not with low completion.	Increased participation No change (completion)
Hardman 2018	Do the social determinants of health affect engagement with pain SMS programmes?	Dropout (attend 3 or less sessions)	CBT-informed tailored SMS (individual or group over 6-12 weeks)	Programme tailored to preference/head	Age 55y mean Sex: 42%MM Income: 82% on welfare benefit Other SES: 27% 'social stressor'	Income not significant post-regression but social stressors (substance abuse history, victim of abuse/assault) significantly associated with dropout.	Increased
Kure-Bergel 2016	Is there a social difference between those who do and don't complete SMS programmes?	Course completion	Tailored SMS individual or group over 6-12 weeks	Programme tailored to preference/head	Age 78% > 40 yrs Sex: 50%MM Edu: 57% < high school graduate	Education not significant post-regression but qualitative interviews suggested social factors (job/carer demands) were important	No change - suggestive of increase
Santorelli 2017	What determines DSME participation and is it affected by the availability of DSME services?	Initial participation	DSME - unspecified type.	Unspecified (multiple programmes)	Survey sample of people living in New Jersey with diabetes	Lack of participation correlated with low education and ethnicity ( $p < 0.001$ ) but not with income.	Increased

<sup>1</sup>Population SES status terms have been structured to maximise comparability between papers.<sup>2</sup>MM ethnic minority<sup>3</sup>Literacy was used as an SES measure where it was clearly correlated with education and income.

flexibility, suggesting that attrition within a low SES population may be influenced by socioeconomic factors that are not captured by education or income alone. Finally, a small RCT [51] of a tailored group programme found that high levels of dropout were significantly associated with low income and education. By contrast, Horrell et al. [45] noted that although SES area predicted enrolment in the Stanford CDSMP, it did not affect rates of completion.

SES is not consistently associated with dropout from SMS interventions. SES may be one of a number of factors associated with programme attrition, as suggested by qualitative studies on this topic [52].

3. Is there evidence that SES affects clinical, behavioural or other specified outcomes following SMS interventions?

Nine studies looked at outcomes following SMS interventions, with four describing group interventions (including 2 of the Stanford CDSMP) and five individual [1] interventions. Only two of the RCTs [53, 54] were sufficiently powered for subgroup analysis and most had follow-up periods of 6 months or less.

Three of the nine studies featured outlier populations (in terms of age, sex and/or level of disadvantage), including the two lower-quality studies [39, 40] and the cohort study [55]. The findings from these studies may not be reliable or relevant to the wider low SES population.

The remaining six studies, of moderate to high quality, described broadly similar populations in terms of age, sex, education and income. Of these studies, one reported increased disparity following the intervention; two reported no change; and three studies reported a reduction in SES disparity.

Three of the studies, all individual interventions, described programmes specifically tailored for low SES groups, including extra supports and literacy adaptations. These included a 6-month peer support programme [56] and two 12-month phone support programmes [53, 57] (conducted by the same research group, but with different chronic diseases and interventions). All studies reported clinically and statistically significant changes in either hospitalisation rates [53] or HbA1c [56, 57] in favour of the intervention. Two of the studies also reported a reduction in SES disparity from the intervention, with low-literacy patients experiencing greater benefit from the intervention than their higher literacy counterparts. In an already low-SES population, this was found to be a stronger predictor than income or education. The third study (the peer support programme) reported no change in disparity, with benefits across all education levels and the greatest benefit experienced by those with poorer medication adherence and self-management ability.

The remaining studies – comprising one individual and two group interventions – did not provide specific tailoring for low SES participants. The individual intervention [58], a 6-week CBT programme designed to increase self-efficacy, found clinically significant improvements in depression only in the higher educated, with no change and higher rates of dropout in the lower educated. The group interventions, which were both for people with heart failure, included the 6-week CDSMP and a year-long SMS group programme. The CDSMP study did show short-term benefits as compared to usual care, but no overall gains at 6 or 12 months. The lower educated patients did better than their higher educated counterparts in terms of cardiac quality of life (QOL) ( $p=0.018$ ) over 12 months, suggesting a reduction in SES disparity, although it was not clear whether this was clinically significant. The second group programme [54] used an active education control and found no additional benefit from an SMS group. Low-income participants receiving the intervention did have a longer time to cardiac event (death or hospitalisation), but this was not statistically significant. Overall there was no change in SES disparity, nor any added benefit from the intervention.

There is limited evidence to suggest that SES does affect outcomes following SMS interventions. Interventions that were tailored for low SES participants reported significant improvements in clinical outcomes, which in some cases also included a reduction in SES disparity following the intervention.

## Discussion

### Main findings

This systematic review of disparities related to SMS interventions has reinforced observations [18–20, 22, 25] that there is a lack of research in this area. Although many studies of low SES groups have been undertaken, very few have focused on whether the outcomes compare favourably to those in higher SES groups. There are practical and statistical challenges in comparing population subgroups. Many studies had SES groupings that were fairly homogenous, limiting the ability to compare outcomes within the analysis, and almost all subgroup analyses were insufficiently powered. Larger studies and co-operation between different study populations are needed so that there is a more distinct contrast between SES levels across groups.

Responses to study questions.

1. Is there evidence that SES influences participation rates in SMS interventions?

This review confirms that low SES groups are significantly less likely to participate in SMS interventions



[42–46]. Thus, healthcare disparity is increasing before an intervention even commences. In order to reach those who need the intervention, targeted recruitment and retention strategies will be needed. Self-selection runs the risk of spending limited resources on those who need them least [46].

## 2. Is there evidence that SES influences rates of retention or dropout from SMS interventions?

The findings in relation to retention and dropout are less clear-cut, with few studies and small sample sizes. Social factors do appear to be important [49–51], although a simple measure of SES may not capture the barriers to engagement.

## 3. Is there evidence that SES affects clinical, behavioural or other specified outcomes following SMS interventions?

With the limited number of high-quality studies available, there was some evidence that SES does affect outcomes following SMS interventions, depending on the type of intervention on offer. No trends were observed in terms of the SM components, which varied little between studies, or the type of service providers involved.

Programme structure (group or individual) did seem to affect both dropout rates and outcomes, with fewer benefits observed in the group interventions. In the few programmes that recorded dropout by SES, it appeared that attrition was also greater from group programmes (see Table 4 and Table 5). High rates of dropout from group programmes have been reported in several reviews of CD interventions in low SES and other vulnerable groups [21, 59], while other reviews [13, 60, 61] have noted that individually tailored interventions appear to reduce disparity. Other authors have noted that although group programmes provide beneficial social support and peer modelling [5], they can also present many barriers to a low SES population who may have less flexibility in terms of work, transport or caring demands [21, 59]. In the current review, interventions over longer time periods (6–12 months) also seemed to be more effective at reducing disparity [53, 56, 57], consistent with a CD review on similar populations [13].

## Interpretation of findings

### 1. 'Low SES' is a heterogeneous group

This review suggests that SMS interventions may impact differently on low SES populations, and that more individualised treatment over longer time periods may be needed. Some writers have suggested that SES could

be used as a 'high risk' predictor to identify those needing an earlier or more intensive intervention [23, 62], although this encompasses a large population group and has significant resource implications, emphasising the need for appropriate targeting of interventions.

Data from the current review indicates that low SES groups are heterogeneous, with additional factors such as literacy, social stressors and social capital influencing SM ability, engagement, health outcomes [49, 50, 53, 57] and thus disparity. Therefore, some low SES groups may benefit simply from better marketing of and access to generic SM courses [45] and lower-level interventions, while others will require a more intensive, tailored approach. The ability to accurately identify these groups, perhaps by using a triage instrument, could lead to more effective resource allocation, increased participation and better outcomes in terms of both efficacy and equity.

### 2. Are self-management mechanisms different in low SES populations?

Few studies reviewed described the theory behind the proposed SMS intervention, as noted in other reviews of SMS [12, 63], although several referred to the role of self-efficacy [40, 54, 58, 64], as described in Bandura's social-cognitive theory [4, 5]. The studies which targeted a low SES or otherwise diverse population did note particular challenges for disadvantaged groups in terms of knowledge or literacy [47, 53, 56, 57], and those which adapted to these challenges often had better outcomes. In contrast, 'one size fits all' programmes [45, 46, 54, 58] had fewer benefits, and in some cases increased disparity.

SMS approaches informed only by self-efficacy have been criticised as overly individualistic [10, 11, 15] and it has been observed that the relationship between self-efficacy and self-management ability is weaker in vulnerable groups [65], indicating that other barriers play an important part. Furthermore, since the development of self-efficacy depends both on one's behaviour and on social/environmental feedback [66], several authors [11, 58] have suggested that increasing self-efficacy may be harder if environmental feedback (e.g. job or housing insecurity) negates a belief in control over one's circumstances.

### 3. What other factors are important for self-management in low SES groups?

This suggests that for SMS interventions to be effective in low SES populations, attention should be paid to other factors that influence self-management ability. Health provider/system issues [67, 68]; resources (literacy, financial, job/carer demands) [67, 69–71]; and condition demands

(multimorbidity, treatment burden) [48, 71, 72] have been consistently identified in qualitative reviews as barriers to self-management. Each of these factors will impact disproportionately on a low SES population. Health providers/systems can be less accessible due to cost, literacy levels and a limited understanding of the social determinants of health by providers [67, 68]. Although few studies of SM in disadvantaged populations look at interventions at the health provider/system level [18, 21], it would seem a potentially effective way to reduce disparity without increasing the patient's treatment burden.

Barriers related to resources and condition demands are far greater for the low SES population [73–75], who have fewer financial and social resources; higher levels of overall social complexity (job/housing insecurity, family demands, trauma history [3]); and higher rates of multimorbidity at earlier ages [76]. They experience both more disease-related workload (treatment burden) and non-disease workload (life burden) [73, 77]. Unfortunately, many SMS interventions, especially those requiring regular attendances or homework, will increase workload. Approaches that reduce patient workload or increase access to resources are rarely tried, but are likely to be important in low SES groups [73]. Phone consultations, problem-solving of specific barriers, integrating healthcare with social services and directing interventions toward healthcare practitioners rather than individual patients can all reduce treatment burden and maximise resources. Coventry [76], in a qualitative study of SM and multimorbidity, identifies three factors required for engagement in SM: capacity (resources, knowledge and energy); responsibility (shared understanding between the patient and provider about how to manage the treatment workload) and motivation. All three are negatively impacted by low SES, yet many SMS interventions [10] aim to increase motivation without recognising responsibility or capacity, and thus may contribute to increasing disparity in low SES groups.

#### Strengths and limitations

This review identifies important gaps in knowledge and potential directions for future research. It reveals the assumptions informing SMS approaches and the inadequacy of using 'low SES' to define a population group. The study limitations include the lack of published research on disparity in SM interventions. It was difficult to conduct a comprehensive literature search of this topic because many subgroup analyses were a relatively small part of the overall paper. It is possible that some studies were missed that may have provided useful data. Meta-analysis was not possible due to the variety of studies available; therefore, no strong conclusions can be formed. In addition, the methodology of many of the studies prohibited causal inference: several studies were

cross-sectional and most subgroup analyses were underpowered or did not formulate a priori hypotheses.

#### Conclusion

This review has identified several important themes in relation to self-management and socioeconomic disparity. First and most obviously, there is a great need for equity considerations to be included in CD studies, as advocated by Cochrane reviewers [22, 25]. Given the strength of evidence available about social determinants of health, it should be possible to establish a priori hypotheses and sample sizes sufficient for subgroup analysis (including the availability of relevant comparator groups) for many interventions.

Secondly, any intervention in a low SES or otherwise disadvantaged group should consider its theoretical basis. Social-contextual approaches, rather than self-efficacy approaches, may be more effective. Paying greater attention to the large and consistent body of qualitative studies on barriers to SM can provide both theoretical and practical guidance as to interventions that can address disparity. Approaches such as the Cumulative Complexity Model [77], which is founded on patient burden-capacity balance, have much to offer.

Finally, levels of disadvantage vary, and there is a need for risk identification within the low SES population. For many people, improving access to simple SM interventions (e.g. assistance with childcare or transport, free programmes at community locations) may be all that is needed. For others – especially those with multimorbidity, poor literacy or social complexity – an individually tailored approach will be needed to be effective. Research to develop a risk assessment system may ensure that those most in need receive the greatest support as opposed to the current situation.

#### Supplementary information

Supplementary information accompanies this paper at <https://doi.org/10.1186/s12913-020-5010-4>.

Additional file 1.

Additional file 2.

Additional file 3.

#### Abbreviations

CD: Chronic disease; CDSMP: Chronic disease self-management programme; COPD: Chronic obstructive pulmonary disease; CVD: Cardiovascular disease; DSME: Diabetes self-management education; MSK: Musculoskeletal; RCTs: Randomised controlled trials; SES: Socioeconomic status; SM: Self-management; SMS: Self-management support

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**Authors' contributions**

RH conducted the initial search with assistance from ES. RH drafted the initial manuscript, and ES and SB edited and further developed the manuscript. All authors read and approved the final manuscript.

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**Availability of data and materials**

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

**Ethics approval and consent to participate**

Not applicable.

**Consent for publication**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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## **Appendix B: Chapter 2 Supplementary Files**

### **Contents:**

1. Systematic search terms and example of PubMed search
2. PRISMA checklist
3. Trial quality assessment
4. Articles excluded, with reasons

## 1. Systematic search terms and example of PubMed search

**MeSH terms:** Chronic Disease Self Care or self-management Social determinants of health

### Search 1:

'chronic disease' OR 'chronic illness' OR 'chronic condition' OR 'pulmonary disease' OR 'respiratory disease' OR 'diabetes' OR 'arthritis' OR 'chronic pain' OR 'cardiovascular disease' OR 'back pain' OR 'musculoskeletal conditions'

### Search 2:

'self care' OR self-care OR 'self management' OR self-management OR 'behaviour change' OR 'behavior change' OR 'biopsychosocial rehabilitation' OR 'behaviour\* therapy' OR 'behavior\* therapy'

### Search 3:

socio-economic OR socioeconomic OR equity OR inequity OR disparity OR 'social determinants of health' OR 'vulnerable groups' OR disadvantaged

### Search 4:

outcome OR efficacy\* OR participat\* OR attrition OR dropout OR drop-out OR adherence OR evaluation OR access OR engage\* OR attend\* OR barrier OR effective\* OR retention OR compliance

### MEDLINE SEARCH

Search ID#	Search terms	Notes	Results
Search 1	exp Chronic disease		251809
S2	"chronic disease" OR "chronic illness" OR "chronic condition" OR "pulmonary disease" OR "respiratory disease" OR diabetes OR arthritis OR "chronic pain" OR "cardiovascular disease" OR "back pain" OR "musculoskeletal condition"		1243123
S3	S1 or S2		1243484
S4	exp Self Care or exp Self-Management		48117
S5	"self care" OR self-care OR "self management" OR self-management OR "behaviour change" OR "behavior change" OR "biopsychosocial rehabilitation" OR "behaviour* therapy" OR "behaviour* therapy"		59639 + 42364
S6	S4 or S5		99617
S7	exp "Social Determinants of Health"		1762
S8	socio-economic OR socioeconomic OR equity OR inequity OR disparity OR disadvantaged OR "social determinants of health" OR "vulnerable groups"		255837
S9	S7 or S8		255837
S10	outcome OR efficacy* OR participat* OR attrition OR dropout OR drop-out OR adherence OR evaluation OR access OR engage* OR attend* OR barrier OR effective* OR retention OR compliance		5758281
S11	S3 and S6 and S9 and S10		805
S11	Titles reviewed		805
S12	Imported		100
S13	Meet sys RV criteria		28

## 2. PRISMA checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	p1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	p2-3
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Background para 3 p4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Background para 4 p4-5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	No protocol.
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Methods para 2 p5-6 and table 1
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Methods para 1 p5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Additional file 3
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Methods para 3 p6; table 2;

			additional file 2
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Methods para 3 p6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Methods para 4 p6
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Methods para 5 p7; additional file 1
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A no meta-analysis Methods para 6 p7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	N/A

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Discussion: limitations section (para 10 discussion, p14)
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Methods para 3 p6; Table 2;



			additional file 2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Results para 1 p7; table 3
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Results para 2 p7; additional file 1
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Results p7-10; table 4
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A no meta-analysis
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Discussion p10-14
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Discussion p14 para 10
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Discussion p15
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Page 16 line 6

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

### 3. Trial Quality Assessment

Y = yes; N= no; N/A = not applicable; U = unspecified/unclear in study; score = number of criteria met.

#### (a) RCT studies quality assessment (Johanna Briggs Institute)

Author/date	Correct randomisation	Concealed allocation	Similar baselines intervention/control	Blind participant	Blind assessor	Identical treatment	Follow-up complete	ITT analysis	Same outcomes	Outcomes reliable	Appropriate analysis	Appropriate design	Score
Bosma 2011	Y	Y	Y	N/A	Y	Y	Y	Y	Y	Y	Y	Y	11
Dattalo 2012	Y (cluster)	Y	Y	N/A	Y	Y	Y	Y	Y	Y	Y	Y	11
DeWalt 2012	Y	Y	N (adjusted)	N/A	Y	Y	Y	Y	Y	Y	Y	Y	10
Jonker 2012	Y (cluster)	U	N (not adjusted)	N/A	U	Y	Y	N excluded dropouts and dementia patients	Y	U	Y	Y	6
Moskowitz 2013	Y	Y	N (adjusted)	N/A	Y	Y	Y	Y	Y	Y	Y	Y	10
Nour 2006	U	U	Y	N/A	Y	U – other services also available.	U	Y	Y	U	U	Y	5
Poduval 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	12
Powell 2010	Y	Y	Y	N/A	Y	Y	Y	Y	Y	Y	Y	Y	11
Rothman 2004	Y	Y	Y	N/A	Y	Y	Y	Y	Y	Y	Y	Y	11
Smeulders 2010	Y	Y	N (adjusted)	N/A	Y	Y	Y	Y	Y	Y	Y	Y	10
Thorn 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	12

#### (b) Subgroup analysis quality assessment (Sun/Oxman criteria)

Study	Clinical importance	Statistical significance	A priori hypothesis	Few hypotheses	Within study comparison	Consistency across studies	Theory supported	Variables specified pre-randomisation	Apriori direction specified	Independent effect -not confounders	Consistent interaction in study	Score
Bosma 2011	Y	Y	Y	Y	Y	Unclear – few studies	Y	Y	N- opposite	Y	Y	9
Dattalo 2012	Y	Weak - one poorly validated outcome	N – looking for predictors	Y- regression, 1 outcome only	Y	N	N	Y	N	Y	U	5
DeWalt 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Jonker 2012	Y	Weak $p < 0.05$ for 1 outcome only	N – looking for predictors	N - 10 variables 7 outcomes	Y	U	Y	Y	N	Y	N – only relevant to 1 outcome	5
Moskowitz 2013	Y	Yes – $p = 0.02$ for SM ability	N – looking for predictors	Y – regression, 1 outcome only	Y	U	Y	Y	Y	Y	Y	9

Nour 2006	Y	Weak – one poorly validated outcome	N – looking for predictors	No – 7 variables, 8 outcomes	Y	U	Y	Y	N	Y	N - only relevant to 1 outcome	5
Poduval 2018	Y	Y (null hypothesis supported)	Y	Y – limited variables	Y	U	Y	Y	Y	Y	Y	10
Powell 2010	Y	N	N - looking for predictors	Y – regression, 1 outcome only	Y	U	Y	Y	N	Y	U	6
Rothman 2004	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11
Smeulders 2010	Y	Y – p=0.018	N - looking for predictors	Y- regression, 1 outcome only	Y	U	Y	Y	N	Y	U	7
Thorn 2011	Y	Y p=0.01 and 0.02	N- looking for predictors	Y – regression, 1 outcome only	Y	Y	Y	Y	N	Y	Y	9

**(c) Cross sectional studies quality assessment (Johanna Briggs Institute)**

Study name	Inclusion criteria	Subjects and setting	Exposure measurement	Condition measurement	Confounders	Confounder strategies	Outcome measurement	Appropriate analysis	Score
Adjae Boakye 2018	Y	Y	Y	Y	Y	Y	Y	Y	8
Glasgow 2018	Y	Y	Y	Y	Y	Y	Y	Y	8
Hardman 2018	Y	Y	Y	Y	Y	Y	Y	Y	8
Horrell 2017	Y	Y	Y	Y	Y	Y	Y	Y	8
Kure-Beigel 2016	Y	Y	Y	Y	Y	Y	Y	Y	8
Santorelli 2017	Y	Y	Y	Y	Y	U	Y	U	6

**(d) Cohort studies quality assessment (Johanna Briggs Institute)**

Study	Similar groups	Exposure details	Exposure measurement	Confounders	Confounding strategies	Outcome freedom	Outcomes measured	Follow-up time	Follow-up complete	Follow-up strategies	Appropriate analysis	Score
Cauch-Dudek 2014	Y	Y	Y	Y	Y	Y	Y	Y- 8 months	Y	N/A	Y	10
Govil 2009	N	Y	Y	Y	Y	Y	Y	N- immediate post-intervention only	Y	Y	Y	9

**Articles excluded, with reasons.**

Total full-text articles reviewed: 308 (including saved articles) minus 5 duplicates = 303

## Rejection reasons:

1. Not chronic disease: 20
2. Not SES: no clear reference/definition SES, focus on ethnicity exclusively: 30
3. No self-management intervention: includes reviews, commentaries, surveys of self-care or adherence without being related to a self-management intervention: 114
4. Protocol or study design/description: 31
5. Not full text or peer-reviewed (conference abstracts, unpublished dissertations): 23
6. No English translation: 2
7. Qualitative studies: 30
8. SES recorded/noted but no disparity analysis undertaken: 34

## Articles kept: 19

Author/date	Rejection reason	Code No.
Ackerman 2012	No self-management intervention	3
Adams 2010	No clear reference/definition SES	2
Agurs-Collins 1997	Looks at ethnicity not SES	2
Albright 2005	Not chronic disease	1
Alter 2011	No self-management intervention	3
Anderson 2010	Not full-text	5
Anderson 2005	Looks at ethnicity not SES	2
Antoniou 2003	No clear reference/definition SES	2
Ashe 2007	No clear reference/definition SES	2
Ausili 2016	No self-management intervention	3
Ausili 2018	No self-management intervention	3
Bachmann 2003	No self-management intervention	3
Bains 2011	No self-management intervention	3
Baird 2009	Not chronic disease	1
Baldassari 2013	No self-management intervention	3
Banerjee 2009	No self-management intervention	3
Beauchamp 2014	Not chronic disease	1
Beauchamp 2010	Sys review - no intervention	3
Becker 2004	No self-management intervention	3
Bennett 2018	No analysis SES disparity	8
Benton 2018	Looks at ethnicity not SES	2
Bergner 2017	Protocol or design study	4
Bjarnason-Wehrens 2007	No analysis SES disparity	8
Blackford 2017	Not chronic disease	1
Blustein 2008	No self-management intervention	3
Boehmer 2018	Qualitative study	7
Boelsen-Robinson 2015	Not chronic disease	1
Boldy 2006	Protocol or design study	4

Borkhoff 2011	Sys review - no intervention	3
Bos-Touwen 2015	No self-management intervention	3
Boyd 2006	Protocol or design study	4
Brown 2012	Cost not SES analysis	8
Brown 2007	No self-management intervention	3
Brown 2018	Not chronic disease	1
Cadzow 2014	Protocol or design study	4
Call 2016	Qualitative study	7
Campbell 2014	No self-management intervention	3
Campbell 2017	No self-management intervention	3
Carnes 2013	Protocol or design study	4
Carpenter 2017	Protocol or design study	4
Carr 2005	Not chronic disease	1
Chakkalakal 2015	No self-management intervention	3
Chouinard 2013	Protocol or design study	4
Clark 2014	No self-management intervention	3
Conway 2017	Qualitative study	7
Coventry 2014	Qualitative study	7
Cramm 2011	No self-management intervention	3
Cramm 2012	Qualitative study	7
Crowley 2013	No analysis SES disparity	8
Cubbin 2005	No self-management intervention	3
David 2013	Not chronic disease	1
Davis 2009	No analysis SES disparity	8
De Groot 2017	Protocol or design study	4
De Walt 2006	Duplicate	
De Walt 2006	No analysis SES disparity	8
Dean 2015	No clear reference/definition SES	2
De Jong 2004	Not SM (exercise only)	3
Demonte 2015	No self-management intervention	3
Dennis 2013	Sys review – no intervention	3
Diaz-Toro 2015	No self-management intervention	3
Disler 2012	Qualitative study	7
Duenas 2018	Protocol or design study	4
Dye 2018	Protocol or design study	4
Dye 2018	Duplicate	
Eakin 2002	Sys review – no intervention	3
Eakin 2010	No analysis SES disparity	8
Edlind 2018	No analysis SES disparity	8

Edwards 2012	Qualitative study	7
Ell 2009	Protocol or design study	4
Ell 2010	No analysis SES disparity	8
Emerson 2015	Protocol or design study	4
Ettner 2009	No self-management intervention	3
Everson-Hock 2013	Not chronic disease	1
Eyer 2016	Protocol or design study	4
Feltner 2017	No self-management intervention	3
Figaro 2009	Qualitative study	7
Forbes 2016	No self-management intervention	3
Foster 2008	No self-management intervention	3
Fraser-Rodgers 2009	No analysis SES disparity	8
Freeman 2012	Not chronic disease	1
Fritz 2017	Qualitative study	7
Furler 2011	No self-management intervention	3
Gallagher 2011	No self-management intervention	3
GeBoers 2016	No self-management intervention	3
Glazier 2006	Sys review – no intervention	3
Goeppinger 2007	Looks at ethnicity not SES	2
Goldman 2002	No self-management intervention	3
Goldsmith 2014	No self-management intervention	3
Golin 2002	No self-management intervention	3
Gonzalez 2011	Not full-text	5
Grande 2017	Not full-text	5
Greene 2005	No self-management intervention	3
Grimmer-Somers 2009	Qualitative study	7
Guillemin 2014	No self-management intervention	3
Hale 2010	No self-management intervention	3
Hankonen 2009	Not chronic disease – at risk only	1
Harley 2013	Not chronic disease	1
Harris 2017	Not full-text	5
Harris 2017	Duplicate	
Harris 2018	Not full-text	5
Harris 2017	Duplicate	
Harrison 2012	No clear reference/definition SES	2
Harvey 2007	No self-management intervention	3
Hawe 2009	No self-management intervention	3
Hecht 2015	No self-management intervention	3
Heisler 2003	No self-management intervention	3

Heltberg 2017	No self-management intervention	3
Henderson 2014	Qualitative study	7
Hertroijs 2016	Not full-text	5
Hibbard 2008	No self-management intervention	3
Higgins 2015	Not chronic disease	1
Higgins 2018	Not chronic disease	1
Higgs 2017	Protocol or design study	4
Hill-Briggs 2011	No analysis SES disparity	8
Hong 2018	Cost not SES analysis	8
Houle 2016	No self-management intervention	3
Hopkins 2013	Not full-text	5
Horrell 2018	Unpublished dissertation no peer review	5
Hughes 2016	No analysis SES disparity	8
Humphry 1997	Demonstration only, ethnic only	2
Jack 2012	No self-management intervention	3
Jaramillo 2013	No self-management intervention	3
Jeong 2018	No analysis SES disparity	8
Jinks 2010	Qualitative study	7
John 2007	No clear reference/definition SES	2
Junquiera 2016	No self-management intervention	3
Kandula 2009	No analysis SES disparity	8
Kane 2016	No analysis SES disparity	8
Kane 2018	No self-management intervention	3
Kangovi 2016	Not full-text	5
Kangvoi 2016	No analysis SES disparity	8
Kaplan 2013	Looks at ethnicity not SES	2
Karter 2007	No self-management intervention	3
Keene 2018	Qualitative study	7
Kellar 2011	Not chronic disease	1
Kenealy 2010	Looks at ethnicity not SES	2
Keosaian 2016	Qualitative study	7
Kim 2016	Sys review – no intervention	3
Kinser 2016	No self-management intervention	3
Knight 2012	No self-management intervention	3
Knutsen 2017	No English translation	6
Kolbe 2002	Not chronic disease	1
Krist 2017	No self-management intervention	3
Laba 2013	No self-management intervention	3
Lachance 2018	Protocol or design study	4

LaVeist 2011	No self-management intervention	3
Lawlor 2017	Not full-text	5
Li 2013	Not full-text	5
Lloyd 2006	No self-management intervention	3
Lopez-defede 2016	No self-management intervention	3
Lounsbury 2014	No self-management intervention	3
Lowe 2013	Not full-text	5
Lynch 2011	No self-management intervention	3
Machenbach 2008	No self-management intervention	3
Maindal 2011	Not chronic disease	1
Maitra 2010	No self-management intervention	3
Mao 2017	Qualitative study	7
Margolis 2013	Not chronic disease	1
Mayberry 2016	Protocol or design study	4
Mayberry 2016	No self-management intervention	3
McCarthy 2013	Protocol or design study	4
McCollum 2009	No self-management intervention	3
Mead 2010	Qualitative study	7
Meland 2011	No self-management intervention	3
Merius 2017	Sys review - no intervention	3
Miech 2009	No self-management intervention	3
Mills 2015	No self-management intervention	3
Mills 2014	Protocol or design study	4
Mishra 2011	No self-management intervention	3
Mitchell 2012	Looks at ethnicity not SES	2
Moser 2017	Not full-text	5
Murimi 2010	Not chronic disease	1
Naranjo 2012	Looks at ethnicity not SES	2
Nelson 2016	Not full-text	5
Oh 2017	No self-management intervention	3
Omachi 2013	No self-management intervention	3
O'Neil 2014	No self-management intervention	3
Osborn 2016	No self-management intervention	3
Osborn 2013	No self-management intervention	3
Osborn 2014	Protocol or design study	4
Osborne 2013	Protocol or design study	4
Packer 2012	No analysis SES disparity	8
Pandit 2014	No self-management intervention	3
Parker 2018	Sys review - no intervention	3



Parsons 2017	Qualitative study	7
Patel 2016	No self-management intervention	3
Pavlishyn 2016	No self-management intervention	3
Peek 2014	No self-management intervention	3
Pesantes 2015	Sys review - no intervention	3
Piette 2013	No self-management intervention	3
Piper 2015	No self-management intervention	3
Piper 2013	No self-management intervention	3
Plaksin 2016	Not full-text	5
Poleshuck 2010	Protocol or design study	4
Potter 2018	Qualitative study	7
Protheroe 2013	Qualitative study	7
Protheroe 2016	Protocol or design study	4
Ramal 2012	Qualitative study	7
Rashid 2017	Looks at ethnicity not SES	2
Rebecca Paradiso 2017	No self-management intervention	3
Redman 2007	No self-management intervention	3
Rendle 2013	Qualitative study	7
Ricci-Caballo 2013	Protocol or design study	4
Roberts 2015	Protocol or design study	4
Rosal 2009	Protocol or design study	4
Rosal 2011	No analysis SES disparity	8
Rotberg 2013	Not full-text	5
Rotberg 2014	Not full-text	5
Rothschild 2016	Protocol or design study	4
Ruggiero 1997	No self-management intervention	3
Ryan 2013	No analysis SES disparity	8
Ryvicker 2012	No self-management intervention	3
Sajatovic 2018	No analysis SES disparity	8
Sarkar 2006	No self-management intervention	3
Schafer 2010	No clear reference/definition SES	2
Schecteman 2008	No self-management intervention	3
Schillinger 2009	No analysis SES disparity	8
Schillinger 2006	No self-management intervention	3
Schmiltz 2009	No self-management intervention	3
Schoenberg 2011	Qualitative study	7
Schulman-Green 2016	Qualitative study	7
Schulz 2005	Protocol or design study	4
Secrest 2011	No self-management intervention	3

Selhy 2007	No self-management intervention	3
Shah 2009	No clear reference/definition SES	2
Sheridan 2015	Qualitative study	7
Shippee 2012	No self-management intervention	3
Shreck 2014	No clear reference/definition SES	2
Silverman 2018	Qualitative study	7
Sixta 2008	No analysis SES disparity	8
Skelly 2009	No analysis SES disparity	8
Small 2013	No clear reference/definition SES	2
Smith 2012	No clear reference/definition SES	2
Smith 2013	No clear reference/definition SES	2
Smith 2010	No self-management intervention	3
Sokol 2016	Duplicate	
Sokol 2016	Sys review - no intervention	3
Solomon 2012	Protocol or design study	4
Srulovici 2018	No analysis SES disparity	8
Stafford 2012	No self-management intervention	3
Stalker 2015	No self-management intervention	3
Surapeni 2018	Not full-text	5
Swavely 2014	No analysis SES disparity	8
Tan 2015	No self-management intervention	3
Thackeray 2004	Looks at ethnicity not SES	2
Thom 2013	No analysis SES disparity	8
Thompson 2014	No self-management intervention	3
Thorn 2018	No analysis SES disparity	8
Tiliakos 2011	Not full-text	5
Torres 2010	No English translation	6
Torres 2107	Not full-text	5
Trief 2013	Looks at ethnicity not SES	2
Trief 2013	No analysis SES disparity	8
Tucker 2014	No analysis SES disparity	8
Vaccaro 2016	Looks at ethnicity not SES	2
Vaccaro 2012	Looks at ethnicity not SES	2
Van der Vlegel 2016	Not full-text	5
Van Dyke 2013	Not full-text	5
Van Hecke 2017	Sys review - no intervention	3
Van Scoyoc 2010	Sys review - no intervention	3
Varming 2018	Protocol or design study	4
Verevkina 2014	No clear reference/definition SES	2

Verma 2017	Limited self-management – exercise only	3
Vest 2013	Qualitative study	7
Vijayaraghavan 2011	No self-management intervention	3
Vissenberg 2017	Qualitative study	7
Vissenberg 2017	No analysis SES disparity	8
Von Leupoldt 2012	No clear reference/definition SES	2
Walker 2003	No self-management intervention	3
Walker 2010	No self-management intervention	3
Walker 2014	No self-management intervention	3
Walker 2014	Protocol or design study	4
Walker 2015	No self-management intervention	3
Walker 2015	No self-management intervention	3
Walker 2016	No self-management intervention	3
Wallace 2013	No self-management intervention	3
Walters 2012	Qualitative study	7
Walton 2012	Protocol or design study	4
Walton-Moss 2014	Sys review - no intervention	3
Wayne 2015	No analysis SES disparity	8
Weaver 2014	Qualitative study	7
White 2015	No analysis SES disparity	8
Wilson 2017	Not chronic disease	1
Wilson 2017	Qualitative study	7
Wolf 2014	No analysis SES disparity	8
Wong 2015	No clear reference/definition SES	2
Yadav 2018	No clear reference/definition SES	2
Yamashita 2012	No self-management intervention	3
Young 2009	Not full-text	5

**Appendix C: Chapter 4 Publication**

RESEARCH ARTICLE

Open Access



# Healthcare professionals' perspective on treatment burden and patient capacity in low-income rural populations: challenges and opportunities

Ruth Hardman<sup>1,2\*</sup>, Stephen Begg<sup>3</sup> and Evelien Spelten<sup>1</sup>

## Abstract

**Background:** The challenges of chronic disease self-management in multimorbidity are well-known. Shippee's Cumulative Complexity Model provides useful insights on burden and capacity factors affecting healthcare engagement and outcomes. This model reflects patient experience, but healthcare providers are reported to have a limited understanding of these concepts. Understanding burden and capacity is important for clinicians, since they can influence these factors both positively and negatively. This study aimed to explore the perspectives of healthcare providers using burden and capacity frameworks previously used only in patient studies.

**Methods:** Participants were twelve nursing and allied health providers providing chronic disease self-management support in low-income primary care settings. We used written vignettes, constructed from interviews with multimorbid patients at the same health centres, to explore how clinicians understood burden and capacity. Interviews were recorded and transcribed verbatim. Analysis was by the framework method, using Normalisation Process Theory to explore burden and the Theory of Patient Capacity to explore capacity.

**Results:** The framework analysis categories fitted the data well. All participants clearly understood capacity and were highly conscious of social (e.g. income, family demands), and psychological (e.g. cognitive, mental health) factors, in influencing engagement with healthcare. Not all clinicians recognised the term 'treatment burden', but the concept that it represented was familiar, with participants relating it both to specific treatment demands and to healthcare system deficiencies. Financial resources, health literacy and mental health were considered to have the biggest impact on capacity. Interaction between these factors and health system barriers (leading to increased burden) was a common and challenging occurrence that clinicians struggled to deal with.

**Conclusions:** The ability of health professionals to recognise burden and capacity has been questioned, but participants in this study displayed a level of understanding comparable to the patient literature. Many of the challenges identified were related to health system issues, which participants felt powerless to address. Despite their awareness of burden and capacity, health providers continued to operate within a single-disease model, likely to increase burden. These findings have implications for health system organisation, particularly the need for alternative models of care in multimorbidity.

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**Keywords:** Treatment burden, Patient capacity, Healthcare providers, Qualitative research, Self management, Multimorbidity

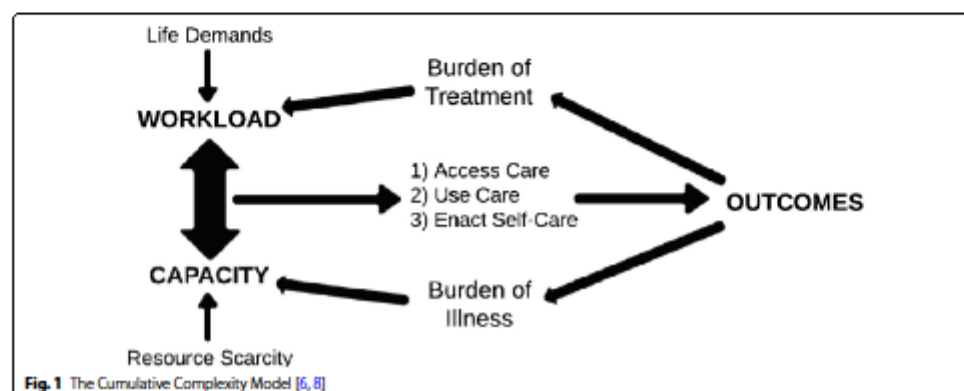
### Background

Lifestyle-related chronic diseases (CDs) such as diabetes, arthritis, cardiovascular and respiratory conditions require a long-term commitment to active self-management; however ongoing adherence is often poor. Known barriers to successful CD self-management include social, cognitive, biomedical and health system factors [1–5]. These factors frequently interact, leading to reduced adherence and CD escalation.

Shippee's Cumulative Complexity Model (CuCoM) [6] describes how different factors (such as poverty or polypharmacy) come together with the patient, their social environment and the healthcare environment to either promote or detract from a desired health outcome. In this model, complexity is not a medical diagnosis but a dynamic balance between patient workload (including self-management tasks, interactions with the healthcare system and everyday life demands) and capacity (including social support, socioeconomic resources and level of mental/physical functioning). The patient requires sufficient capacity to service their workload. Inadequate capacity or overwhelming workload may cause symptoms to escalate, which is then dealt with by intensifying treatment. Ironically, this increases workload even further and can result in a spiral of cumulative complexity [6–8], as illustrated in Fig. 1. The CuCoM is particularly applicable to people with multimorbidity (because of higher treatment workloads) and to those who are socially disadvantaged (since they have fewer resources), and can explain the poor outcomes and reduced adherence commonly seen in these groups [1, 4].

The concepts of workload and capacity have been explored in several qualitative studies [1, 9–11]. Although Shippee's original concept of 'workload' refers to both direct treatment work and life demands, to increase clarity and consistency with the wider literature, we will hereafter use the term 'treatment burden' rather than 'workload'. In line with other researchers, we define treatment burden as consisting of both direct treatment work and the impact on daily life, including work, social and caring responsibilities [12–14]. May [12], working with this definition, has proposed Normalisation Process Theory (NPT) [15, 16] as an appropriate tool to analyse treatment burden. This describes how new practices, such as learning how to manage chronic health conditions, become integrated into daily life, and has been successfully applied in several patient qualitative studies of treatment burden [13, 17]. Less attention has been paid to the concept of patient capacity as described in the CuCoM, although several taxonomies of capacity have been proposed [13, 18]. Boehmer [18] in a large qualitative review and synthesis used the acronym 'BREWS' to describe capacity as the interaction between Resource mobilisation, Work realisation and Social functioning accomplished within a person's Biographical reframing and Environment. This approach recognises that capacity is more comprehensive than a list of individual abilities or resources, and highlights its interactive, dynamic nature.

Although the Cumulative Complexity Model is supported by evidence from patient qualitative studies [1, 9, 11, 13], the concept is yet to be embraced by the healthcare system, as evidenced by reviews of



medical records, clinical guidelines and CD management interventions [19–21]. Patients report that individual healthcare providers (HCPs) are often ignorant of burden and capacity factors [9, 10]; studies of HCPs support this view, noting a limited understanding of treatment burden [22], an ad hoc approach to the assessment of capacity [23], and discordant patient-practitioner perceptions of factors contributing to treatment burden [24].

Understanding burden and capacity is important for HCPs, not just because of their effect on treatment adherence, but because HCPs can directly influence these factors either negatively (by excessive treatment demands), or positively (by supporting capacity and reducing burden)[2]. This is even more applicable in vulnerable or disadvantaged populations who experience high levels of CD prevalence and multimorbidity, and whose life experiences may diverge significantly from the HCPs with whom they engage.

This study aims to explore how clinicians working in self-management support with rural socially disadvantaged populations understand and address burden and capacity factors in their patients. Short written vignettes describing patients were used to investigate HCP assessment and decision-making. Vignette responses have been shown to more closely approximate a clinician's real-world behaviour than interviews, especially when looking at clinical decision-making, while also allowing motivators behind decisions to be explored in greater depth than in an observational study [25, 26]. The knowledge generated is intended to provide direction on ways of incorporating the concepts of workload, capacity and cumulative complexity into clinical practice, leading to improvements in treatment adherence and health outcomes.

We aimed to answer the following research questions:

1. Can HCPs working in chronic disease self-management support (CD-SMS) identify burden and capacity factors in patient case-studies (vignettes)?
2. How do HCPs working in CD-SMS understand burden and capacity, as described by Normalisation Process Theory (NPT) and the Theory of Patient Capacity (BREWS)?
3. What strategies do HCPs use to reduce burden or build capacity and what barriers do they identify?

## Methods

### Overall study design

This was a pragmatic qualitative study, analysed using the Framework Method [27]. We used the COREQ

checklist for reporting of qualitative studies (see Additional file 1). Research was conducted in accordance with national ethics guidelines and approval was granted by the La Trobe University Human Research Ethics Committee.

### Participants and setting

All participants were clinicians (nurses and allied health professionals) working in chronic disease self-management support at two large (150–200 employees) regional community health centres in Victoria, Australia. SMS includes education, behaviour change interventions, goal-setting, symptom management and assisting with condition impacts on physical, psychological and social functioning [28]. In Australia, nurses and allied health professionals are the dominant providers of CD-SMS, both as first-contact providers and in collaboration with general practitioners (GPs). Community health centres cater for disadvantaged and low-income populations, many of whom experience complex multimorbidity. HCPs working in adult CD management at each health centre who described SMS as an integral part of their job were emailed with information about the study and invited to participate. Interviewees were purposively selected to ensure a range of different professions and years of experience. Data saturation was obtained after ten interviews, but a further two interviews were undertaken for confirmation.

### Interview process

Prior to commencing the interview, participants completed an informed consent form and a brief survey recording their demographic details. HCPs were then asked to read a vignette case study (described below) and to imagine that it was a referral for a new patient, presenting to them in their current role at the Community Health Centre. They were encouraged to verbalise any initial thoughts, using the 'think aloud' method [29], which reflects how clinicians typically respond when presented with a new patient. They were then asked to consider the vignette from two points of view—the patient, and the health provider – and reflect on the likely tasks that would need to be undertaken (burden) and skills required (capacity) for that person to successfully manage their health. Two vignettes (from a total of six case-studies) were selected for each clinician to view, chosen to closely reflect the HCP's reported patient profile. Each vignette was commented on by four HCPs.

The second half of the interview consisted of general questions about the concepts of treatment burden, patient capacity and complexity, including the HCP's thoughts about how such challenges could be



overcome. Interview questions, including all vignettes, were trialled with two clinicians experienced in chronic disease management and modified in response to feedback. The interview protocol is available in Additional file 2.

#### Vignette development/procedure

Six vignettes were constructed using interview data from thirteen multimorbid patients attending the same community health centres, who were part of a wider study. This approach enabled us to maximise data validity, by using case studies that closely represented the HCP's usual patient population, whilst also addressing privacy concerns (since both patients and HCPs lived and worked in the same two rural communities) by blending and merging patient stories. Additional file 3 contains all six vignettes.

When writing a vignette, the use of both controlled variables, which provide the setting and context of the case-study but are not considered to greatly influence responses, and manipulated variables, which relate directly to the research questions, is recommended [25]. Table 1 describes each variable and their role in the vignettes. In this study, the controlled variables were age, gender and number and type of chronic conditions. Manipulated variables were of two types: information about environmental conditions (housing, family structure and source of income) and narrative features representing differing levels of patient capacity. The controlled and environmental variables were abstracted directly from the patient interviews and distributed across the six vignettes based on their frequency of occurrence in the patient interviews.

The narrative features were based on four areas of patient capacity – physical, social, personal and employment – identified from the chronic disease management literature [3, 13, 18]. These features of patient capacity had previously been identified in the patient interviews and were distributed across the vignettes. Since this was a qualitative study it was not considered necessary to allocate variables using a factorial method; instead the aim was to provide a wide range of scenarios that closely represented the HCP's daily caseload. All vignettes were written in the form recommended by Evans [25] to maximise realism and rigour.

#### Analysis

Since our intention was to explore whether HCPs' understanding was similar to or different from that of patients, we did not structure the interviews around the BREWS or NPT frameworks, instead asking general questions about burden and capacity. We wished to see whether HCPs were able to spontaneously identify burden and

capacity domains (as described by BREWS and NPT) that had previously been identified from patient qualitative studies. After interview completion, we applied the same thematic constructs as in patient studies (BREWS and NPT) and tracked any data that did not fit this framework. We used the Framework Method for data analysis, working through each stage from familiarisation to interpretation [27]. Data was initially coded into the broad categories of burden and capacity. All data relating to burden was then coded to the four NPT themes of sense-making, relationship work, enacted work, and appraisal. All capacity data was coded to the five BREWS themes of biography, resource mobilisation, environment, work realisation, and social support. Table 2 describes key features of each burden (NPT) and capacity (BREWS) factor. All interviews were transcribed verbatim and initially coded by RH by hand. NVivo 12 software was then used and coding was reviewed and further explored by SB and ES. Disagreements were resolved in discussion with all three researchers.

## Results

#### Participant and interview characteristics

Twelve interviews were conducted with health professionals. Due to the COVID-19 pandemic, six interviews were via phone and six via video link, depending on interviewee preference and technology capacity. Eleven interviews were conducted by RH and one by SB. Six of the interviewees were known to RH who worked part-time as a clinician at one of the centres, but none of the participants were in a subordinate or supervisory relationship with RH. Interview duration ranged from 38 to 60 min (average 45'). Following interviews, brief field notes were made to record the key themes and impressions of the interview. All interviews were audio recorded and transcribed verbatim by RH. Table 3 records key characteristics of the health professionals and their reported patient profile.

#### Vignette validity

We addressed rigour and realism in the written vignettes by modelling the case studies on actual community health clients, trialling the vignettes with experienced clinicians and then presenting them to the participants in the form of a referral letter. During the interviews, we took further steps known to maximise validity [25] including matching the vignettes to each HCP's reported patient population, asking the HCPs to respond as if the patient presented to them in their current role, and using a 'think aloud' process when responding to vignettes. We also asked participants to confirm that the vignettes were representative of their usual patients. This was strongly supported by the HCPs, who commented:



**Table 1** Vignette design

	Variables	Variables in each vignette (I indicates number of vignettes which included the variable)
<b>Controlled variables</b>	Age	50–60 yrs (3 vignettes); 60–75 yrs (3)
	Gender	Male (3) Female (3)
	Chronic conditions	All vignette patients had at least 3 of the following conditions: musculoskeletal pain/arthritis (6); type 2 diabetes (4); diabetic sequelae (2); mental health (4); gut/bowel (3); cardiovascular (3); respiratory (2)
<b>Environmental variables</b>	Income source	Age pension (2); disability pension (1); unemployed (2); part-time work (1)
	Family situation	Living with spouse (3—all 60+ yr); spouse and children (1); single parent (1); alone (1)
	Housing	Rental (3); own home (2); mobile home (1)
<b>Narrative (capacity) variables</b>		<b>These factors were distributed across the vignettes</b>
	Physical	Diabetes complications, blood sugar control, multiple surgeries, functional or mobility impairments
	Personal	Mental health issues, motivation, memory
	Social	Family proximity, carer demands, quality of family relationships, family stressors (e.g. substance use), socially engaged or isolated
	Employment	Job loss, manual work history, self-employment, voluntary work, carer demands

*"they are so typical... both of them" (B4) "it sounds like one of my clients..." (S3).*

#### Ability of HCPs to identify burden and capacity factors in vignettes

HCPs were initially asked to 'think aloud' about each vignette, and then to consider barriers and enablers to CD management from both the patient and the HCP perspective. During both the 'think-aloud' and patient perspective responses, HCPs focussed on environmental stressors, especially life demands (work, caring), finances, social situation, and functional difficulties, rather than specific health conditions. When considering the

vignette from the HCP perspective, the focus changed to treatment options, onward referrals and concerns about engagement with self-management. We compared the HCP 'patient' responses with the key capacity issues described in each vignette, based on the variables outlined in Table 1. This confirmed that all sociodemographic and capacity variables featured in Table 1 were identified and referred to by the participants and that the controlled variables were not unduly influencing responses. Table 4 illustrates the key issues in each written vignette and the participant responses. HCPs were easily able to identify the key issues in vignettes and often expanded on how these factors might impact on health management, especially in terms of the person's ability

**Table 2** Burden and Capacity coding

Normalisation Process Theory (NPT)		Patient capacity (BREWS)	
Coherence (Sense-making)	Understanding the condition and treatments, planning care, setting goals	(B) Biography	Reframing to create a meaningful life that includes illness and treatment
Cognitive participation (Relationship work)	Obtaining support from family, friends and HCPs; managing difficulties in relationships	(R) Resource mobilisation	Access to, and ability to mobilise physical (energy, physical function); cognitive (literacy, memory); personal (resilience, self-efficacy); financial; and instrumental (time, transport etc.) resources
Collective action (Enacting work)	Carrying out work – adhering to treatments, making lifestyle and psychological adjustments, attending appointments	(E) Environment	Healthcare and social environments that fit with healthcare needs without interfering with other priorities
Reflexive monitoring (Appraisal)	Monitoring symptoms, reflecting on work undertaken and adjusting as necessary	(W) Work realisation	The experience of, and ability to normalise treatment workload as well as other life roles
		(S) Social functioning	Ability to socialise; practical social support; social acceptance of the patients' CD and limitations; relations with HCPs

**Table 3** Characteristics of health professional interviewees

Location	Site 1: 7 participants, Site 2: 5 participants
Gender	All female
Age	24–56 years, mean 41 years
Profession	2 nurses; 4 diabetes educators (all nurses); 3 occupational therapists; 1 physiotherapist; 1 exercise physiologist; 1 podiatrist
Years since graduation	1–34 years, mean 13 years
Years in CDSM	1–18 years, mean 9 years
Specific postgraduate training in CDSM	7/12 reported formal training in CDSM
Reported typical patient population	Low socioeconomic status: blue-collar workers or healthcare card holders Age group: over 50 Chronic health conditions: Diabetes, COPD, cardiovascular disease, chronic pain, arthritis, anxiety/depression, obesity and multimorbidity

to prioritise health in the face of other life demands, and their ability to access healthcare services to support them.

#### HCPs' understanding of burden and capacity, as described by the Theory of Patient Capacity (BREWS) and Normalisation Process Theory (NPT)

HCPs discussed capacity and burden specifically in relation to the vignette studies, but also more generally in terms of barriers and enablers, including ways to build capacity or reduce burden.

#### Analysis of capacity

All HCPs were familiar with the concept of patient capacity and most reported undertaking a formal assessment of physical, social, economic and cognitive capacity for their patients. The Theory of Patient Capacity (BREWS) fitted the data well. Quotations related to a specific vignette have been noted (as V1,2 etc.)

HCPs discussed biography in terms of an individual's future orientation. They discussed three possible responses for the vignette characters in managing their

health. Firstly, denial and ignoring the future, associated with resistance to change and often (in the vignette portrayals) relating to the perception that immediate life demands were making it difficult for the person to prioritise their health.

*"... they haven't prioritised their own health for quite a while and they've just been working and putting food on the table ... so sometimes there's some resistance to change ..."* (S3, V4)

Secondly, viewing the future as an inevitable decline into old age and increasing disability.

*"...they just think they're getting older and this is just normal... we just put up with it..."* (B5, V6).

Finally, reframing which meant coming to terms with loss, seeing the future as positive and having meaningful goals.

*"...an acceptance of the situation and a hope for the future... understanding that you have this pain, the pain's not going to go away but having hope that there [are] ways that you can manage it..."* (S2, V5).

**Table 4** HCPs' responses to each vignette in relation to key capacity features

Vignette no	Key capacity issues in vignette	Issues discussed by at least 3 HCPs (each vignette was reviewed by 4 HCPs)
1 'Pete'	Complex multimorbidity and functional impairment, housing situation, limited family support	Likely high treatment demands, difficult housing situation, ability to access healthcare, reduced family support
2 'Angela'	Insulin dependent diabetic, some carer responsibilities, good social support	Low income, ability to prioritise health due to carer demands, good social support, needs good support for diabetes management
3 'Lyn'	Poor diabetes control, poverty, carer demands, lack of social support, family dysfunction, mental health	Inability to prioritise health due to life demands, mental health, social isolation, financial stress, needs significant support from healthcare system but access may be difficult
4 'Steve'	Work demands/stress related to business, long history of depression, poor diabetes management	Financial stress, depression, prioritising work over health leading to escalating health issues
5 'Mark'	Rural/isolated location, functional impairments, poverty	Functional limitations for day to day tasks, social isolation, ability to access healthcare, housing security, financial stress, health literacy
6 'Irene'	Caring responsibilities, social isolation, pain-related functional limitations, anxiety	Carer responsibilities affecting ability to prioritise health, social isolation, ability to access healthcare services

HCPs considered that the ability to reframe identity and live a meaningful life with goals was vital for effective self-management. Some clinicians recognised that coming to this point could be very difficult since it meant dealing with loss and the realisation that life had changed permanently.

*"...it's not just for 6 or 8 weeks but for a lifetime and that's a lot to take on board..." (S1, V3)*

*"...there's sort of no quick fix for them there's no we'll fix it with this ...it's you have a chronic disease it's going to be there for the rest of your life..." (B4)*

#### Resource mobilisation

Resources fell into three categories: Physical, practical and personal. Physical resources related to illness burden and the functional impact on a wide range of daily activities, mood and sleep. HCPs identified chronic pain as the greatest contributor to illness burden, although other symptoms (fatigue and shortness of breath) were also discussed.

*"...he is probably noticing his back pain more than his erratic sugar levels...for people that have chronic pain it is often hard to see past the pain..." (B2, V4)*

*"...I would imagine (the pain) would have an effect on all the other things that are happening... so that would probably be where I would imagine Mark would want to ...is get to the bottom of the pain..." (S6, V5)*

Practical resources included financial status, access to government or organisational support, and personal resources such as transport or computer literacy. Financial resources were considered by all interviewees to be one of the most significant barriers to capacity. Lack of money was particularly discussed in terms of its impact on treatment burden, affecting one's ability to pay for appointments, medication, transport, healthy food and support services.

*"...financially he is on Newstart and he is rurally isolated ... there is going to be the fuel cost plus the financial cost of paying the gap payment to see any specialists..." (S1, V5)*

*"...they are on the age pension they may or may not have money difficulties... transport or services..." (S2, V6)*

*"...she has been on the pension for the past 10 years...she'll probably be under some financial stress..." (S7, V2)*

Personal capacity included health literacy, cognitive abilities and mental health issues. HCPs rated health literacy (along with financial resources) as the most important contributor to capacity, but also saw it as closely connected to mental health, cognitive capacity and motivation.

*"... for some people, there are some huge health issues that have kind of never been explained to them properly by any health professional..." (S1)*

*"...[to] have the confidence to ask the right questions that I need to ask for my health... for example why am I taking that medication how is it going to help... if that doesn't work what is next what's my next step so having that confidence..." (S4)*

Potential mental health difficulties were discussed by most HCPs for every vignette, especially their interaction with physical symptoms, cognition and motivation.

*"...he's got a history of depression which is probably compounded now by all these other things... sometimes until that is dealt with they're not going to move forward with and they're not motivated to make the other changes..." (S3, V4)*

*"...when people have a lot of pain and then ... that affects their mental health their ability to problem solve becomes quite impaired..." (S6, V5)*

#### Environment

Nearly all clinicians stressed the importance of a health-care environment where a patient felt supported and listened to as important to build capacity, and saw the provision of this as an important part of their role. They also recognised that without this, patients often disengaged from healthcare.

*"... humans are about building relationships and that is in terms of your health relationships as well... you need to feel confident and comfortable with the healthcare professional that you are going to see..." (S5, V2)*

*"...trust and rapport... that really helps with self-management because they feel valued ...that makes a big difference to the outcomes that the client has..." (S7)*

*"...I think a really big important one is the services that they have been engaged with in the past ...if you've had a bad experience previously you are just*

*likely to live with a bad health condition and not address it ..."* (S1, V5).

The patient's home environment was discussed both in terms of their housing suitability and security, and whether their life demands allowed people to prioritise their own health (most commonly referred to in relation to women with caring responsibilities).

*"...I think if she's got a lot going on in her life...it can be difficult to get people to worry about themselves when they are worrying about other people a lot..."* (B1, V3)

*"...he lives in a local caravan park which in my mind becomes relevant because of his living conditions... whether that is safe with his chronic back pain..."* (B3, V1)

*"...I would dare say that she probably puts other people's needs before her own and you know that will lead to a decline in her diabetes management ..."* (S5, V2)

Stressful government-service environments such as the unemployment and child support systems were also referred to as factors that could impact on capacity.

*"...he's on Newstart...that system is just going to set him up to drive that pain even further because of the stress that will put him under..."* (S6, V5)

#### Work Realisation

Many HCPs acknowledged the difficulty of successfully incorporating self-management work into daily life. Demands related to employment or caring were often associated with people not prioritising their health and thus reducing self-management ability. Most HCPs emphasised the importance of taking small steps and prioritising based on patient-identified goals and values. On the other hand, the successful achievement of treatment tasks was considered an important way to build capacity, by both increasing self-efficacy and reducing illness burden.

*"...at the next session say how did you go with that ... I'll say you did do well maybe we can build on that ... that increases their capacity to do things because they can see the benefit of what they've done ..."* (S3).

#### Social Functioning

All HCPs referred to the importance of social networks and being connected to family, friends and community

in terms of overall health outcomes, especially mental health. HCPs recognised that physical limitations and mental health interacted with social capacity.

*"...if we are talking about being socially isolated as well it's all that stuff drives people's mental health which will have an effect on his pain and vice versa..."* (S6, V5)

*"...how are those family connections and how does he feel about that... is he depressed or upset about that... is that going to affect his ability to look after his health..."* (S5, V1)

HCPs noted that social connections could increase access to resources (money, transport, home help) and enable the pursuit of meaningful activities, thus building biographical capacity.

#### Analysis of burden

Apart from the diabetes educators, most HCPs were unfamiliar with the term 'treatment burden', but all presumed that it meant the demands of healthcare work. HCPs had a broad view of these demands and described both direct tasks such as pill-taking and attending appointments, but also life impacts such as the clash between treatment needs and family responsibilities, and the patients' emotional burden of unremitting healthcare. Several also related it directly to patient capacity, describing how psychosocial stressors or resource deficits could lead to increased treatment burden. HCPs saw treatment burden as emerging both from specific treatment tasks and from difficulties in dealing with the healthcare system. This dual aspect of treatment burden has also been observed in patient studies [13].

#### Coherence

All HCPs considered that a patient's understanding of their health condition(s) was vital for self-management and an important element of treatment work.

*"...I'd guess number one is finding out if Mark has any idea about pain... you really can't manage that until you get a good understanding of what the condition is..."* (S6, V5)

Participants had a broad conception of 'Sense-making'. Making sense of health conditions was seen to be much more than learning a series of condition-specific skills or facts. It could enable people to take control of their health and plan a meaningful future. People's beliefs, expectations and health literacy could make this task difficult. Some HCPs also acknowledged that the amount



of knowledge required for effective self-management when there was co-morbidity could be overwhelming for patients.

*"...they don't have that knowledge so we have to provide that knowledge to them but then again it does become overwhelming the amount of knowledge that we are providing..." (S5)*

The literacy level of many educational resources, as well as differing and often inconsistent messages from different HCPs, was frequently identified as an issue.

*"...a lot of people just give out brochures and things like that and expect people to read them but they don't they just go in the bin..." (B1)*

*"...it can be overwhelming for people to be told lots of different things by lots of different health professionals who are looking after lots of different things..." (S1)*

#### Cognitive Participation

HCPs all stressed the importance of the patients engaging with multiple HCPs to manage their health. Each HCP recommended the involvement of at least three different HCPs per vignette, despite simultaneously recognising that this would increase the burden.

*"...people who are seeing multiple specialists ...sometimes people are just ticking a box they are going to an appointment at times they are not sure why they're there and they are too overburdened to actually take anything on board..." (S1, V4)*

*"...the issue is what we all like to do is send people off to 7 different Professionals and then that can be ... that's where we lose them sometimes isn't it so that's an issue" (S6)*

They also stressed the importance of the therapeutic alliance and their role as a facilitator working on mutually agreed goals, rather than a director of care. Many HCPs also recommended social services for the vignette patients (respite, home help, financial counselling) but noted that access was often limited.

Poor health service communication and co-ordination was acknowledged as a universal issue and a major contributor to burden. HCPs felt powerless to address these failings, which they believed could only be dealt with by more integrated technology and increased funding. Several HCPs reported that these failings resulted in their own 'treatment burden' since they were often working outside of their roles to compensate for shortfalls in the system. This required time and emotional energy.

*"...it's not so much the number of clients that we are seeing in a day it's the level of...like there's an awful lot of emotional energy that goes into our work..." (B4)*

#### Collective action

HCPs listed a range of self-management tasks that the vignette patients would need to complete, including management of medication, appointments, blood sugar testing, diet, exercise, mental health and sticking to a routine. Integrating chronic disease management into daily life was recognised as potentially very time consuming especially for diabetics, those with caring responsibilities and those with multiple health conditions.

*"...things you can no longer do... you can no longer eat your time is not your own anymore because you have appointment after appointment after appointment at all different places ... trying to keep up and manage your life around your health..." (B5)*

*"...lots of medications to take at home... things like exercise programs that people have to do at home ...not being able to live the rest of your life because you're always having to do things for your health..." (B1)*

Treatment costs, particularly specialist and psychology appointments, travel costs (given the rural setting) and the costs of home help or equipment were identified as burdensome. Services that were more affordable inevitably had long waiting lists or restricted eligibility. HCPs also described how patients often needed to attend multiple locations or appointments due to poor health service co-ordination. Improved service co-ordination, afterhours access and co-location were identified as factors that could assist patients to complete their treatment tasks.

*"...if you do a referral that's one thing but getting into that appointment or accessing the dietitian or the physio it's sometimes restricted and then they think oh what's the point I haven't got in so I won't bother..." (S3, V3)*

*"...some people just cannot afford the gap payments for psychologists...if you ask them to find \$80 a fortnight some people just cannot afford that..." (B4)*

*"...not all services are in the same place and some services can change quickly depending on government funding..." (S4)*

### Reflexive monitoring

HCPs referred to this in the vignettes when discussing patient priorities and the need for the patient to decide what was important to them in terms of their health management.

*"...for Mark it's a case of ... getting him to prioritise what would he like to achieve in life and then what would it take to get where he wants to be so what steps could we put in place..." (S1, VS).*

They recognised that many people would not be able to achieve all treatment tasks and that it was appropriate to reflect on and plan for what was possible rather than ideal.

*"...you're not trying to solve all of their health issues ...just if you can make one thing easier for them today sometimes that's a really important thing... and I think that is often missed... there [are] constant demands that the patient achieves everything all of the time and it is unrealistic ... that if they can achieve something they should be really proud of that..." (B3).*

### Strategies to reduce burden and increase capacity, and barriers identified.

#### Building capacity

HCPs reported that the combination of insufficient income, excessive life demands and poor mental health often impacted capacity cumulatively.

*"...the psychosocial stuff in the background that makes it complex ...the finance, the family situation, the culture, the language... all those additional things that are outside of the biomedical situation ..." (S7).*

*"...they have numerous health conditions or a range of health conditions... their home situation they might have a complex family or socioeconomic status whether there is a range of barriers..." (B2)*

They considered that accepting, understanding and being confident in treatment management was key to increasing capacity, although most felt that patients would find it difficult to do this on their own and would need ongoing support from a HCP, as well as available time and the right 'head space' to achieve this.

*"...a lot of it does come down to relationships with our clients and linking them into services that can help... link them in and sticking to what's important to a person..." (S2)*

HCPs considered that health literacy (which included both understanding and accepting chronic health conditions) and financial resources were the most important factors influencing capacity, closely followed by mental health status. Participants felt that they could assist in building capacity by improving health literacy, providing symptom management strategies and creating a supportive environment, but they often felt powerless to address issues related to finances, life demands and mental health.

*"...finances, finances, finances and finances... I think the vast majority of people that we see are surviving very few are thriving..." (S1)*

*"...oh god we just need more money... people with complex care needs need to be able to access things without having to pay a gap..." (B3)*

*"...one of the biggest challenges when their mental health is a long-standing mental health issue that has never been adequately addressed ... sometimes we are seeing people and it has been 40 years... when that's been something that has driven a lot of their health concerns the whole time and trying to unpack that 40 years later is challenging..." (S6).*

*"...I think someone's mental health is going to be one of the most important things... if they're mentally not in a space that they feel that they can change or where they feel they are not in control then I think you're fighting a battle that is out of your control..." (S7).*

#### Reducing Burden

Interviewees thought that a patient's ability to reduce burden independently of HCPs or the health system was quite limited, apart from prioritising and routinizing self-care tasks where possible. They noted that capacity-building strategies (as listed in Table 5) could also assist with perceived treatment burden. HCPs struggled with many health system barriers which increased treatment burden but could not be easily addressed either by the patient or the individual HCP. Lack of adequate and consistent funding for services, and service co-ordination were identified as the biggest factors contributing to treatment burden.

*"...where there are multiple services if they are all in one place it helps to co-ordinate your care..." (S4)*

*"...there is a lot of jumping to and fro between various organisations as well..." (B5)*

**Table 5** HCPs views: Factors that reduce burden or build capacity

<b>Reducing burden</b>	<ul style="list-style-type: none"> <li>• Assistance with system navigation</li> <li>• Knowledge of available resources and greater access (waitlists, funding for equipment and social services)</li> <li>• Improved access to specialists and mental health services (telehealth, transport support, no gap payments, address waitlists and workforce).</li> <li>• Technology to improve service co-ordination (shared healthcare information plus time to read it)</li> <li>• Supportive HCPs who are patient-centred</li> <li>• Sustainable (long-term) service funding</li> </ul>
<b>Increasing capacity</b>	<ul style="list-style-type: none"> <li>• Available income</li> <li>• Understanding their condition and the point of treatment, being confident in management</li> <li>• Acceptance of condition and recognition of the need to address it</li> <li>• Ability to prioritise health</li> <li>• Living in a healthy environment</li> <li>• Availability of services (home help, respite)</li> <li>• Having goals and a purpose</li> <li>• Early provision of services (before people become too disabled)</li> <li>• Good mental health</li> <li>• Good social relationships</li> </ul>
<b>Both</b>	<ul style="list-style-type: none"> <li>• Established routine/integrating treatment into life, able to troubleshoot and prioritise</li> <li>• Manageable life demands (e.g. caring role)</li> </ul>

*"...we have some clients who aren't eligible with home care packages but it really would be beneficial for them...so I think funding has a lot to do with it..." (B2)*

HCPs frequently suggested ways to reduce treatment burden, then immediately discounted them as being unrealistic.

*"...it would be really nice if we had multiple access to multiple providers in one location that they could get into at one time...that would be nice... it's a bit pie in the sky..." (B3)*

Many saw telehealth as a positive development to reduce costs and increase access, but there were concerns about computer literacy and broadband access in low income populations. Disengaging from healthcare altogether was noted to be one way that patients might deal with a high treatment burden. The issue of multiple appointments with different people, each focussing on a different part of the body, was recognised as a challenge that could not be easily solved, especially due to the sheer number of treatment options available.

*"...it's lovely that we have so many services but that just adds to the [feeling of] being overwhelmed really doesn't it..." (S6)*

Several participants noted that many patients did not have a strong relationship with their general practitioner (GP). This was a common issue in rural areas due to workforce shortages and transient staffing and reduced the likelihood of co-ordinated care.

*"...when I have had someone who has come in and they are complex it's not often that the general practitioner is all over it...I think that the GP can become*

*overwhelmed in that scenario..." (S5)*

These factors are summarised in Table 5.

## Discussion

### Main findings

This study aimed to investigate how HCPs working in CD-SMS understood the elements of complexity, as described by the Cumulative Complexity Model. Our use of structured vignettes, rather than patient histories, allowed us to concentrate on specific capacity variables without compromising anonymity. All study participants were able to identify and discuss burden and capacity factors in the vignettes, and the data could be analysed using Normalisation Process Theory (NPT) and the Theory of Patient Capacity (BREWS), previously only explored with patients. HCPs listed a wide range of strategies to reduce burden or build capacity, but frequently reported health system challenges in implementing these strategies. HCP views were consistent across a wide range of disciplines and years of experience, although experienced clinicians were more likely to highlight the interaction between motivation for self-management and contextual factors such as low education.

### HCPs views compared with the literature

#### Patient literature

The study findings are strongly consistent with literature exploring the taxonomy of burden and capacity [11, 13, 18], with the HCP accounts describing all burden and capacity components. The interacting nature of burden and capacity [9, 13, 30, 31], especially how increased capacity can reduce burden, was also discussed by the HCPs. The HCPs also characterised burden as



comprising both treatment tasks and health system deficiencies, as described by Gallacher et al. [13].

#### Health provider literature

The ability of HCPs to recognise patient burden and capacity constraints has been questioned in several studies [9, 10, 22]. HCPs are reported to focus on biomedical [24, 32] or motivational [23] rather than social-contextual factors when assessing treatment burden or capacity to self-manage. The current study offered a different perspective which may be related to the setting.

Study participants were all HCPs working with rural populations in community health settings, where there is an explicit commitment to the social model of health. In this setting, HCPs were highly cognisant of burden and capacity issues, and their comments on the vignettes were comparable to the patient literature. Other studies have interviewed GPs (physicians) and practice nurses in primary care, where there may be less understanding of SMS [33, 34] and limited access to interdisciplinary services. In contrast, community health CD services are often structured around the Chronic Care Model [35] and HCPs working in this environment generally have more time, greater expertise in SMS (with 7/12 interviewees reporting formal postgraduate training in this area) and access to interdisciplinary services.

Several studies have recommended that HCPs become more aware of access, resource and treatment burden factors in individual patients and tailor treatment accordingly [10, 23, 30], including an increased focus on patient-identified values, preferences and non-medical goals [10, 18, 24, 36, 37]. In the current study, such approaches appeared to be well-established. Even if participants were unfamiliar with the specific term 'treatment burden', they all recognised the importance of avoiding overwhelming treatment demands. Formally identifying and prioritising burden and capacity factors using available tools and measures [38, 39] could provide additional assistance to patients and HCPs, but many burden-capacity challenges require system-level changes that are out of reach of the individual patient or health provider. This echoes findings in a review of integrated care for multimorbidity [40], which noted that successful implementation needs macro-level change, but that most interventions occur at the micro- or meso- level.

#### Recommendations and challenges

All HCPs felt that their efforts to assist with burden and capacity were limited by contextual factors over which they had little power. Consistent with other literature [41, 42], some experienced their own personal 'treatment

burden' in trying to fill the gaps of poor service provision, and others stepped outside of their role to provide additional support or co-ordination if it was unavailable in their healthcare setting. They felt that many barriers could only be dealt with by the injection of more money and practical approaches including better technology, administrative support, stronger linkages between health and social services and time allocated for HCPs to communicate directly to each other.

HCPs also recognised that some of their own actions could increase treatment burden, for example referring the patient to multiple services, most of which were not 'joined-up'. Even with increased funding, the single disease model of healthcare inevitably leads to patients being reduced to body components, with each piece needing treatment by a different person. Without care co-ordination, this results in excessive burden or disengagement. Several HCPs described the care co-ordination role as an 'extra' job they often assumed to help the patient, but to be effective this role needs to be both remunerated and formally recognised by the patient and all other HCPs working with that patient, especially the GP.

Dealing with mental health issues within the context of multimorbidity was seen as particularly challenging. Often the only response was to send the patient off to yet another service provider, this time to deal with their 'head'. Despite the prevalence of co-occurring mental and physical health conditions [43], HCPs and health services continue to work within single-disease models [33, 40, 44] and alternative approaches are needed to avoid burden-capacity imbalance. One suggested approach is for HCPs to use and promote treatments that are effective in a range of conditions (e.g. exercise) so that the same intervention can address multiple health conditions [44]. Greater emphasis on generalist skills that reflect common comorbidities may also help to support patients who cannot manage yet another referral. Given the two-way relationship between anxiety, depression and many chronic health conditions, skills such as capacity coaching, trauma-informed care and mental health first aid [45–47] are likely to be particularly useful.

#### Strengths and limitations

A strength of this study is the vignette methodology, which enabled us to explore how HCPs might actually respond to patients rather than being reliant on their explicit or theoretical knowledge. By using NPT and the theory of patient capacity, we could compare the data to the wider patient literature, strengthening the validity of the research. Interviewing HCPs who directly provide



SMS, rather than GPs in primary care for whom SMS is a secondary role [48], resulted in a different perspective: one informed by negotiating the practical details and challenges of self-management. Requesting HCPs to imagine the patient's perspective when viewing the vignettes (which is known to affect empathy) may have contributed to increased recognition of burden and capacity; however, these factors were also identified at the initial 'think aloud' stage.

The study findings are limited by the fact that the setting is a low income rural population with HCPs who work within a specific model of healthcare and may therefore be more aware of social-contextual issues. Despite this, the community health environment is valuable to explore because there are likely to be greater numbers of people with psychosocial complexity and multimorbidity. Such individuals are at greater risk of burden/capacity imbalance and disengagement from the healthcare system than more advantaged populations. Additionally, in this setting many of the recommendations to address burden and capacity (such as increased HCP awareness and tailored care based on patient priorities) have already been addressed, yet significant challenges remain.

Although challenges related to healthcare costs and accessibility are more relevant in settings with resource and workforce shortages, system co-ordination issues are widespread across all health systems [31]. Therefore, it is likely that the study findings are relevant in other settings.

## Conclusions

HCPs in community health settings have a good understanding of burden and capacity, and the impact of these factors on the ability of their patients to self-manage chronic health conditions. Many of the barriers to address burden and capacity are at the health system or societal level and are difficult to address. Despite their understanding of burden and capacity constraints, HCPs still operate according to a single disease model which may lead to increased burden. More systematic approaches to support patients (e.g. care co-ordination) and/or alternative care models for multimorbidity are needed to support patients in their chronic condition self-management.

## Abbreviations

CD: Chronic disease; CuCoM: Cumulative complexity model; NPT: Normalisation process theory; BREWS: Theory of patient capacity; HCP: Healthcare provider; SMS: Self-management support.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12875-021-01387-y>.

**Additional file 1.** COREQ checklist.

**Additional file 2.** Interview protocol.

**Additional file 3.** Vignette case-studies.

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Research was conducted in accordance with the Declaration of Helsinki and national guidelines. Ethics approval was granted by the La Trobe University Human Research Ethics Committee (HEC19363). Signed informed consent forms were obtained from all participants prior to their interview.

## Authors' contributions

RH and SB conducted the interviews. RH transcribed all interviews and undertook initial coding. All authors contributed to ongoing data coding and analysis. RH drafted the initial manuscript, and ES and SB edited and further developed the manuscript. All authors read and approved the final manuscript.

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## Availability of data and materials

The datasets used during the current study are available from the corresponding author on reasonable request.

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## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no competing interests.

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**Appendix D: Chapter 4 Supplementary files**

1. Interview protocol HCP: also used in chapter 6
2. Patient vignettes used in interviews
3. Burden and Capacity coding: also used in chapter 5
4. COREQ checklist

## 1. Interview Protocol Burden and Capacity:      Healthcare Providers

**Prior to commencement of interview, review the participant information and consent form, reiterate information and ensure participant understands by asking them to state their understanding of the study and procedures.**

### **Introduction:**

In this research we are interested in finding out more about how health professionals assist people to manage their chronic health conditions. We have previously collected information from people with chronic health conditions about the challenges they experience with self-care. We are aiming to discover whether health professionals and clients have the same or different perceptions of these challenges and how to best deal with them.

We hope that this research will enable us to identify ways of better supporting both health providers and people dealing with chronic health conditions. Everything you say in this session will be confidential and no identifying features (such as your name) will be used in this research. If you wish, a printed transcript of the interview can be sent to you. If at any time you want to stop, or have a break, please feel free to let me know.

### **Part 1: Vignette case studies**

For the first part of this interview I would like you to read and discuss two case studies. Remember, there are no right or wrong answers – we are just interested to see how health professionals assess and make decisions about their clients.

(show first vignette)

Take a few minutes to read the first study. Imagine that it describes a client who is presenting to you for the first time. When you are ready, could you verbalise the initial thoughts that come into your head when reading about this client – the key issues that first strike you.

**Now** I want you to try and think about the case-study in two ways – first from the perspective of the person in the story; and then from your perspective as their health provider.

1. What would X need to do to manage their health successfully - what tasks do you think they would need to do?

‘Tasks’ should be understood in a broad sense: covering anything a person might need to do (including thought processes and practical activities) to manage their health.

2. What difficulties might X encounter and what resources or abilities might they need to help?

(Prompts: think about strengths they might have as well as challenges)

Now thinking from your perspective as their health provider:

3. In your current role, how might you assist X with their health management?

(Prompts: Providing education? Referrals? Specific treatments? Emotional support?)

4. What challenges might you as a healthcare worker face in providing assistance to X?  
How might these things be overcome?

(Prompts: Dealing with multiple health issues? Lack of time? Setting goals/prioritising? Factors outside your control?)

Repeat process for the second case-study.

## **Part 2: General interview questions**

We would now like to explore more generally how you assess people who come to see you and how you make decisions about the best ways of assisting them in self-management.

### Firstly, thinking about treatment burden

1. What does the term 'treatment burden' mean to you?
2. What things might 'treatment burden' include?
3. How would you decide if a person has a high treatment burden or not?
4. How can treatment burden be reduced? Consider this in 3 ways:
  - How an individual (person with a chronic disease) could reduce their burden?
  - What can health providers do to reduce burden?
  - What can health organisations, communities or the wider healthcare/political system do to reduce burden?

### Now thinking about individual capacity:

5. How do you determine whether a client has sufficient capacity to manage their health?
6. Which factors do you think are most important?
7. What do you consider the commonest barriers or challenges to client capacity?
8. How can capacity be increased? Again, think about this in 3 ways:
  - What can the individual client do?
  - What can health providers do?
  - What can health organisations, local communities or the wider healthcare/political system do?

### Finally, I would like your thoughts on client complexity:

9. How do you identify or classify a client as 'complex'?
10. What factors are most important in classifying them as complex?
11. When dealing with a 'complex' client, what things might you need to do differently?

(Prompts: types of treatment you offer? appointment structure/time? additional supports or referrals?)

12. As a health provider, what do you find most challenging when dealing with complex clients?

### This is the end of the interview:

Except to ask:

Did you feel that the case studies were a realistic representation of clients you might see in your clinical role?

Is there anything else you wish to say on this topic that you don't think has been covered?

Thank the participant and reiterate that all they have discussed is confidential.

## 2. Vignette case-studies

### Vignette 1

**Pete** is 70 years of age and lives with his wife Jan, aged 68. They are on the age pension and live in a transportable home which they own, in a local caravan park. Pete has had chronic back pain for 20 years, with several surgeries. He was diagnosed with COPD 3 years ago, at which time he stopped smoking. He has had type 2 diabetes (NIDDM) for 20 years with few problems, but he has developed diabetic foot ulcers over the past 3 years which prevent him from walking far. Pete and Jan are on their second marriage and have no contact with Jan's children and grandchildren due to a relationship breakdown, but have established some good friendships at the caravan park.

### Vignette 2

**Angela** is 52 and lives in secure rental accommodation with her two of her children (aged 19 and 21), one of whom has a learning disability. Both children are working, one in a supported environment. She has been on the disability pension for the past 10 years due to type 2 diabetes (insulin-dependent for 3 years), reflux and chronic shoulder pain related to an injury sustained when working as a personal carer. She does voluntary work a few times a week and has a close circle of friends and family. Her elderly parents live nearby and have some health issues, but are physically independent.

### Vignette 3

**Lyn** is 54 and lives in rental accommodation with her partner Bob who is currently employed as a truck driver. Their granddaughter Anna (aged 6) lives with them 3 days a week; Lyn and Bob's only child Teresa, who lives locally, has a long history of substance abuse and Anna has been under a shared custody arrangement since birth. Lyn has been unemployed for 5 years and receives the newstart payment; she previously worked in a supermarket. Lyn has worsening chronic neck and back pain and was diagnosed with type 2 diabetes (non-insulin dependent) and hypertension 3 years ago. She has had depression for the past 10 years. She has poor glycaemic control and is inconsistent in blood sugar testing. She has early signs of diabetic retinopathy. Bob is a supportive partner and tries to help Lyn in daily tasks wherever possible, but is often away due to work.

### Vignette 4

**Steve** is 63 years old and lives with his wife Sue. They live in a small unit, which they own, and have together run their own cleaning business for many years. Steve has suffered from depression for 20 years. He has been overweight for years and was diagnosed with type 2 diabetes (NIDDM) 5 years ago. He has erratic blood sugar levels, and also experiences chronic back pain and irritable bowel syndrome. Because of back pain, Steve has had to reduce his working hours and they are struggling to keep the business going. Steve and Sue have 3 children, two of whom live locally, and several grandchildren, but they find it hard to see them regularly due to the demands of their business.

**Vignette 5**

**Mark** has chronic back, knee and shoulder pain and walks with a stick. He underwent a coronary bypass 3 years ago. He is finding it difficult to manage tasks around the house and garden. He is 57 years old and has lived alone, in a rental property some distance outside town, since his marriage break-up 10 years ago. He has been unemployed for the past 4 years and receives the newstart payment; previously he worked as a farm labourer but was unable to manage the physical demands. He struggles to leave the house and has become socially isolated, although he has a circle of mates who keep in touch and his daughter and young grandchild do visit regularly.

**Vignette 6**

**Irene** is 66 years old and lives in her own home with her husband Dave (68). They receive the age pension; Dave worked in warehousing but had to stop work aged 60 due to worsening cardiovascular health. Irene has been his carer since that time. Irene is overweight and has widespread osteoarthritis, asthma and reflux. She is finding household tasks more difficult to complete, reporting fatigue and pain after walking or standing for more than 10 minutes. She has had anxiety for many years. Irene and Dave moved to the country when they retired and have not developed many local friendships. Their two adult children are in regular communication, but both live interstate.



### 3. Coding Descriptors for Qualitative Analysis

#### Coding categories and subgroups: Burden and capacity

BURDEN	Sense-making	Differentiation (D)
		Communal specification (CS)
		Individual specification (IS)
		Internalisation
BURDEN	Interaction	Enrolment (E)
		Activation (A)
		Initiation (I)
		Legitimation (L)
BURDEN	Enacting work	Skill-set workability (SSW)
		Contextual Integration (CI)
		Interactional Workability (IW)
		Relational Integration (RI)
BURDEN	Appraisal	Reconfiguration (R)
		Communal Appraisal (CA)
		Individual Appraisal (IA)
		Systematisation (S)
CAPACITY	Biography	
CAPACITY	Resources	Personal
		Cognitive
		Financial
		Physical function/illness burden
		Knowledge
		Supports/subsidies
CAPACITY	Environment	Healthcare
		Personal
		Treatment fit
CAPACITY	Work realisation	Treatment workload
		Life workload
CAPACITY	Social	Ability to socialise
		Provision of support
		Social acceptance

## Definitions: Burden

### 1. Coherence/sensemaking

Also known as sense-making work, making tasks meaningful. Understanding the prospect of having it, what it means and how it can be managed

**Differentiation:** Understanding and differentiating between risk factors, investigations, treatments and the roles of different health professionals and services. Prioritising treatments and activities.

**Communal specification:** Gaining information about illness management with the help of others, for example friends, family or health professionals. Receiving diagnosis, or misdiagnosis.

**Individual specification:** Achieving your own understanding of illness management in personal terms, through personal research such as reading, or personal experience.

**Internalisation:** learning how to do tasks in context - relating your experience to the illness and its treatment, understanding its implications, knowing when to seek help, problem solving, understanding one's own contributions to reducing risk. Maintaining motivations and determination, setting goals. Developing expectations of health services. Developing coping strategies.

Examples – finding out about treatments, medications, test results and understanding what they are for; obtaining information from HCPs, knowing when to seek help, planning and goal-setting.

### 2. Interaction

Cognitive participation, relationship work – investing personal and interpersonal commitment to tasks (Relationship work) Investing personal and interpersonal commitment to living with the condition and its management

**Enrolment:** Engaging with friends, family and health professionals with regards to diagnosis and illness management to enable them to provide support. Adjusting relationships to accommodate new roles as a result of illness during management.

**Activation:** Arranging help (e.g. logistical, administrative, or expert) from health professionals, social services or friends and family.

**Initiation:** using organizational skills to arrange one's own contribution to management, such as arranging prescriptions, social care, and transport to appointments

**Legitimation:** Seeking reassurance from others about appropriateness of management plans. Gaining confidence in the success of treatments. Dealing with stigmatisation or a mismatch in ideas and expectation from others. Comparing yourself to others to validate treatments, deciding they are worthwhile.

Examples: Seeking advice or help from health and social care professionals, Gaining support from friends, family, dealing with Strained relationships and stigma, difficulties with HCPs including access, paternalism, mismatch of ideas, poor communication or care co-ordination

### 3. Enacting Work

Collective action – investing effort and resources in management and carrying out necessary tasks

**Skill-set workability:** Setting a routine to cope with symptoms, exacerbations, and emergency situations. Enacting activities with a view to achieving goals.

**Contextual integration:** Making sure you have the right financial and social resources, and integrating the illness into social circumstances. Managing potential environmental dangers through making resources available. Adjusting to new social role in society or life circumstances such as unemployment.

**Interactional workability:** Having treatments, enacting lifestyle changes, attending appointments, enduring side effects. Enduring poor health care or care that does not meet expectations (e.g. poor interactions). Learning self care.

**Relational integration:** Maintaining confidence in health professionals and their interaction with each other. Maintaining confidence in care plan. Coping with multiple caregivers. Enduring system failures caused by poor communication/interaction by service providers

Examples – logistic, practical organisational and financial activities you need to undertake to adhere to treatments, setting routines/systems to eg. Stick to medications, attending appointments, difficulties organising appointments, costs, accessing other health and social services, dealing with poor continuity of care, making lifestyle and emotional adjustments

#### **4. Appraisal work**

Reflexive monitoring – investing in comprehending Reflecting on the effects of therapies in retrospect and determining whether to modify them.

**Reconfiguration:** changing tasks altering a set routine when required, such as medication regimens or appointments, to fit in with daily activities or other arrangements. Learning new ways of doing things. Altering priorities and ways of thinking.

**Communal appraisal:** discussing or altering current management plans already initiated, in discussion with health professionals or friends and family.

**Individual appraisal:** Assessing individually whether to continue or alter current management plans. Recalling previous events. Monitoring symptoms and progress (but not as a routine, see below)

**Systematisation:** Developing ways of keeping up to date with newly available treatments. Routine self monitoring.

Examples – altering medication timing to suit life, adjusting diet and exercise, discussing adjustments with hCPs, attending review appointments, Reflecting on progress.

### Coding categories: Capacity and subheadings

Interaction of the individuals' resources, social functioning and realisation of work within their biography, in the background of their environment. Recognition of interaction between each component – e.g. low resources leading to social isolation impacting on biographical reframing.

- Biography:
  - Ability to reframe life - Create meaning while living with chronic conditions
  - Inability to do this,
- Social:
  - Ability to socialise
  - Ability of their social network to accept the patients condition and the resulting changes
  - Provision of instrumental/practical support
  - Social relationships with healthcare teams
- Resources:
  - Illness burden: energy/fatigue, pain, depression
  - Time
  - Knowledge, learnings from past experience
  - Transportation
  - Practical skills (e.g. computer literate)
  - Physical abilities and functioning – fitness/physical capacity, sight, hearing
  - Finances: available income for medical expenses or expenses related to lifestyle changes, loss of income, access to benefits system
  - Paid support services; aids/equipment; subsidies available from organisations
  - Cognitive capacity – Literacy, Memory, cognitive ability, problem-solving
  - Personal attributes – self-efficacy (related to ability to use relevant resources to achieve meaningful goals), resilience, humour, determination; worry, disorganisation, frustration.
- Realisation of necessary work:
  - Treatment workload:
    - Ability to successfully complete work - increases capacity
    - Ability to normalise treatment workload
    - Ability to prioritise treatment with competing conditions or treatment workload
    - Ability to deal with healthcare system complexity
  - Life demands: Ability to achieve expected life roles, leisure activities, cultural roles
- Environment
  - Kindness and empathy:
    - in healthcare environment
    - or personal environment (e.g. home, workplace)/conversely, lack of flexibility or excessive demands
  - Fit of the condition, healthcare, self-care into people's lives and not interfering with other priorities.

### COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	N/A
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	1
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	appendix B/C
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5/6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5/6
Sample size	12	How many participants were in the study?	7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	table 1, p6
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	appendix B/C,
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	7
Software	27	What software, if applicable, was used to manage the data?	6
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	table 2
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

**Appendix E: Chapter 5 Publication**

## RESEARCH ARTICLE

# Multimorbidity and its effect on perceived burden, capacity and the ability to self-manage in a low-income rural primary care population: A qualitative study

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## Abstract

### Introduction

Multimorbidity is increasing in prevalence, especially in low-income settings. Despite this, chronic conditions are often managed in isolation, potentially leading to burden-capacity imbalance and reduced treatment adherence. We aimed to explore, in a low-income population with common comorbidities, how the specific demands of multimorbidity affect burden and capacity as defined by the Cumulative Complexity Model.

### Materials and methods

Qualitative interviews with thirteen rural community health centre patients in Victoria, Australia. Participants were aged between 47–72 years and reported 3–10 chronic conditions. We asked about perceived capacity and burden in managing health. The Theory of Patient Capacity was used to analyse capacity and Normalisation Process Theory to analyse burden. All data specifically associated with the experience of multimorbidity was extracted from each burden and capacity domain.

### Results

The capacity domains of biography, resource mobilisation and work realisation were important in relation to multimorbidity. Conditions causing functional impairment (e.g. chronic pain, depression) interacted with physical, psychological and financial capacity, leading to biographical disruption and an inability to realise treatment and life work. Despite this, few people had a treatment plan for these conditions. Participants reported that multimorbidity affected all burden domains. Coherence and appraisal were especially challenging due to condition interactions, with clinicians providing little guidance.

### Discussion

The capacity and burden deficits highlighted by participants were not associated with any specific diagnosis, but were due to condition interactions, coupled with the lack of health

## OPEN ACCESS

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**Data Availability Statement:** Restrictions have been placed on our dataset by the La Trobe University Human Ethics board. Data cannot be publicly shared because it consists of qualitative



Interviews with patients conducted in two rural communities where there may be risk of identification. Data are available through the La Trobe University ethics committee or from the corresponding author for researchers who meet the criteria for access to confidential data. Contact information for the La Trobe University Human Ethics board: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) or phone +61 3 9479 1443. The approval reference number is HEC19387.

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**Competing interests:** The authors have declared that no competing interests exist.

provider support to navigate interactions. Physical, psychological and financial capacities were inseparable, but rarely addressed or understood holistically. Understanding and managing condition and treatment interactions was a key burden task for patients but was often difficult, isolating and overwhelming. This suggests that clinicians should become more aware of linkages between conditions, and include generic, synergistic or cross-disciplinary approaches, to build capacity, reduce burden and encourage integrated chronic condition management.

## Introduction

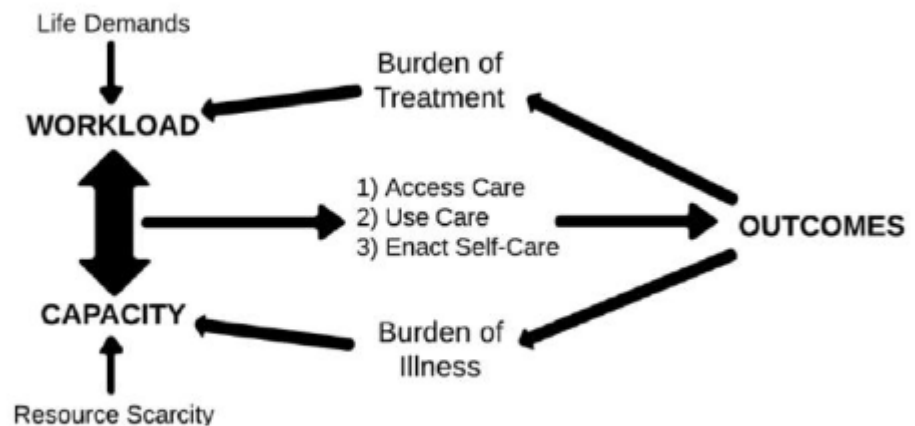
The shift from acute to chronic health conditions as the main driver for worldwide burden of disease has demanded alternative healthcare solutions [1]. More recently, there has been a recognition that many chronic conditions do not exist in isolation, but as clusters of conditions [2]. Multimorbidity, which is defined as the presence of two or more chronic health conditions [3], has become the rule rather than the exception [2,4], especially with increasing age. In common with individual chronic conditions, multimorbidity is also more prevalent in vulnerable groups, including rural [5] and socially deprived populations [4].

This 'new normal' of multimorbidity is not reflected in our health systems, models of care or everyday clinical practice. Although the development of the Chronic Care Model [6] has enabled many healthcare systems and practitioners to transition from acute to chronic care, it remains limited by its single disease focus. Studies of clinical guidelines and qualitative studies with patients and healthcare providers (HCPs) note that multimorbidity is difficult to integrate into a chronic care model due to conflicting treatment recommendations, condition interactions and excessive treatment burden [7–10].

Traditionally, multimorbidity has been understood as a list of separate conditions which are prioritised according to mortality risk [11,12]. In clinical practice, this has led to each condition being managed as a separate entity [10], with precedence given to conditions with a higher risk of future adverse outcomes such as diabetes or cardiovascular disease [13,14]. Interviews with patients suggest that they approach multimorbidity differently, placing greater importance on symptomatic conditions affecting their quality of life [15–19]. This preference has implications for health outcomes, with conditions that may have low symptom burden but high future risk being deprioritised or ignored by patients [16].

Recognising that for most people, multimorbidity is an experience they live with, rather than a condition(s) they die from, researchers have started to pay more attention to the patient experience [16,20–22]. This has drawn out the importance of interactions between the disease (s) and psychosocial factors. The risk of a co-occurring mental health condition (often excluded from morbidity counts) [11] increases with each additional physical condition [23], and socially disadvantaged populations report 10–15 years earlier onset of multimorbidity [4]. Although disease count is important when measuring mortality, functional impairment, psychological distress and social context are more accurate predictors of quality of life [11,24].

In acknowledgement of these social and contextual influences, Coventry [21] has characterised multimorbidity as an 'encounter with complexity', consisting of emotional, environmental and functional as well as medical components. Shippee's Cumulative Complexity Model [25], which defines complexity as the result of an imbalance between an individual's capacity and their workload, is a useful way to understand multimorbidity. This model conceptualises capacity as a person's physical, cognitive and psychological functioning as well as their



**Fig 1. The cumulative complexity model [25,28].**

<https://doi.org/10.1371/journal.pone.0255802.g001>

available resources. Workload comprises treatment and condition requirements plus the demands of everyday life (see Fig 1). Although Shippee's model [25] uses the term 'workload', to increase clarity and consistency with the wider literature we will be using the term 'burden' or 'treatment burden' instead, defined as both the healthcare tasks ('work') of managing chronic illness, and the impact on the patients' life roles and functioning ('life') [26].

Concepts of burden and capacity are important in multimorbidity, since the additional treatment tasks (e.g. medications, condition monitoring, appointments) associated with multiple conditions are likely to increase treatment burden. With sufficient capacity, the burden can be managed; but low capacity (e.g. inadequate income or social support) will reduce a persons' ability to manage their treatment burden (e.g. medication costs, accessing appointments). Burden-capacity imbalance can lead to reduced treatment adherence and declining health outcomes [27]. This model is particularly relevant to socially disadvantaged populations, because they experience higher levels of multimorbidity [4] (therefore greater treatment burden) whilst having fewer resources (lower capacity).

The cumulative complexity model has been explored in a range of populations, including people with diabetes [29], kidney disease [30], stroke [31] and in low-middle income countries [32]. We wished to apply this model to a rural low-income multimorbid population, who were at risk of both high burden (from multiple health conditions) and low capacity (from resource constraints). The point of difference in this study was its focus on how the experiences that are specific to multimorbidity affect perceptions of burden and capacity.

To explore this we will use established taxonomies of workload and capacity, since this will enable us to see how each workload or capacity domain is differentially affected by the demands of multimorbidity. The Theory of Patient Capacity [33], which describes capacity as the interaction between Biographical adjustment, Resource mobilisation, Environmental fit, Work realisation and Social functioning (abbreviated as 'BREWS') will structure our examination of capacity. To explore burden, we will use Normalisation Process Theory (NPT). This theory explains how new practices are integrated into everyday life [34], and has been applied previously in studies of treatment burden [27,31,35].

Our research question was: In low-income rural primary care patients, how does the experience of multimorbidity affect perceived burden and capacity to self-manage their health?

## Materials and methods

### Study design

The study method was qualitative. We employed a phenomenological methodology, which is an approach focussed on the lived experience of participants [36]. Research was conducted in accordance with national ethics guidelines, with approval granted by the La Trobe University Human Research Ethics Committee (HEC19387). The completed COREQ checklist for reporting of qualitative studies is available in [S1 File](#).

### Participant recruitment and setting

Participants were clients of two regional community health centres in Victoria, Australia. Victorian community health centres provide primary care and chronic disease services to low-income and socially disadvantaged populations [37]. People aged between 18–75 years who described themselves as having at least two chronic physical health conditions, such as diabetes, back pain, arthritis, heart or lung conditions were invited to participate. Our focus was on conditions commonly managed in primary care. Since low-income groups are known to experience multimorbidity 10–15 years earlier [4], we looked for people who were middle-aged or early retirees (under 75 years). We were interested in exploring multimorbidity in an age group where there are still societal expectations of active and independent life roles.

Participants were recruited via posters in the waiting rooms of the health centres, as well as by direct invitation from their health care providers. Potential participants were provided with basic study information and their contact details were provided (with permission) to the researchers. Sixteen people expressed interest in the study, with three withdrawing prior to the interview. Recruitment was initially via snowball sampling, with the last four participants purposively selected to ensure gender balance.

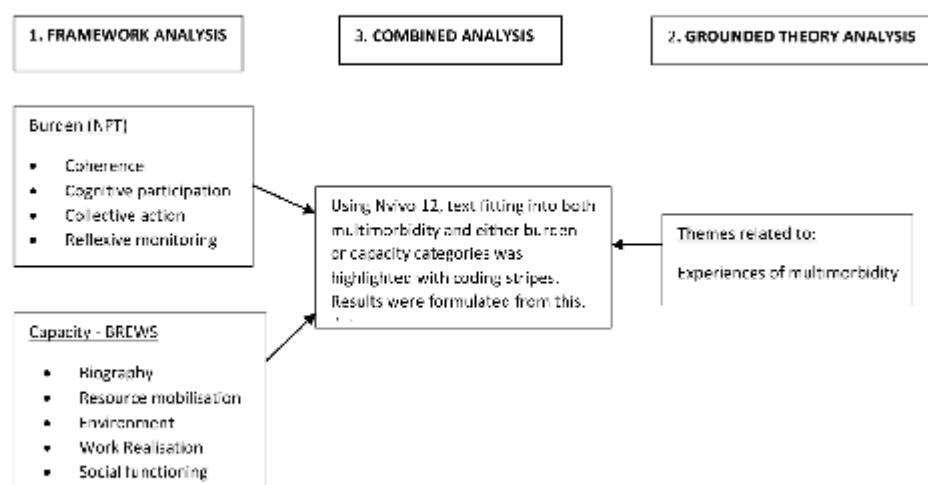
### Data collection

Following completion of written consent, we conducted semi-structured interviews, each lasting for approximately one hour. All interviews were conducted by a single clinician-researcher (RH), either by phone or at a community health centre. The interview protocol was developed following review of the qualitative literature [31,33,38,39], but was not trialled in patients. Interview topics explored all capacity and burden domains as outlined by BREWS and NPT. We asked people to describe their health conditions; how their daily life was affected; the treatments they needed to undertake and the difficulties they experienced in managing their health-care. Interviews were audio recorded and continued until all researchers agreed that saturation had been reached. Interviews were transcribed verbatim by the interviewer (RH). Field notes detailing key issues and observations were made following each interview. The interview protocol is available in [S2 File](#).

Participants also completed a series of self-report scales and sociodemographic details were recorded.

### Data analysis

We aimed to explore how the experience of multimorbidity, as distinct from that of having a single chronic condition, affected each aspect of capacity and burden. For this reason, we undertook analysis in several stages ([Fig 2](#)). First, we explored capacity and burden by dividing



**Fig 2. Description of analysis process.** All data underwent initial framework analysis using the two categories of NPT and BREWS. We then returned to the raw data to record experiences of multimorbidity. Finally, analyses were combined to identify multimorbidity data that was relevant either to burden or capacity.

<https://doi.org/10.1371/journal.pone.0255802.g002>

the interview data into these two broad categories. We then applied framework analysis, which uses a pre-defined coding system (the framework) to structure the data [40]. The coding systems used were the Theory of Patient Capacity to analyse capacity [33] and Normalisation Process Theory to analyse burden [27]. Tables 1 and 2 describe each coding system in terms of its component domains; further details are available in [S3 File](#). Data was transcribed verbatim by RH and initially coded by hand, then imported into NVivo 12. Coding was evaluated and refined by SB and ES. Findings were reviewed and disagreements resolved in discussion with all three researchers.

Since our focus was on the relationship between capacity, burden and the experience of multimorbidity, we then returned to the original data and performed a second analysis, using a grounded theory approach to identify themes related to multimorbidity. Grounded theory is an inductive approach to qualitative research that focusses on the data alone, without an underlying theoretical perspective [36]. We looked for any references to having more than one health condition, including how conditions were prioritised, interactions between conditions and any demands related to managing multiple health conditions. Following the second analysis, by using the coding stripes function on NVivo 12, we could then locate all data associated with both the burden/capacity and the multimorbidity codes. Thus, we could identify the burden and capacity domains perceived by the participants to relate most strongly to multimorbidity.

## Results

### Participant and interview characteristics

Eleven interviews were conducted with thirteen people (two interviews were with couples who both experienced multimorbidity). Nine interviews were conducted face-to-face at a



Table 1. Coding domains for capacity (BREWS).

CAPACITY DOMAINS		
Biography		Ability to maintain purpose and create a meaningful life while living with chronic conditions
Resource mobilisation	Physical	Symptom burden (pain, fatigue etc.), functional capacity (task performance, physical fitness, sensory abilities).
	Psychological	Personal traits (resilience, self-efficacy); mental health burden (anxiety, depression); cognitive capacity (memory, literacy).
	Practical	Financial, personal (e.g. access to transport) and organisational (e.g. aids/equipment, governmental services) resources.
Environment		Support available in healthcare and personal environments; whether treatment demands are a good fit with daily life.
Work realisation		Ability to successfully achieve and normalise all aspects of treatment workload; ability to achieve expected life roles.
Social functioning		Ability to socialise; practical social supports, social acceptance or stigma, social relationships with HCPs.

<https://doi.org/10.1371/journal.pone.0255802.t001>

community health centre, and two by phone, due to COVID-19 restrictions. Interview duration ranged from 31–71 minutes (mean 43 minutes). Participants were aged between 47 and 72 years (mean = 61 years) and reported between 3–10 health conditions each (mean = 7) using the Disease Burden Impact Scale [24,41] to report type and severity of condition. The most common conditions reported were musculoskeletal disorders (back pain, osteoarthritis and/or other chronic pain—reported by 100% of participants), followed by type 2 diabetes ( $n = 10$  people, 77%); cardiovascular conditions (heart disease, peripheral vascular disease and/or hypertension:  $n = 10$ , 77%); overweight/obesity ( $n = 8$ , 62%); mental health conditions (depression, anxiety and/or PTSD:  $n = 8$ , 62%) and gut or bowel disorder ( $n = 8$ , 62%). Other conditions reported by 3–6 participants were respiratory conditions (asthma and COPD), vision and hearing impairments. Table 3 records key characteristics of the participants.

### Multimorbidity and capacity

As illustrated in Table 4, multimorbidity was related to biography, resource mobilisation and work realisation. People reported biographical challenges when a new condition emerged. They had often managed a chronic condition for years without difficulty, but the impact of another condition could make all the difference. This was especially the case with conditions associated with functional impairment, which often placed greater demands on biographical reframing due to the loss of meaningful activities (especially if people had to stop work or lost other significant life roles).

Table 2. Coding domains for burden (NPT).

BURDEN DOMAINS	
Coherence (Sense-Making)	Learning about, understanding and making sense of the condition(s) and treatments, planning care, setting goals.
Cognitive Participation (Relationship work)	Engaging with others (HCPs, services, friends) for help, managing these relationships; in individual organisational tasks to support health care (e.g. transport, arranging prescriptions).
Collective Action (Enacting work)	Specific treatment tasks (appointments, medication, self-care); integration of condition and treatment into daily life (adjusting to work, social or financial changes).
Reflexive Monitoring (Appraisal)	Reflecting on the condition(s) and treatment, reviewing and modifying management individually or in discussion with others.

<https://doi.org/10.1371/journal.pone.0255802.t002>

Table 3. Characteristics of study participants.

ID	Sex	Age	Living situation	Source of income	Health conditions
P1	M	57	With friend	Unemployment payment <sup>1</sup>	Back pain, OA, other chronic pain, depression, PTSD, liver disease, vision.
P2	F	50	Spouse and child	Unemployment payment <sup>1</sup>	T2DM, back pain, other chronic pain, obesity, depression, gut, bowel, vision, HT
P3	M	72	Spouse (P4)	Age pension <sup>2</sup>	RA, back pain, OA, CVD, HT, gut, vision, overweight
P4	F	71	Spouse (P3)	Age pension <sup>2</sup>	RA, T2DM, back pain, OA, overweight, gut, bowel, asthma
P5	M	70	Spouse	Age pension <sup>2</sup>	CVD, HT, T2DM, PVD, vision, hearing, OA, kidney disease
P6	M	54	Alone	Unemployment payment <sup>1</sup>	T2DM, OA, back pain, other chronic pain, PVD, HT, overweight, vision, depression, thyroid.
P7	M	65	Spouse, other family	Part time work <sup>3</sup>	T2DM, HT, back pain, other chronic pain, gut, depression/anxiety, sleep apnoea, obesity, hearing
P8	M	59	Alone	Unemployment payment <sup>1</sup>	T2DM, PVD, overweight, depression/anxiety, OA, back pain, other chronic pain.
P9	F	57	Children	Disability pension <sup>2</sup>	T2DM, OA, back pain, gut, COPD, asthma, depression/anxiety, incontinence, HT
P10	F	66	Spouse (P11)	Part time work <sup>3</sup>	OA, asthma, depression/anxiety
P11	M	68	Spouse (P10)	Age pension <sup>2</sup>	CVD, HT, T2DM, PVD, hearing, cancer, gut, asthma, depression/anxiety, COPD, chronic back pain, other chronic pain
P12	F	47	Other family	Carer pension <sup>2</sup>	T2DM, OA, other chronic pain, back pain, kidney disease, liver disease, cancer, obesity, gut, bowel, HT
P13	F	60	Alone	Disability pension <sup>2</sup>	T2DM, OA, back pain, other chronic pain, HT, obesity, COPD, gut, lymphoedema, sleep apnoea

CVD = cardiovascular disease; HT = hypertension; T2DM = type 2 diabetes; COPD = pulmonary disease; RA = rheumatoid arthritis; PVD = peripheral vascular disease; OA = osteoarthritis; PTSD = post-traumatic stress disorder.

1 = income  $\approx$  A\$15000 p/a - below poverty line; 2 = income  $\approx$  A\$22000 p/a - equivalent to Australian poverty line; 3 = unskilled occupation, < 20hr/week.

<https://doi.org/10.1371/journal.pone.0255802.t003>

*Participant 6: I've always been an outdoor labouring person working all my life you can't just flick the switch and sit in front of a computer I'd rather shoot myself to be honest [I feel] just not as happy... because you're not going forward... in life because you haven't got a job... it's like you're just stagnant*

For those people who were waiting (or hoping) for a definitive diagnosis, treatment or explanation of their condition, building biographical capacity was difficult. They felt that they were in limbo and unable to 'move on' with their lives.

Multimorbidity had a profound effect on resource mobilisation. Physical, psychological and financial capacity were all compromised. Eight of the thirteen participants reported chronic pain conditions (osteoarthritis (3), shoulder pain (1), back pain (2), leg/foot pain (2)) and two reported diabetic foot ulcers as their most important condition. All ten participants related condition priority to the associated loss of physical capacity, including the ability to

Table 4. The relationship of multimorbidity to capacity domains.

CAPACITY DOMAINS	THEMES RELATED TO BOTH CAPACITY AND MULTIMORBIDITY
Biography	Each new condition requires biography work. Certain conditions (e.g. undiagnosed, disabling) place greater demands on biography.
Resources	Physical: Conditions causing functional impairment are prioritised.
	Psychological: Poor mental health affects ability to look after other conditions.
	Financial: Multiplying health care costs. 'Tipping point' where increased number of conditions or disability results in loss of income.
Environment	No issues specific to multimorbidity
Work	Treatment workload is easier to achieve if conditions have low symptom burden or are perceived as interrelated; harder if mental health is poor.
Social	No issues specific to multimorbidity

<https://doi.org/10.1371/journal.pone.0255802.t004>

work, exercise, undertake household tasks and leisure activities. Both couples prioritised their partner's chronic pain condition above their own chronic pain conditions because of the additional physical demands it placed on them as carers, further reducing their own (already restricted) physical capacity.

*Participant 11: [my biggest issue is] the shoulders more than diabetes. . .because if I do something I shouldn't do I pay for it. . .Participant 10 (spouse): and it impacts on sleep and me having to do things*

Psychological capacity was also essential. Although we selected participants based on their physical health conditions, eight people also reported a mental health diagnosis. The remaining five interviewees also described emotional difficulties, with several having undergone mental health treatment in the absence of a formal diagnosis. Two participants rated depression as their most important condition, and one prioritised obesity due to its impact on her mental health. Again, these conditions were prioritised because they prevented the attainment of desired goals including the ability to socialise, work, undertake study, and engage in family life. Participants also described how depression affected their adherence to, and motivation for, treatment of other health conditions. All those having trouble with their diabetes management reported moderate to severe depression.

*Participant 1: I get depressed because things don't seem to happen quickly enough for me and I get upset that I can't do things so I don't eat, I stop taking my meds, I self-harm . . . things like that*

All participants noted that multiple chronic conditions led to increased healthcare expenditure, thus reducing financial capacity. All but one interviewee stated that they had not undertaken recommended treatments or appointments at times due to cost.

*Participant 12: the psychologist that I'm seeing I . . . pay out-of-pocket to see her. . .I have to think about what don't I get done that week do I not pay my phone or power. . .*

Four participants paid for private health insurance. Although there was a recognition that this provided a better quality, faster service, participants felt that the cost could not be sustained into the future without additional funds provided by ongoing employment or other family members.

Increased healthcare costs were often complicated by loss of income. As multimorbidity increased, functional capacity declined, with ten of the thirteen participants reporting that their health conditions had forced them to stop work. Several people described a 'tipping point' where they were no longer able to work due either to a gradual increase in disability or due to a new health condition which resulted in greater functional impairment. Most were unable to access the disability or aged pension (at least initially), which could provide a low but secure income, and were reliant on savings or financial support from their family.

*Participant 6: I've lost my house that was the main thing. . .I nearly had it paid off [but] I had no insurance because I had shoulder operations before and they wouldn't give me income insurance so I couldn't get that . . .when this happened I was buggered couldn't work so I had to sell my house*

The ability to build capacity by work realisation depended on the nature of the condition. Conditions such as diabetes which had a low symptom burden, were reasonably predictable and had a clear management plan were cited as easier to successfully manage than more unpredictable or difficult to control conditions such as chronic pain, rheumatoid arthritis or depression.

*Participant 4: [managing condition workload] it depends on what sort of health conditions you've got because my diabetes is really just diet and of course medication but the rheumatoid arthritis is one that you need to keep in check...if you have a flare-up*

If the person saw their conditions as interrelated in terms of cause or treatment, they were more able to manage it, compared to seeing it as a series of separate conditions. Those with the greatest difficulty in successfully accomplishing treatment work all reported mental health issues, associated with a sense of being overwhelmed and disorganised, rather than enormous treatment demands.

*Participant 2:... it'd be so much easier if I just had one health problem I could work on and not have multiple problems and you just think...put your hands up...I got really bad a few months ago...I just stopped taking everything...I went into a really deep depression and couldn't be bothered doing a thing*

**Interacting capacities.** Loss of capacity often snowballed. The interaction between mental and physical health conditions was a common theme. Some thought of depression as the trigger for all their health conditions, often related to past trauma. For others, depression developed after other health conditions, either directly (e.g. following heart surgery) or due to pain or functional incapacity.

*Participant 8: that's where depression comes in you're just sitting in the same house all day every day when I was working I would have holidays for 8–10 weeks a year*

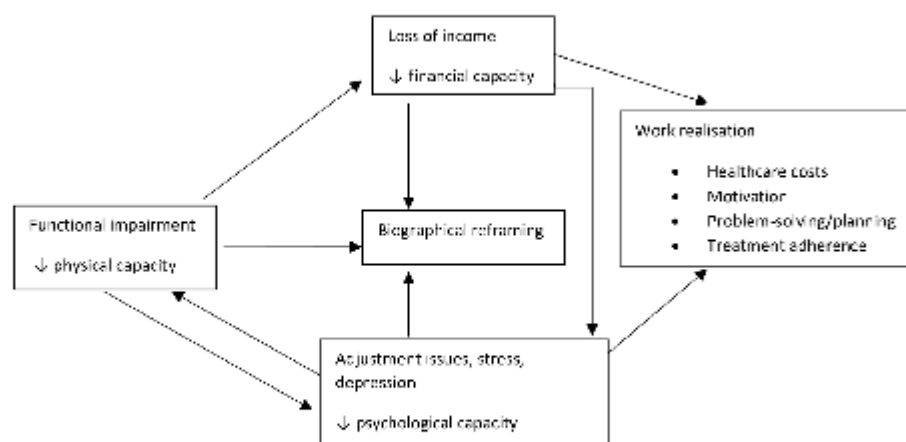
Loss of physical capacity, in turn, provided multiple triggers for mental health decline. It had direct impacts on income (ability to work) and on biography (loss of life role, ability to engage in meaningful activity), as well as the symptom burden of pain or fatigue. Worsening depression, whether triggered by a physical health issue or not, affected work realisation, reducing adherence to treatment tasks, affecting motivation and problem-solving ability. It could thus exacerbate co-existing physical health conditions.

Financial resources could bolster capacity. Those who had a secure (if limited) income, compared to those receiving unemployment benefit or in an insecure work environment had fewer mental health difficulties and more effective strategies to manage their mental health. The two participants working part-time chose to continue because they recognised the mental health benefits (boosting psychological capacity) despite the fact that it exacerbated their chronic pain (reducing physical capacity).

*Participant 7: with depression people handle it in different ways I keep busy I work I do things if I can't work what happens I go downhill...as soon as I stop doing things I go downhill*

All three resource mobilisation factors were closely related to biographical disruption (Fig 3). Reduced physical capacity led to the loss of preferred and meaningful activities, including





**Fig 3. Interacting capacities.** Functional impairment leads to loss of income, biographical difficulties and psychological stress. Loss of income affects biography, psychology and work realisation. Psychological stress affects biography, physical capacity and work realisation.

<https://doi.org/10.1371/journal.pone.0255802.g003>

important life roles such as work. This could lead to depression (reduced psychological capacity), which then affected motivation and future planning. Reduced financial capacity often resulted from the loss of physical capacity (inability to earn an income) but lack of income also limited people's access to meaningful or enjoyable activities, as well as access to health care (which could potentially improve physical and psychological capacity). Those with greater financial security (e.g. access to the pension) were more able to put their energies into meaningful activity which assisted with biographical reframing.

### Multimorbidity and burden

The relationship between multimorbidity and the different aspects of burden, as described by NPT, is demonstrated in Table 5.

The ability to form a coherent understanding of health problems was easier if the conditions were seen to be interconnected or to stem from the same cause. Disparate health issues often felt overwhelming and some people struggled to make sense of them. These participants often had depression as their primary (initial) health condition.

**Table 5. The relationship of multimorbidity to burden domains.**

BURDEN DOMAINS		THEMES RELATED TO BOTH BURDEN AND MULTIMORBIDITY
<b>Coherence</b>		Making sense of conditions is easier when they are interconnected but harder if depression dominates. HCPs help with diabetes understanding but less so with other conditions.
<b>Cognitive participation</b>	HCP relationships	Multiple HCP involvement, poor service co-ordination between conditions
	Individual	Mental health affects ability to organise healthcare
<b>Collective action</b>	Treatment tasks	More tasks to undertake (polypharmacy, appointments, self-care), but for many this becomes a routine not a burden.
	Contextual Integration	Greater healthcare costs, often combined with loss of income, are the main barrier
<b>Reflexive monitoring (Appraisal)</b>		Constant need to reassess due to interactions between conditions and treatments. Little guidance or assistance from HCPs.

<https://doi.org/10.1371/journal.pone.0255802.t005>

*Participant 5 [managing multiple health conditions is not a problem]...because I got them all together and they're sort of all related. ...I was diagnosed [with diabetes] in 89 and I had my first heart attack in 92 so it's the same period of time and there is no doubt about the fact that they were all related to my drinking. ...I see it as one big problem instead of separate things*

Many people reported that HCPs had provided them with information and education about diabetes, but few other conditions were addressed. Of note, HCPs were rarely seen as sources of information about conditions causing functional impairment (pain, mental health, fatigue). Learning about these conditions was either via trial and error or the internet.

*Participant 10 ...[learning about osteoarthritis] I've self-managed I've experimented with myself*

In the cognitive participation domain, interactions with HCPs multiplied as numbers of health conditions increased. All participants reported involvement with several providers, with most seeing 3–5 HCPs regularly. This could be challenging if HCPs were time-limited, unsympathetic or transient (common in rural areas). Some people found it hard to keep track of who they were seeing and for what condition. Multidisciplinary and co-located services were noted to be very helpful and the need for co-ordination was repeatedly discussed.

*Participant 11: every time you go there [to the GP clinic] they change the doctors around and the doctor changes the tablets Interviewer: seeing different doctors all the time? Participant 11: yeah*

Individual organisation was important in multimorbidity. Those who had a routine, or a system to manage medication coped better. Poor medication adherence was associated with a lack of routine and was frequently associated with mental health conditions.

The topic of collective action was explored in relation to the numbers of treatment tasks, and the ability to integrate the condition into daily life. All participants were asked which of their health condition(s) required the most treatment work. Four people selected diabetes as having the greatest workload and three nominated conditions related to wound healing and dressing. The remaining participants did not identify a specific condition. Six of those with diabetes felt that their diabetes management was normalised and fully integrated into their lives.

Despite this, all participants recognised that having multiple health conditions meant additional treatment tasks. Some incorporated it into their daily routine, with several people describing it as their 'job', but others found the workload too great. Everyone reported poly-pharmacy, and many had concerns about medication interactions and side-effects. Those living more remotely (6 hours travel from the state capital city) had significantly greater time and money costs associated with travelling to appointments, as well as fewer treatment choices, compared to those living in an inner regional area (2 hours from the capital). Some people managed their treatment load by recognising that the same treatment (e.g. exercise) could work for several conditions.

For most people, the additional costs of healthcare associated with multimorbidity was the main barrier to the integration of the conditions into their daily life, especially for those who were no longer able to work.

Finally, reflexive monitoring (appraisal) played an important role in the management of multimorbidity. People had to undertake more cognitive work to understand how treatments and conditions interacted, and needed to constantly reassess and reconsider one condition in

the light of their other conditions. This ongoing instability could make normalising treatment workload more difficult. Participants reported undertaking appraisal in relation to both medication use and lifestyle recommendations. Most people had concerns about polypharmacy and were keen to minimise medication use, but struggled to unravel the interactions between conditions and medications.

*Participant 13: because it's all combined as I said when I went for oncology there yesterday because I take a tablet that can cause hot flushes. . . they ask do you get hot flushes. . . I don't know I've got so many health problems. . .*

Lifestyle recommendations were often questioned because participants felt they were unrealistic (for diet), or because people did not know how to undertake exercise when they had coexisting chronic pain.

*Participant 3: everywhere we go it whether you go to see the GP or [the dietician] . . . the physiotherapist or whatever they all say exercise and I said but it's just not possible we can't do it. . . because of the pain*

Those with diabetes frequently described the process of appraising and modifying treatment due to the impact of stress, pain or illness on their blood sugar levels. Some were confident in 'trouble shooting' their various health conditions and could monitor and adjust treatment as needed, while others found that additional health conditions 'muddled the waters' and made it harder to plan what to do.

*Participant 7 [managing diabetes when first diagnosed] because it was new it was a bit of a novelty and I knew what I had to do but as time goes on. . . I've had lots of other health issues. . . I have to think oh I've got to look after my shoulder I've got to be careful of my hernia and it takes you away from the diabetes*

Many participants engaged in individual appraisal and adjusted their treatments (including medication) without necessarily discussing the changes with a HCP.

*Participant 8: when I was going to [the hospital] they wanted four [blood sugar] readings a day but you run out of the strips after a while. . . I did that for about 4 or 5 weeks but it there wasn't really a great deal gained by it so I can't see the point.*

## Discussion

### Main findings

This study aimed to investigate how the additional challenges of multimorbidity influence different aspects of capacity and burden, as described in the literature. For this rural, low-income population, the nature of the condition was of key importance. Conditions associated with functional impairment, especially chronic pain and mental health conditions, had the greatest influence on capacity. In our analysis of burden, multimorbidity was associated with a greater number of treatment tasks, costs, and appointments with HCPs, as has been well-documented previously [42,43]. The domains of coherence (sense-making) and reflexive monitoring (appraisal) were particularly important and this was related to the interactions between capacities, conditions and treatments that most participants dealt with.

### The nature of the condition

Several studies [15,16,18,22], have reported that patients prioritise health conditions based on their functional impact, and this study reports similar findings. Analysis of specific capacity domains showed that pain and mental health conditions (as well as diabetic foot ulcers) had the greatest impact on capacity. In this low-income rural setting, most participants had been manual workers, and the biggest functional impact was the loss of employment. This had multiple impacts on other capacity domains including biographical, financial, psychological and work realisation, and could affect motivation for, and adherence to, self-management of other health conditions [21,39].

The loss of capacity associated with functional and psychosocial conditions indicates the need for targeted treatment to bolster capacity. However, for many participants, treatment work was focussed on conditions with few symptoms (e.g. diabetes), with limited formal treatment for their chronic pain or depression. In an ideal world, per the Cumulative Complexity Model, successfully managing treatment work should reduce illness burden and increase capacity, thus making it easier to normalise health conditions. In this population, effectively managing treatment work often had little impact on capacity, since loss of capacity was related to conditions which had few treatment demands. Without observed capacity benefits, this may discourage people from engaging in treatment work [44]. Although the Cumulative Complexity Model and the associated burden and capacity frameworks fitted the data well, the issue of mismatch between treatment burden and capacity deficits has not been previously noted. This may be an important factor in multimorbidity self-management which deserves further attention.

While some participants had structured management approaches for their pain or mental health conditions, this was often developed without HCP input. Others did not see such conditions as having a treatment pathway at all, but just as symptoms to endure. However, these conditions are often responsive to generic interventions such as exercise or mindfulness, which means that their management need not increase treatment work: the use of synergistic treatments which work across a range of health conditions has been recommended for multimorbidity [10,19,22]. The challenge may lie in convincing patients of treatment efficacy. Despite its known efficacy for chronic pain and depression [45], many participants believed that exercise was contra-indicated, or did not know how to approach it. This may be an important but neglected role for HCPs working in chronic disease management. Providing education about the relationships between pain, mental health and other chronic conditions, as well as synergistic treatments such as exercise and mindfulness could be helpful, although a low HCP knowledge base in these areas [46,47] and insufficient funding of non-pharmacological interventions (noted by several participants) remains a barrier.

The role of mental health in treatment adherence makes it a particularly important area to be formally addressed in the chronic disease management environment. For all participants, their mental health was closely entwined with, and responsive to, their physical and financial capacity. Unfortunately, as a relic of dualism, mental health conditions are often dealt with and funded in isolation from other chronic diseases, and many mental health providers have limited knowledge of physical health conditions and limitations. This study emphasises the importance of ensuring that mental health interventions are integrated and tailored to people with co-existing physical health conditions, thus reflecting the reality of people's experience as unified beings, not as minds and bodies.

### Interactions and integration

The increase in treatment tasks and HCP interactions as a result of multimorbidity is widely recognised, and has led to the development of treatment burden assessment tools [26,48,49].



There has been less attention paid to the importance of coherence and appraisal, which emerged as important in this study. Participants frequently engaged in coherence and appraisal work to help them understand and manage the interactions between capacities, conditions and treatments. Psychological, physical and social capacities were inextricably linked, and although stand-alone mental health treatment was important for some people, understanding the connections between, and integrating all three aspects of well-being was the key for those who were managing well.

In terms of individual conditions, people struggled more to make sense of conditions with functional impairment, but this may have been related to the lack of HCP input for these conditions. People reported a greater knowledge of diabetes, with most having received education, but few understood how it interacted with other conditions. Those who saw the linkages between their conditions had a more integrated understanding of their health overall and reported greater confidence in self-management and lower perceived burden.

Although study participants regularly engaged in appraisal, reviewing, prioritising and adjusting their treatments, HCP input into these decisions was limited. Many participants considered that 'juggling' their different conditions was up to them and that the HCPs' role was to provide instruction or treatment on specific individual conditions. An important role for HCPs, which would potentially increase treatment adherence and complement the provision of 'synergistic' treatment interventions, might be to help patients explore the linkages between conditions [20,22]. Making treatment decisions based on a good understanding of how different conditions interact and affect capacity and workload is likely to be useful for both the patient and the HCP.

### Limitations and strengths

This was a small qualitative study of a low-income rural population, and therefore the observations may be less relevant to more advantaged urban groups or in countries with greater levels of social medicine than Australia. The fact that two interviews were conducted by phone (due to Covid-19) could be considered a limitation, although no difference was noted in the interview length or topics covered. The findings remain useful because the research participants came from the most relevant population, as distilled from the literature [4]. Multimorbidity in younger (pre-retirement) age groups is becoming more common especially amongst low-income populations, and there is a need to explore more effective self-management interventions for this group. Our phenomenological focus of prioritising individual experience meant that we could explore a wide and varied range of responses from people facing similar life challenges. The use of existing taxonomies, allowing us to explore different aspects of capacity and burden, was a further strength of this study.

### Conclusion

Our exploration of burden and capacity in this qualitative study confirmed the importance of understanding multimorbidity in its broadest sense. Multimorbidity consists of far more than a list of diagnoses, and to manage multimorbid chronic conditions effectively, HCPs must address the crucial and interacting role of functional and psychosocial factors. Additionally, understanding the links between conditions is important to help patients to integrate and normalise their conditions into their daily life. Patients need support from HCPs to build bridges between conditions and make choices that best fit their needs and preferences. Finally, this study also highlighted the overwhelmingly negative effect of financial insecurity on burden and capacity. Financial hardship associated with chronic illness is well-known [50]. The

additional impact experienced by those who are already disadvantaged underlines the importance of health and social policies to address the challenges faced by this population.

### Supporting information

**S1 File. COREQ checklist.**  
(PDF)

**S2 File. Interview protocol.**  
(DOCX)

**S3 File. Burden and capacity coding.**  
(DOCX)

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**Appendix F: Chapter 5 Supplementary files**

- a. Patient interview protocol (also used in chapter 6)
- b. COREQ checklist

### **Client Interview Protocol**

**Prior to commencement of interview, review the participant information and consent form, reiterate information and ensure participant understands by asking them to state their understanding of the study.**

A lot of people today have chronic health conditions that require ongoing treatment and self-care. Many people report that looking after their health can become a full-time job in itself. We are interested in finding out how people manage the workload associated with their health and the things that make it harder or easier for them to do this.

First we will complete a survey to find out about your health conditions, the demands they place on your life, and the resources (such as financial and social supports) that you have currently. Then I will be interviewing you to find out more about how you manage your health and what the challenges are for you. I will be recording the interview, so I can remember all that you have said.

We hope that this research will enable us to teach health professionals how to better support people with chronic health conditions and reduce their workload. Everything you say in this session will be confidential and no identifying features (such as your name) will be used in this research. If at any time you want to stop, or have a break, please feel free to let me know.

### **Age in years**

### **Gender**

### **Employment status**

- ☐ Employed      Full or part time?      Occupation:.....
- ☐ On government benefit
- ☐ Age pension
  - ☐ Disability pension
  - ☐ Newstart (due/not due to health)
  - ☐ Single parent pension
  - ☐ Other
- ☐ Home duties
- ☐ Student
- ☐ Self-funded retiree
- ☐ Other:.....

### **Social status**

Who lives in your house?

- ☐ Live alone
- ☐ Partner/spouse
- ☐ Children      Number and ages
- ☐ Other (family, friends, housemates) Who and how many:

### **Surveys: completed independently by the participant or read aloud as preferred.**

1. Multimorbidity Treatment Burden Questionnaire
2. Disease Burden Impact Scale
3. Adapted Illness Intrusiveness Scale
4. DiP-Care Q

**Interview questions:**

**1. Can you describe to me what your different health problems are?**

**2. Thinking about these different conditions, can you tell me how they affect the rest of your life?**

How do they affect:

- Things at home
  - Household chores
  - Basic personal care such as washing, dressing, eating, sleeping
  - Relationships with family members including any caring responsibilities
  - Other home-based activities like gardening or hobbies
- Things outside the home
  - Socialising with family or friends
  - Hobby leisure or sporting activities
  - Ability to work, study, volunteer.

What are the costs associated with your health conditions?

- Financial costs (appointment fees, medications, other treatments)
- Time costs (travelling, appointments and organising appointments, time to do things like exercise, dietary prep, other treatments etc.)

Of your different health conditions, is there one that is a 'stand-out', that you rate as the most important condition? Why this condition?

**3. Next: I would like you to think about the things you do to manage your health problems and the treatments you need to undertake.**

Have you needed to:

- Educate yourself about your health conditions - what they are and how to manage them?
  - How have you learned to do this? From health providers; family/friends; the internet; community support groups?
- Attend appointments?
  - Who, where, how much/often?
- Take medications?
  - How often, how much?
- Monitor your symptoms? (e.g. blood pressure, blood sugar, monitor pain/fatigue levels?)
  - Do you need to do this regularly (how often) or occasionally? Who has taught you or helped you with this?
- Alter your lifestyle – changes in diet, exercise or activity?
  - What do you need to do differently in each of these areas? Who has taught you or helped you with this?
- Deal with your feelings and emotions about your health?
  - How have your health problems affected your mood or changed how you see yourself? What do you do to help you deal with these feelings? Has anyone helped you with this?

Of your different health conditions, is there one that is a 'stand-out' in terms of needing more management/having a greater treatment workload? Why this condition?

When thinking about your different health conditions, which areas do you think that you are able to take care of yourself and which areas do you think that health professionals need to do or to help you with?

**4. Now I would like you to think about the difficulties you face when caring for your health.**

Have you had or are you having any difficulty with:

- Educating yourself or finding out about your health problems?
  - Why?
  - Probes if needed: don't know where to look/what information is safe, health professionals not helpful, literacy/difficulty understanding; mental issues (depression/motivation)
- Attending appointments
  - Why?
  - Probes if needed: time, forgetfulness, transport issues, cost, not sure of benefit, physical issues (pain, fatigue), mental issues (depression/motivation), lack of support?
- Sticking to your medication regime?
  - Why?
  - Probes if needed: forgetfulness, cost, side-effects, worries about benefit; not sure what to do?
- Monitoring your symptoms – e.g. keeping track of symptoms, blood sugar levels etc?
  - Why?
  - Probes if needed: time, forgetfulness, not sure of benefit, physical issues (pain, fatigue), mental issues (depression/motivation), lack of support?
- Following diet/exercise/activity recommendations
  - Why?
  - Probes if needed: time, cost, physical issues (pain, fatigue), mental issues (depression/motivation), worries about benefit, not sure what to do, lack of support?
- Managing your feelings and emotions in relation to your health?
  - Why?
  - Probes if needed: lack of support from family/friends/health professionals, other mental health issues, other life demands making it difficult?

**5. Thinking overall about how you look after your health...:**

- Do you find that sometimes you make a choice between doing the things you need to do to care for your health, and other life priorities?
  - Why? Can you give some examples of this?
- Do you think generally that having more than one health condition makes managing your health more difficult?
  - In what way is it more difficult?
- Is there anything that you think would make it easier for you to take care of your health?
  - How would this thing (or things) help you to manage your health?
  - If you are having difficulty identifying anything, think about the previous things that made it difficult.

**6. Finally I want to ask about the other people involved in your healthcare.**

- Health professionals:
  - Who is involved, what do they do?
  - Have they been helpful or unhelpful? Any difficulties in dealing with them?

- Are there things that could be improved?
- Family:
  - Who is involved, what do they do?
  - Have they been helpful or unhelpful? Any difficulties in dealing with them?
  - Are there things that could be improved?
- Friends:
  - Who is involved, what do they do?
  - Have they been helpful or unhelpful? Any difficulties in dealing with them?
  - Are there things that could be improved?
- Government services e.g. NDIS, Centrelink, social support services like MFC
  - Who is involved, what do they do?
  - Have they been helpful or unhelpful? Any difficulties in dealing with them?
  - Are there things that could be improved?
- Community services e.g. support groups (local or online), exercise or social groups
  - Who is involved, what do they do?
  - Have they been helpful or unhelpful? Any difficulties in dealing with them?
  - Are there things that could be improved?

## **7. End of interview**

Is there anything else you would like to mention about your healthcare that hasn't been covered? Thank the participant and reiterate that all they have discussed is confidential.

### COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	8
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	N/A
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	N/A
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	7
Sample size	12	How many participants were in the study?	11
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	11
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	11
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	11/12
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	8**, S2
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	8
Field notes	20	Were field notes made during and/or after the inter view or focus group?	8
Duration	21	What was the duration of the inter views or focus group?	11
Data saturation	22	Was data saturation discussed?	8
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	8/9
Description of the coding tree	25	Did authors provide a description of the coding tree?	9/10, S3
Derivation of themes	26	Were themes identified in advance or derived from the data?	8-10
Software	27	What software, if applicable, was used to manage the data?	8/9
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	13-23
Data and findings consistent	30	Was there consistency between the data presented and the findings?	13-23
Clarity of major themes	31	Were major themes clearly presented in the findings?	13-23
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	13-23

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**



**Appendix G: Chapter 6 Publication**



Original Research Article



# Self-efficacy in disadvantaged communities: Perspectives of healthcare providers and clients

Chronic Illness

1–14

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and Evellen Spelten<sup>1</sup>

## Abstract

**Objective:** Most chronic disease self-management interventions emphasise the integral role of self-efficacy in achieving behaviour change. We explored the applicability of this model in a low-income setting, from the perspective of both patients and clinicians.

**Methods:** Interviews with multimorbid patients and their health providers at two rural community health centres in Victoria, Australia. We used a phenomenological methodology, exploring themes of confidence to manage health, outcome expectations and goals.

**Results:** Many assumptions in which the self-efficacy model is grounded did not apply to this population. Past experiences and resource constraints, especially poverty and healthcare access, influenced confidence, expectations and the ability to achieve desired outcomes.

**Discussion:** The focus of traditional self-management support on individual behaviour change disadvantages rural low-income patients, who face barriers related to life experience and resource constraints. For this group, self-management support needs to return to its roots, moving away from a narrow conception of behaviour change and reinstating the role of 'support' into 'self-management support' interventions. Health providers working in rural low-income settings should recognise the limits inherent in self-efficacy focussed interventions and think broadly about engaging with their clients in whatever way supports them to find a life with meaning and purpose.

## Keywords

self-management, self-efficacy, chronic disease, rural, low income

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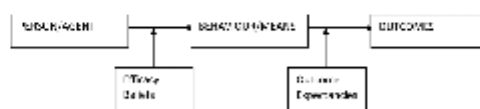
## Introduction

Chronic health conditions (CHCs) such as diabetes, arthritis, cardiovascular disease and depression are common and frequently comorbid. Effective management of these conditions requires long-term commitment to treatment adherence and lifestyle modifications, and thus is often reliant on the quality of an individual's self-management skills.<sup>1,2</sup> Self-management encompasses everything that a person with a CHC needs to do to manage their condition(s) and its impact, including condition management (appointments, treatment adherence, lifestyle changes) and adjustment to changes in life roles, emotions and social relationships.<sup>1,2</sup> To assist in this process, self-management support (SMS) interventions have been developed to help people learn about their CHCs and use generic skills such as problem solving, decision making and resource utilisation to take control of their conditions, optimise health and create a purposeful life.<sup>1,3,4</sup>

SMS interventions, whether individual, group, peer or professional-led, are usually grounded in Bandura's theory of self-efficacy<sup>1-4</sup> defined as confidence in one's ability to perform actions required to produce a given outcome.<sup>5</sup> Knowledge of a CHC and its treatment must be supplemented with adequate self-efficacy for behaviour change to occur. This should in turn lead to better control over the condition(s) and reduce their impact on peoples' lives. Most providers of SMS embed self-efficacy enhancing techniques such as performance mastery, symptom interpretation and modelling into the knowledge and skills training they provide.<sup>1-3</sup>

Although SMS interventions are consistently associated with increased self-efficacy, this has not necessarily translated into improved clinical and behavioural outcomes.<sup>2,3,6</sup> A common criticism is that positive findings are often limited to a narrow patient cohort, usually socioeconomically advantaged volunteers,<sup>3,7</sup> with lower participation and higher attrition rates seen in lower socioeconomic status (SES) groups.<sup>8</sup> Whether these positive outcomes, and the proposed behaviour change processes driving them, are relevant in other contexts has been questioned. The behaviour change pathway described by Bandura (see Figure 1)<sup>5</sup> has several components: in addition to self-efficacy, there must be a sense of individual agency; a belief that self-management actions will lead to beneficial outcomes (outcome expectations); and outcomes (goals, priorities) that are agreed between patients and health providers and relate to improved health or function.<sup>5</sup> The fact that most participants in SMS intervention research are volunteers means that they are already likely to have a sense of individual agency; a belief that their actions will achieve desired goals; and goals related to improved health. Self-efficacy is the missing link, but this may differ in low SES settings.

Low SES groups are known to have both lower baseline self-efficacy,<sup>9,10</sup> more negative outcome expectations,<sup>9,11,12</sup> and priorities that differ from higher SES groups.<sup>9,11</sup> Explanations for these findings include fewer experiences of control in peoples' daily lives,<sup>9,13</sup> limited exposure to modelling of self-efficacy, greater vicarious experiences of poor health outcomes<sup>11-13</sup> lower education levels, greater practical or resource barriers to achieving desired outcomes<sup>14</sup>



**Figure 1.** Adapted from Bandura's description of the relationship between self-efficacy and outcome expectations<sup>5, 16</sup> and Skinner's taxonomy of control terminology<sup>16</sup>.

and fewer social supports.<sup>6,11</sup> If the components of the behaviour change pathway (Figure 1) are operating differently in low SES settings, this may explain why self-efficacy approaches are more effective in higher SES groups.<sup>10,15</sup> We wished to investigate this further in the current study.

This study is part of a wider qualitative project exploring the challenges of chronic disease self-management (CDSM) in rural low-income settings. Rural populations experience limited healthcare access in addition to high levels of social disadvantage and disease burden.<sup>16</sup> Using the same interview data, we have explored three key barriers to self-management: health providers and systems;<sup>17</sup> health demands (multimorbidity); and (in this study) self-efficacy. The new element to this research is that we are investigating the relationship between self-efficacy, SMS and social disadvantage from the perspective of Bandura's pathway between person and outcomes (see Figure 1). By basing our analysis on the theory that most commonly informs SMS interventions, we hope to clarify or identify the different approaches needed for SMS in this context. Therefore, our research question is: What is the place of self-efficacy in self-management interventions for low-income rural populations?

## Methods

### Overall study design

The study design was qualitative. We first interviewed thirteen people living with multimorbidity, using a phenomenological methodology, then undertook a pragmatic study with twelve healthcare providers (HCPs). Sample size was determined by data saturation. Research was conducted in accordance with national ethics guidelines, and approval was granted by the La Trobe University Human Research Ethics Committee (HEC19387; HEC19363). The completed COREQ checklist for qualitative studies is available in Appendix A.

### Participant recruitment and setting

Participants were recipients or providers of chronic disease SMS services in two community health centres in Victoria, Australia. Community health centres provide primary care services, including chronic disease SMS, for low-income and socially disadvantaged populations. The health centres were based in towns with 118,000/56,000 inhabitants, 150 km/540 km away from the state capital and servicing the surrounding regions.

Client participants met study inclusion if they were aged between 18–75 years, with at least two chronic health conditions and in receipt of government income support or a healthcare card (signifying low income). Clients were recruited directly by their HCPs or via posters displayed in the health centre waiting areas, directing them to discuss the study with their HCPs if they wished to participate. HCP participants were all nurses and allied health professionals who worked in chronic disease management and who described SMS as an integral part of their job. We did not include GPs (physicians) since our focus was on clinicians who exclusively provided chronic disease SMS. Potential HCP participants were identified via the community health employee database, then emailed directly with information about the study and invited to participate. Selection was purposive to ensure a range of disciplines and years of experience.

### Data collection

Following completion of informed consent and collection of sociodemographic variables, we conducted individual semi-structured interviews from December 2019 to June 2020. Clients were asked to describe their health conditions, the healthcare tasks they needed to undertake and difficulties or barriers they encountered. Healthcare professionals were presented with two vignettes which had been modelled on the patient participants, and asked to reflect on self-management capacity,

treatment burden and perceived barriers to self-management. The interview protocols, which are available in Appendices B and C, were trialled and modified in response to feedback. Interviews were conducted by RH and SB and continued until all authors agreed that saturation had been reached. Six HCP interviewees were known to RH, who worked at one health centre, but none had a supervisory or subordinate relationship with her. Interviews were audio recorded, transcribed verbatim by RH and imported into NVivo 12. Field notes detailing key issues and observations were made following each interview.

### Data analysis

Following importation of the interviews and field notes into the NVivo12 programme, all authors read through the data independently several times. We undertook a deductive approach to our thematic analysis, using self-efficacy theory as our guide. During data familiarisation, we used NVivo coding stripes to highlight text related to self-efficacy, such as confidence in undertaking self-management tasks; reported psychological/cognitive barriers to self-management; references to outcome expectations; descriptions of goals, priorities, expected outcomes and future hopes.

After data familiarisation and group discussion, we decided to use the behaviour change pathway described in Figure 1 as an initial coding structure. We used Skinner's<sup>18</sup> headings of: Agency (the individual person); Agent-means (the connection between the person and their actions, including self-efficacy); Means-outcomes (connection between actions and outcomes) and Outcomes (goals) as the four main coding categories in nVivo12. Data coding into these categories was first undertaken by RH, then reviewed and revised by ES and SB. Following initial data categorisation, we used an iterative approach, triangulating between interview data, discussion amongst the authors, review of the literature, then back to the data. This evolved into a shared

understanding of the important themes and sub-themes.

## Results

### Participant and interview characteristics

We conducted eleven interviews with thirteen community health clients (two interviews were with couples who both had multiple CHCs). Two interviews were by phone due to COVID-19 restrictions and all others were conducted face-to-face in a community health centre interview room. Interview duration ranged from 31–71 min (mean 43 min). Twelve health providers were interviewed, all by phone or video link (determined by individual preference and technology capacity) due to the COVID-19 pandemic. Interview duration ranged from 38 to 60 min (mean 45'). Tables 1 and 2 record key participant characteristics.

### Main themes

As described earlier, our initial coding categories were informed by self-efficacy theory.<sup>5,18</sup> These categories: agency; agent-means; means-outcomes; and outcomes, fitted the interview data well.

### Agency

Self-management and self-efficacy are premised on a concept of the 'self'.<sup>6</sup> This theme explored ownership and responsibility for self-management tasks and healthcare generally.

Both clients and HCPs discussed the need for acceptance of CHCs as a prerequisite for taking action. ... *There's no good whinging about it or carrying on it's just the way it is I've got a heart problem...* (Client 5)

Some clients described the transition from denial to 'facing up' to their CHCs. HCPs discussed how fear, mental health, cultural and health system barriers could lead to denial.

...*he may be in denial that he has diabetes and that he has got other health issues... but he doesn't want to change anything...* (HCP 4)



Table 1. Characteristics of client participants.

ID	Sex	Age	Living situation	Source of income	Health conditions (as reported using the Disease Burden Impact Scale).
P1	M	57	With friend	Unemployment payment <sup>1</sup>	Back pain, osteoarthritis (OA), other chronic pain, depression, PTSD, liver disease, vision problems.
P2	F	50	Spouse and child	Unemployment payment <sup>1</sup>	Type 2 diabetes (T2DM), back pain, other chronic pain, obesity, depression, gut problems, bowel problems, vision, hypertension (HT)
P3	M	72	Spouse (P4)	Age pension <sup>3</sup>	Rheumatoid arthritis, OA, HT, back pain, cardiovascular disease (CVD), gut, vision, overweight
P4	F	71	Spouse (P3)	Age pension <sup>3</sup>	Rheumatoid arthritis, OA, T2DM, back pain, overweight, gut, bowel, asthma
P5	M	70	Spouse	Age pension <sup>3</sup>	CVD, HT, T2DM, OA, peripheral vascular disease (PVD), vision, hearing, kidney disease
P6	M	54	Alone	Unemployment payment <sup>1</sup>	T2DM, OA, HT, PVD, back pain, other chronic pain, overweight, vision, depression, thyroid.
P7	M	65	Spouse, other family	Part time work <sup>2</sup>	T2DM, HT, back pain, other chronic pain, gut, depression/anxiety, sleep apnoea, obesity, hearing
P8	M	59	Alone	Unemployment payment <sup>1</sup>	T2DM, OA, PVD, overweight, depression/anxiety, back pain, other chronic pain.
P9	F	57	Children	Disability pension <sup>3</sup>	T2DM, OA, HT, back pain, gut, COPD, asthma, depression/anxiety, incontinence.
P10	F	66	Spouse (P11)	Part time work <sup>2</sup>	OA, asthma, depression/anxiety
P11	M	68	Spouse (P10)	Age pension <sup>3</sup>	CVD, HT, T2DM, PVD, hearing, cancer, gut, asthma, depression/anxiety, COPD, chronic back pain, other chronic pain
P12	F	47	Other family	Carer pension <sup>3</sup>	T2DM, HT, OA, other chronic pain, back pain, kidney disease, liver disease, cancer, obesity, gut, bowel.
P13	F	60	Alone	Disability pension <sup>3</sup>	Diabetes, osteoarthritis, hypertension, back pain, other chronic pain, obesity, COPD, gut, lymphoedema, sleep apnoea

Income categories: 1 = Income  $\approx$  A\$ 15,000 p/a—below poverty line; 2 = Income  $\approx$  A\$ 22,000 p/a—equivalent to Australian poverty line; 3 = unskilled occupation, < 20hr/week, supplemented by Income support payment.

Most clients endorsed a sense of responsibility for their healthcare, even if they recognised that they were not managing it well. Some expressed a strong sense of ownership, describing self-management tasks as something they did for their own benefit – ‘for me’,

... I'm losing weight I'm monitoring my blood and I'm actually doing that as something for myself... (Client 13)

whilst others viewed these tasks as things required by HCPs and done ‘for them’.

...I've made a lot of changes but it's still not enough for what they want...it's very rare I get

it [blood sugar] as low as they want - they want it under 7... (Client 8).

The ‘me-them’ distinction was echoed by HCPs when describing the contrast between people who self-referred for SMS and those who had been referred by their GP.

...the client turns up and they are not exactly sure why they are here they say I don't know my doctor sent me here ... (HCP 2)

The self-referred clients had usually done so because they wished to improve their health (‘for me’), but the latter group often had little idea of self-management and (apart from

Table 2. Characteristics of HCP participants.

	Number/range	%/Mean (SD)
Female gender	12	100
Age in years	24–56	41 (12.3)
Profession		
Nurse	2	16.7
Diabetes educator	4	33.3
Occupational therapist	3	25
Physiotherapist	1	8.3
Exercise Physiologist	1	8.3
Podiatrist	1	8.3
Years since graduation	1–34	14.9 (10.8)
Years worked in chronic disease SMS	1–18	9 (5.2)
Number reported postgraduate training in SMS	7	58

medication prescription) rarely discussed their condition with their doctor.

*...I would want to look at what her goals are - she has presented to me - has that been self-motivated or was it directed for her... (HCP 9)*

All participants were asked to reflect on the division of labour between clients and HCPs. Some clients retained a highly passive view and were looking for a 'fix',

*[In reference to visiting the GP] ... if she couldn't say I know how to fix it she would know where to send you... (Client 7)*

but most agreed that engagement with self-management was needed. For the majority, their responsibility was limited to following (or trying to follow) the instructions of their HCPs (compliance), with some reports of shared decision-making over how best to integrate self-management tasks into their life.

*... our GP did uni for so many years to do all this sort of thing...I trust him what he says...as far as anything medical goes that's the professionals job not Mr Google... (Client 3)*

A few clients reported that they made decisions about their health without seeking HCP input. Sometimes this was a choice based on knowledge of their CHC, but it could also be driven by poor relationships with HCPs or lack of agreed goals.

*...when you've been treated the way we have [by doctors] you tend to shut them out*

*and try and do things yourself because you think well are they going to tell me the truth are they going to be honest... (Client 10)*

Some HCPs experienced frustration over passive clients who wanted to 'get something for free' from the service. Others emphasised the use of strategies such as motivational interviewing to promote a sense of agency. Most HCPs reported that increased complexity and resource constraints in rural low-income settings made this more difficult.

### Agent-means

This theme described peoples' ability and confidence to carry out self-management tasks, as well as HCP's understanding of self-efficacy and the methods they employed to enhance this.

Almost all HCPs considered that the development of self-efficacy was crucial for effective self-management, and described techniques such as building rapport, gauging confidence, client-directed goals, using feedback and grading tasks to promote performance mastery. HCPs stressed that a key feature of self-efficacy was having the confidence not just to undertake tasks, but to troubleshoot when circumstances changed or conditions were exacerbated.

*...a lot of people that we see ...pretty much hand their health over to the doctor so that when there are changes to [their] conditions [they]*

*don't have an understanding of what's important or how to put strategies in place to make sure that those conditions don't worsen... (HCP 11).*

They also discussed how lower education levels and higher life demands (e.g. caring responsibilities, financial constraints) in low-income populations influenced self-efficacy.

*...when you have low education too you often lack confidence...you perhaps feel less confidence that you can manage those things... (HCP 11)*

*... the specialists they talk about what's wrong...half the time you don't understand what they're saying and you're trying to google it to work it out... (Client 2)*

Practical ways of modifying SMS for these populations, such as addressing literacy, were discussed but there was also widespread recognition that building self-efficacy could only occur if the person's environment was sufficiently resourced.

Client accounts also highlighted the importance of problem-solving and adjusting to changing circumstances, not just performing treatment tasks. Those who were skilled at this had greater knowledge of their health conditions and long-term relationships with their HCPs.

*...one of my readings was 3.5 which is technically a hyper...I actually took myself off it [the insulin] which the doctor was right behind me with... (Client 13)*

About half the participants reported established self-management routines, and described how they had integrated this into their lives. This included making lifestyle changes and finding new ways to engage in preferred activities. These clients described themselves as mostly adherent rather than rigidly compliant, deviating at times from 'ideal' self-management according to their priorities.

*...we do eat a bit of stuff we're not supposed to eat ...oh god we're 71 for god's sake can't we have a chip now and then... but we're pretty good... (Client 4)*

Self-efficacy to exercise was an outlier, in that several people who were self-efficacious

in other areas reported low confidence in this area, usually related to chronic pain conditions.

The remaining clients were not confident to undertake self-management tasks. This included those who saw self-management as something required by HCPs rather than for their own benefit, as well as those who felt responsible for their self-management, but experienced mental health barriers.

*...I get depressed because things don't seem to happen quickly enough for me and I get upset that I can't do things so I don't eat I stop taking my meds... (Client 1)*

*[the diabetes educator said] you aren't doing many blood sugars... I said yes I should have been doing it but everything was getting on top of me... (Client 7)*

### Means-outcome

This theme explored the connections between specific actions or behaviours, including self-management tasks, and expected or desired outcomes.

Virtually all HCPs stressed the need to understand one's CHCs, to make sense of the connection between self-management behaviours (e.g. diet, medication adherence) and outcomes.

*...you get told what you should be doing for your own health but if you don't understand why then you are less likely to take those things on board... (HCP 8)*

Some clients also recognised that limited understanding of their CHC had contributed to condition exacerbation,

*...I [thought] well I take my medications I'll be fine until they told me that I had kidney problems...so I thought maybe I should find out more... (Client 12)*

and both groups agreed that poorly delivered healthcare information was often to blame. Most HCPs believed that greater knowledge would promote engagement in self-management by explicating the behaviour-outcome connection. Some clients also reported this, either because they had been



'scared' into action by the threat of negative outcomes

*...my blood sugar was at the point of massive organ failure and it freaked me out and that was like a little slap in the face... this is a reality check... (Client 13)*

or because they had seen their actions lead directly to positive outcomes. These views were espoused by those with higher levels of self-efficacy; in less confident clients, fear led to paralysis rather than action.

*...since I've known about this kidney disease I think oh my god when am I going to die... (Client 12)*

Participants also discussed negative expectations and uncertain health outcomes. Some clients viewed their conditions fatalistically, believing there was little they could do to change the situation or slow their decline.

*... it's just constant it won't change it's something I have to put up with... (Client 6)*

This was often related to wider social or environmental factors such as the experiences of family or friends (e.g. relatively early deaths), or loss of income resulting from their inability to work.

*...living those last 3 years before I turned 66 I was thinking oh my god I'm going to be just like her [my mother] I'm going to die of cancer... now I'm worried because I'm thinking maybe that's what's wrong... (Client 4)*

HCPs noted how disability and poor health was often considered a part of normal aging amongst their clients.

*...they tend to get used to the condition and used to how it impacts and then it is really hard to get back function ...so acceptance of disability... (HCP 7)*

In contrast to their advocacy of condition knowledge as a driver for self-management, HCPs also reflected on the reality that many CHCs do have uncertain outcomes despite good self-management, *...they're living with the underlying knowledge that this causes severe morbidity and mortality ...these are overwhelming issues... (HCP 10)*

or require significant effort to achieve only modest outcomes.

*... [does he] believe that with assistance he can slightly improve his quality of life without giving him the impression [he can] be completely pain-free... (HCP 6)*

Maintaining hope in these circumstances was a challenge, possibly for both HCPs and clients. Some clients maintained a phlegmatic outlook and for these individuals, social connections (including hobby clubs, peer support groups and time with grandchildren) were often of great importance. Having a degree of income security (i.e. receiving a pension) was a consistent feature for these individuals.

## Outcomes

The final theme explored the desired outcomes (goals, priorities) reported by each group, where they differed, and how they aligned with the agent-means-outcome pathway.

For most clients, looking after their health was a high priority. Some felt that they had integrated their health conditions into their lives while still retaining purpose and meaning, in line with the outcomes expected for successful self-management.

*...even though it's [our health is] ruling our lives we try not to let it rule our lives if that makes sense... (Client 3)*

For others, their CHCs had become incorporated into their lives, but had essentially taken over their lives:

*...I look after it [my health] as best I can ... it's a full-time job but [it] never goes away... (Client 6)*

and a third group were overwhelmed by their health conditions and managing poorly.

*... [taking medication] I just seem to miss a couple of days...I get too mixed up in everything else ...on one of my visits to hospital they put me in for 3 days and the girl from pharmacy came in and she was horrified because I had big gaps in it... (Client 7)*

Both clients and HCPs noted that caring responsibilities, employment and complex life

stresses (often interacting environmental and mental health factors) could detract from one's healthcare, and this was common in clients overwhelmed by their CHCs.

*...I have my family that are constantly needing help or ringing so I'm always trying to fix things for them and I just get put on the backburner... (Client 2).*

HCPs reported that in these situations, they focussed on addressing environmental factors rather than SMS, but resource constraints often limited their effectiveness.

Virtually all HCPs stressed the importance of identifying the goals and concerns of clients when engaging with SMS, with several also acknowledging that goals may differ between HCPs and clients. *... [I try to] ensure that the goals that the client has are very specific to themselves and is relevant for what they want to do so the client cares about it... (HCP 12)*

As expected, given their roles as providers of SMS for chronic health conditions, most HCPs focussed on health-related outcomes and linked these directly to self-management behaviours, for example, improving fitness (behaviour) to maintain independence and reduce pain (outcomes), modifying diet to stabilise diabetes and establishing routines to reduce treatment burden.

Client goals were often less specific, but still focussed on maintaining activity and independence, as well as spending time with friends or family. Several clients wanted to be employed in the future, but few believed this was likely. Although these goals appear amenable to SMS interventions, a different story emerged when clients talked about how they expected to achieve their goals. In contrast to the HCPs, who linked goal achievement to effective self-management, the pathways to clients' desired outcomes rarely prioritised self-management. Some clients were already self-managing effectively, but important goals remained out of reach, and could not be attained (at least in their view) via self-management, instead requiring some external

support. Of the thirteen interviewees, seven reported that lack of access to surgery or specialist medical services was the key barrier to achieving their goals. Those living more remotely (540 km from the state capital) reported greater difficulty accessing specialist appointments and additional transport and accommodation costs.

*...every time you've got to do something you've got to go away to Melbourne or Bendigo or Adelaide there's just not enough professionals here which is a pain... (Client 6)*

Access to social welfare services, and provision of aids, equipment and home care services (which were either unaffordable or had long waiting times) were also seen by several participants as the most effective way to increase independence and achieve their desired outcomes.

*... there's probably a lot more services out there than people realise you just don't know how to access them... (Client 5)*

*... I often ... think of having one person that can like I can call and say look this and that and then they can chase it up... (Client 1)*

*... we are registered with My Aged Care but you can't get the services...you're on the waiting list... (Client 12)*

Only two participants believed that working on self-management tasks with their HCP was the main pathway to their goals.

## Discussion

### Summary of findings

Our aim was to explore the place of self-efficacy in self-management interventions for low-income rural populations. We looked at how community health clients and their HCPs negotiated the behaviour change pathway from agent, via self-efficacy beliefs and outcome expectations, to outcome.

All HCPs, and most clients, recognised the initial importance of taking responsibility (owning) their CHCs. For most HCPs, building self-efficacy was an important focus for SMS. However, clients and HCPs both identified

psychological and environmental barriers to self-efficacy development, and some felt that positive outcome expectations were unrealistic given their life situation. For many clients, resource constraints formed barriers to their desired outcomes that could not be overcome by behaviour change. Both clients and HCPs felt that the task of building confidence (self-efficacy) and optimism (outcome expectations) was at times misplaced, given the past experiences and present realities faced by many clients. For this population, the concept of 'self-management support' needs revisiting, to emphasise 'support', rather than focussing only on 'self-management'.

### *Confidence, optimism and life experience*

In common with other studies, past experiences and current life demands were associated with lower self-efficacy.<sup>9,10</sup> People who have had limited success with education or employment, or have few healthy role-models will struggle more with self-efficacy boosting techniques such as performance mastery and vicarious learning.<sup>5</sup> Since social support is known to bolster self-efficacy, peer support may be especially important in this population,<sup>19</sup> given that there are likely to be greater cultural differences (therefore less opportunity for vicarious learning) between clients and their HCPs. Online peer support could provide a wider range of role models and maintain privacy (important in smaller rural communities), if barriers relating to technology literacy (common in low-income settings) and rural internet connectivity are addressed.

Lower outcome expectations have been observed previously in socioeconomically disadvantaged groups<sup>9,11</sup> and in this study, the influence of both rurality and income was clear. Negative expectations were commonly related to people's experience of additional losses in consequence of their health conditions, including loss of employment (for ten of the thirteen clients), housing, social and leisure pursuits. A history of manual work, lack of financial

cushioning and living in regions with few employment opportunities was common, thus the ability for participants to recoup their losses was limited. Experiences of early death or disability amongst family and friends appeared to influence future outlooks and this has also been reported elsewhere in similar contexts.<sup>11,12</sup> Unfortunately, such negative expectations also reflect the reality of health outcomes in rural low-income populations, who experience both poorer health and poorer healthcare.<sup>16</sup> HCPs recognised this tension between promoting positive expectations and the reality of uncertain health outcomes. Both groups stressed the importance of meaningful goals, to enable hope in the face of uncertainty.

### *Revisiting the meaning of 'self-management support'*

Other studies have reported discordance between HCPs and patients over expected outcomes from self-management, with HCPs focussed on compliance and healthcare utilisation and patients seeking improvements in quality of life.<sup>20,21</sup> In the current study, the two groups agreed over desired outcomes, with both prioritising increased control over CHCs and better quality of life. However, opinions differed over how these goals could be achieved. Whilst HCPs saw the solution in behaviour change, clients (even those who were self-managing well) identified external (resource) rather than individual (belief/behaviour) barriers to achieving desired outcomes, with income and rurality acting as resource constraints. This reiterates the importance of context and suggests that a broader conception of SMS is needed for this population.

Chronic disease self-management should encompass three aspects: medical management, role management and emotional management.<sup>1,22</sup> Most HCPs providing SMS focus on medical management: skill-building and behaviour change,<sup>20,23</sup> but the aspects of role and emotional management are critical in (re) creating a life with purpose and meaning.<sup>24</sup>



For many people, the process of developing confidence and learning self-management skills will facilitate and enable emotional and life role adjustment. For others, having insufficient income or transport may present a barrier to living a meaningful life that cannot be overcome by any amount of confidence or lifestyle change.<sup>25</sup> Therefore, HCPs working in these settings may need to view SMS more broadly, moving beyond traditional behaviour change interventions to explore other ways to support their clients and facilitate outcomes that provide purpose and hope.

This approach is not without its own set of challenges. Firstly, how to have this conversation. HCPs typically focus on a single condition at a time and may feel that exploring meaning and purpose is outside their discipline boundaries and comfort zone. Decision-making tools such as ICAN<sup>26</sup> or PPC<sup>27</sup> are potentially useful to initiate such discussions, if coupled with clear pathways to resources and supports. Second, the health system often dictates the HCP role (to provide health-focussed self-management 'education') and requires time-limited measurable outcomes which may not fit the client's needs and preferences. The mantra of 'patient centred care' rarely allows for interventions that are primarily social, environmental or involve advocacy, even though these factors may form the greatest barriers.<sup>28</sup> Community health centres, which often bring together social and health perspectives, may be best placed to take on this challenge.

### *Strengths and limitations*

The study focus on a multimorbid low-income population in rural Australia prevents generalisation to other settings. However, the need to analyse and modify self-management approaches in different contexts remains relevant, especially since the chronic disease burden is far higher in disadvantaged populations.

The strengths of this study lie in the consistency of the data obtained from both HCPs and their clients, who were based in the same rural

communities. By grounding the study in self-management and self-efficacy theory, we could explore these topics in terms of what they were originally designed to do and consider their fit in a different context.

Study limitations include the necessity of conducting some interviews by phone due to Covid-19 and the small sample size, although the same topics were canvassed in both interview settings and data saturation was achieved, with no new themes identified in later interviews. A further limitation is the lack of inclusion of GP interviewees. This was deliberate, since the focus was on HCPs whose primary role was provision of SMS. However, a GP perspective would have been useful especially since both HCPs and clients appeared to view them as relatively peripheral to the SMS landscape, possibly related to rural GP workforce scarcity.

### **Conclusion and practice implications**

As Kendall<sup>25</sup> has noted, privileging self-efficacy as the foundation for SMS puts the onus on the individual and ignores the social context that each of us inhabits. This disadvantages rural low-income populations, who face barriers related to life experience and resource constraints. HCPs working in these settings should redefine and rediscover self-management support, moving beyond a narrow conception of behaviour change to encompass whatever is needed to support a life with meaning. If we are to truly aspire to patient-centred care, we must take a much wider view on what gives people hope and purpose (and how to help them achieve it) whilst living with long-term conditions.

### **List of abbreviations**

CHC: chronic health condition; SES: socio-economic status; HCP: healthcare provider; SMS: self-management support; GP: general practitioner.

### Availability of data and materials

Restrictions have been placed on our dataset by the La Trobe University Human Ethics board. The decision was based on the fact that this was a qualitative study of a small rural sample, involving sensitive health information that was potentially identifiable. The data may be obtained through the corresponding author or the La Trobe University Human Ethics board who may be contacted via email: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) or phone +61 3 9479 1443. The approval reference numbers are HEC19387 and HEC19363.

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### Author Contributions

RH researched the literature and conceived the study. All authors were involved in protocol development, gaining ethical approval, patient recruitment and data analysis. RH and SB conducted the interviews. RH wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

### Declarations of Conflicting Interests

The Authors declare that there is no conflict of interest.

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### Informed consent

Written informed consent was obtained from all subjects before the study.

### Ethical approval

Ethical approval for this study was obtained from the La Trobe University Human Research Ethics Committee (HEC19363 and HEC19387).

### Guarantor

RH

### Contributorship

RH researched the literature and conceived the study. All authors were involved in protocol development, gaining ethical approval, patient recruitment and data analysis. RH and SB conducted the interviews. RH wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

### Declaration of conflicting interests


The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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### Trial registration

Not applicable, because this article does not contain any clinical trials.

### Supplemental material

Supplemental material for this article is available online.

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**Appendix H: Chapter 6 Supplementary files**

- a. COREQ checklist



### COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	N/A
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	1
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	appendix B/C
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5/6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5/6
Sample size	12	How many participants were in the study?	7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	table 1, p6
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	appendix B/C,
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	7
Software	27	What software, if applicable, was used to manage the data?	6
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	table 2
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

**Appendix I: Chapter 7 Supplementary files**

- a. Survey and consent form
- b. STROBE checklist

## Survey Participants Needed:

### Measuring capacity in chronic health conditions

Researchers at La Trobe University and Sunraysia Community Health Services are seeking volunteers to complete a short survey about how people cope with their chronic health conditions. This research will be used to help healthcare professionals to better support their clients.

### Who is the survey for?

The survey is for anyone who:

- Is over 18 years
- Has a chronic health condition (such as diabetes, arthritis, back pain, COPD, cardiovascular disease).

### How do I take part in the study?

If you are interested in participating, please:

- Read the attached participant information and consent form
- Complete the survey (approx. 15 minutes)
- Return it to us in the supplied reply-paid envelope.

The survey is anonymous – no personal details are recorded.

If you would like more information, please contact:

**Name:** Dr Evelien Spelten

**School/Department** La Trobe Rural Health School

**Email:** E.Spelten@latrobe.edu.au

**Phone:** 03 5051 4071

**Ethics Approval Number** HEC19517

## Participation Information and consent form

The research is being carried out in partial fulfilment of a PhD under the supervision of Dr Evelien Spelten and Dr Steve Begg. The following researchers will be conducting the study:

Role	Name	Organisation
Chief Investigator	Dr Evelien Spelten	LaTrobe University
Postgraduate Student	Ms Ruth Hardman	LaTrobe University/SCHS
Co-investigator	Dr Steve Begg	LaTrobe University
Co-investigator	Dr Kelly Naess	SCHS
Research funder	This research is supported by in-kind support by La Trobe University and SCHS	

### What is the study about?

You are invited to participate in a study that looks at how peoples' daily life demands, including work, family, health and finances, affects their ability to manage chronic health conditions. We hope to find out whether people who need extra support in managing their health can be more easily identified.

### Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study we ask that you read the information below carefully and ask us any questions.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

### Who is being asked to participate?

Anyone who has one or more chronic health conditions (e.g. arthritis, diabetes, chronic pain, heart or lung disease) that impact on their day-to-day life.

### What will I be asked to do?

If you want to take part in this study, we will ask you to complete a brief survey. It will take approximately 10-15 minutes of your time.

### What are the benefits?

There are no direct benefits to you in taking part in this study. The expected benefits to society in general is that by identifying people who might have difficulties managing their health, we can provide support earlier and prevent health decline.

### What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
Dr Evelien Spelten	Chief Investigator	03 5051 4071	E.Spelten@latrobe.edu.au

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

- Some people experience distress when thinking about the difficulties in managing their health.
- We don't expect any other risks associated with this study.

### What will happen to information about me?

We will **collect** information about you in ways that will not reveal who you are.

We will **store** information about you in ways that will not reveal who you are.

We will **publish** information about you in ways that will not be identified in any type of publication from this study.

We will **keep** your information for 7 years after the project is completed. After this time we will destroy all of your data.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy](https://policies.latrobe.edu.au/document/view.php?id=106/) <https://policies.latrobe.edu.au/document/view.php?id=106/>.

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic).

Subject to any exceptions in relevant laws, you have the right to access and correct your personal information by contacting the research team.

#### **Will I hear about the results of the study?**

The study results may be published in professional journals. We cannot let you know individually about the results of the study since we are not recording your contact details.

#### **What if I change my mind?**

If you no longer want to complete the questionnaire, don't return it to us. If you change your mind after sending in the survey, we cannot withdraw your responses because we cannot link who you are with your questionnaire responses.

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

#### **Who can I contact for questions or want more information?**

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Dr Evelien Spelten	Chief Investigator	03 5051 4071	E.Spelten@latrobe.edu.au

#### **What if I have a complaint?**

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC 19517	Senior Research Ethics Officer	+61 3 9479 1443	<a href="mailto:humanethics@latrobe.edu.au">humanethics@latrobe.edu.au</a>

#### **Consent Form – Declaration by Participant**

I (the participant) have read and understood the Participant Information Statement, and any questions have been answered to my satisfaction. I agree to participate in the study. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:

☐ Only used for this specific study.

**I agree, start questionnaire**

**This survey is designed to help us understand the challenges people face when living with chronic health conditions. First, we would like some general information about you and the health conditions you have.**

**Please check the box or fill in the blank as indicated.**

**Your age in years:** \_\_\_\_\_

**Your sex:**

- ☐ **Male**
- ☐ **Female**
- ☐ **Prefer not to say**

**Your employment status (tick all relevant boxes):**

- ☐ **Employed full-time**
- ☐ **Employed part-time**
- ☐ **Looking for work**
- ☐ **Not working due to health**
- ☐ **Home duties or full-time carer**
- ☐ **Retired**
- ☐ **Student**
- ☐ **Other:** \_\_\_\_\_

**Do you have any of the following conditions?(1)**

If yes, indicate how much each condition interferes with your daily activities by circling the number.

1 = no impact on daily activities; 5 = severe impact on daily activities

**Only tick the box if you have the condition.**

Do you have..	Amount of interference				
<input type="checkbox"/> Angina/heart disease	1	2	3	4	5
<input type="checkbox"/> High blood pressure	1	2	3	4	5
<input type="checkbox"/> High cholesterol	1	2	3	4	5
<input type="checkbox"/> Heart failure	1	2	3	4	5
<input type="checkbox"/> Poor circulation	1	2	3	4	5
<input type="checkbox"/> Back pain/sciatica	1	2	3	4	5
<input type="checkbox"/> Osteoarthritis	1	2	3	4	5
<input type="checkbox"/> Osteoporosis	1	2	3	4	5
<input type="checkbox"/> Rheumatoid arthritis	1	2	3	4	5
<input type="checkbox"/> Other pain problem	1	2	3	4	5
<input type="checkbox"/> Overweight	1	2	3	4	5
<input type="checkbox"/> Vision problem (apart from glasses)	1	2	3	4	5
<input type="checkbox"/> Hearing problem/deafness	1	2	3	4	5
<input type="checkbox"/> Diabetes	1	2	3	4	5
<input type="checkbox"/> Cancer (in last 5 years)	1	2	3	4	5
<input type="checkbox"/> Stroke	1	2	3	4	5
<input type="checkbox"/> Neurological condition (e.g. MS, Parkinsons, epilepsy)	1	2	3	4	5
<input type="checkbox"/> Gut problems (e.g. gastritis, reflux)	1	2	3	4	5
<input type="checkbox"/> Bowel problems (e.g. IBS, diverticulitis)	1	2	3	4	5
<input type="checkbox"/> Asthma	1	2	3	4	5
<input type="checkbox"/> Bronchitis /COPD	1	2	3	4	5
<input type="checkbox"/> Depression/anxiety	1	2	3	4	5
<input type="checkbox"/> Other mental health (eg Bipolar,PTSD)	1	2	3	4	5
<input type="checkbox"/> Thyroid problems	1	2	3	4	5
<input type="checkbox"/> Kidney disease	1	2	3	4	5
<input type="checkbox"/> Liver disease	1	2	3	4	5
<input type="checkbox"/> Other:	1	2	3	4	5
<input type="checkbox"/> Other:	1	2	3	4	5
<input type="checkbox"/> Other:	1	2	3	4	5





**The next four statements relate to the confidence you have in your ability to manage your health conditions. How strongly do you agree or disagree with the following? Tick the box that applies to you. (3)**

I succeed in the projects I undertake to manage my health conditions.

- ☐ Strongly agree
- ☐ Somewhat agree
- ☐ Neither agree or disagree
- ☐ Somewhat disagree
- ☐ Strongly disagree

Typically, my plans for managing my conditions don't work out well.

- ☐ Strongly agree
- ☐ Somewhat agree
- ☐ Neither agree or disagree
- ☐ Somewhat disagree
- ☐ Strongly disagree

No matter how hard I try, managing my health conditions doesn't turn out the way I would like.

- ☐ Strongly agree
- ☐ Somewhat agree
- ☐ Neither agree or disagree
- ☐ Somewhat disagree
- ☐ Strongly disagree

I'm generally able to accomplish my goals with respect to managing my health conditions.

- ☐ Strongly agree
- ☐ Somewhat agree
- ☐ Neither agree or disagree
- ☐ Somewhat disagree
- ☐ Strongly disagree



Many people report difficulty in following all the recommendations given by their healthcare providers. How often was each of the following statements true for you **over the past 4 weeks?**(5). Tick the box that applies to you.

**1. I had a hard time doing what my health providers suggested I do.**

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time.

**2. I followed my health providers instructions exactly.**

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time.

**3. I was unable to do what was necessary to follow my health providers' treatment plans.**

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time.

**4. I found it easy to do the things my health providers suggested I do.**

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time.

**5. Overall, how often were you able to do what your health providers told you to do?**

- ☐ None of the time
- ☐ A little of the time
- ☐ Some of the time
- ☐ A good bit of the time
- ☐ Most of the time
- ☐ All of the time.

Living with chronic conditions often leads to high levels of financial strain and social isolation. To better understand this, we would appreciate your answers to the following questions about your personal finances, social environment and general health. Please tick the box that applies to your situation.(6)

<b>During the last 12 months</b> , have you had trouble paying your household bills? (tax, insurance, phone, electricity, credit cards etc?)	<b>Yes</b>	<b>No</b>
<b>During the last 12 months</b> , have you had to ask your immediate family for money to cover your basic day-to-day needs?	<b>Yes</b>	<b>No</b>
<b>During the last 12 months</b> , has a member of your household not sought treatment (dentist, doctor, buying medication) because you didn't have enough money?	<b>Yes</b>	<b>No</b>
<b>During the last 12 months</b> , have you feared being evicted from or losing your home?	<b>Yes</b>	<b>No</b>
<b>During the last 12 months</b> , have you not bought clothes even though you or a member of your household needed them?	<b>Yes</b>	<b>No</b>
<b>During the last 12 months</b> , have you not bought furniture or household goods even though you or a member of your household needed them?	<b>Yes</b>	<b>No</b>
<b>During the last 12 months</b> , have you gone on holiday?	<b>Yes</b>	<b>No</b>
<b>During the last 3 months</b> , have you spent an evening in the company of close family members or friends?	<b>Yes</b>	<b>No</b>
<b>During the last 3 months</b> , have you been to the cinema, theatre, a concert or a sports event?	<b>Yes</b>	<b>No</b>
<b>During the last month</b> , has there been an occasion when your household did not have enough to eat?	<b>Yes</b>	<b>No</b>
<b>During the last month</b> , have you been able to access the internet (at home, work, at a library, internet café etc)?	<b>Yes</b>	<b>No</b>
If you're in difficulty, is there someone <b>outside your household</b> to whom you can turn for material help (money, food accommodation)?	<b>Yes</b>	<b>No</b>
<b>Are you currently</b> finding it very difficult to pay back money (to the bank, family etc)?	<b>Yes</b>	<b>No</b>
<b>Do you currently</b> suffer from a physical disability that has a major impact on your day-to-day life?	<b>Yes</b>	<b>No</b>
<b>Do you currently</b> suffer from mental health issues or problems that have a major impact on your day-to-day life?	<b>Yes</b>	<b>No</b>
<b>Do you currently</b> have problems linked to alcohol consumption, drug-taking, gambling etc.?	<b>Yes</b>	<b>No</b>
Deprivation in Primary Care Questionnaire: Vaucher P, Bischoff T, Diserens EA, Herzig L, Meystre-Agustoni G, Panese F, Favrat B, Sass C, Bodenmann P. Detecting and measuring deprivation in primary care: development, reliability and validity of a self-reported questionnaire: the DiPCare-Q. BMJ Open. 2012 Feb 3;2(1):e000692.		

**EQ-5D quality of life questions(7)**

Under each heading, please tick the ONE box that best describes your health TODAY.

**MOBILITY**

- I have no problems with walking around ☐
- I have slight problems with walking around ☐
- I have moderate problems with walking around ☐
- I have severe problems with walking around ☐
- I am unable to walk around ☐

**PERSONAL CARE**

- I have no problems with washing or dressing myself ☐
- I have slight problems with washing or dressing myself ☐
- I have moderate problems with washing or dressing myself ☐
- I have severe problems with washing or dressing myself ☐
- I am unable to wash or dress myself ☐

**USUAL ACTIVITIES** (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities ☐
- I have slight problems doing my usual activities ☐
- I have moderate problems doing my usual activities ☐
- I have severe problems doing my usual activities ☐
- I am unable to do my usual activities ☐

**PAIN / DISCOMFORT**

- I have no pain or discomfort ☐
- I have slight pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have severe pain or discomfort ☐
- I have extreme pain or discomfort ☐

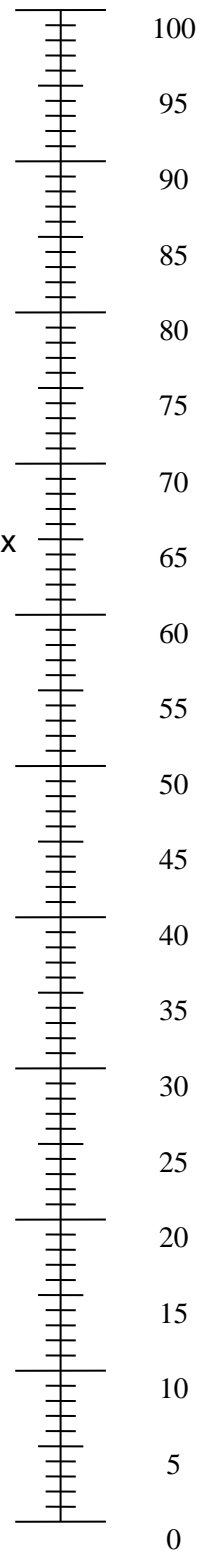
**ANXIETY / DEPRESSION**

- I am not anxious or depressed ☐
- I am slightly anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am severely anxious or depressed ☐
- I am extremely anxious or depressed ☐

The best health you  
can imagine

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.  
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =



The worst health  
you can imagine

**Thank you for completing the survey.**

Please return it to SCHS in the envelope provided.

### Information about support services

Some people experience distress after thinking about their health and associated difficulties in managing it. If this is the case for you, please seek support from family members, trusted friends, your GP or other mental health support services you have used in the past.

The following 24-hour phone services can also provide support:

Lifeline: 13 11 14

Nurse-On-Call: 1300 60 60 24

### References

1. Bayliss EA, Ellis JL, Steiner JF. Subjective assessments of comorbidity correlate with quality of life health outcomes: Initial validation of a comorbidity assessment instrument. *Health and Quality of Life Outcomes*. 2005;3(1):51.
2. Devins GM. Using the illness intrusiveness ratings scale to understand health-related quality of life in chronic disease. *J Psychosom Res*. 2010;68(6):591-602.
3. Wild MG, Ostini R, Harrington M, Cavanaugh KL, Wallston KA. Validation of the shortened Perceived Medical Condition Self-Management Scale in patients with chronic disease. *Psychol Assess*. 2018;30(10):1300-7.
4. Duncan P, Murphy M, Man MS, Chaplin K, Gaunt D, Salisbury C. Development and validation of the Multimorbidity Treatment Burden Questionnaire (MTBQ). *BMJ Open*. 2018;8(4):e019413.
5. Kravitz RL, Hays RD, Sherbourne CD, DiMatteo R, Rogers WH, Ordway L, et al. Recall of Recommendations and Adherence to Advice Among Patients With Chronic Medical Conditions. *Arch Intern Med*. 1993;153:1869-78.
6. Vaucher P, Bischoff T, Diserens EA, Herzig L, Meystre-Agustoni G, Panese F, et al. Detecting and measuring deprivation in primary care: development, reliability and validity of a self-reported questionnaire: the DiPCare-Q. *BMJ Open*. 2012;2(1):e000692.
7. Herdman M, Gudex C, Lloyd A, Janssen MF, Kind P, Parkin D, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation - Official Journal of the International Society of Quality of Life Research*. 2011;20(10):1727-36.





**STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies***

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	6
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-7
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	6-7
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7-9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	7-9
Bias	9	Describe any efforts to address potential sources of bias	11,15,19
Study size	10	Explain how the study size was arrived at	10
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9-10
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	10-16
		(b) Describe any methods used to examine subgroups and interactions	N/A
		(c) Explain how missing data were addressed	15

		(d) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(e) Describe any sensitivity analyses	N/A
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7,10
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10-12
		(b) Indicate number of participants with missing data for each variable of interest	12
Outcome data	15*	Report numbers of outcome events or summary measures	N/A
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	15-16
		(b) Report category boundaries when continuous variables were categorized	7,11,12
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	15-16
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	17-18
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17-18
Generalisability	21	Discuss the generalisability (external validity) of the study results	19
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	20-21

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

**Appendix J: Chapter 8 Supplementary files**

- a. SPIRIT checklist



STANDARD PROTOCOL ITEMS: RECOMMENDATIONS FOR INTERVENTIONAL TRIALS

# **SPIRIT 2013 Checklist: Recommended items to address in a clinical trial protocol and related documents\***

Section/item	Item number	Description	Page
<b>Administrative information</b>			
Title	1	Descriptive title identifying the study design, population, interventions, and, if applicable, trial acronym	1
Trial registration	2a	Trial identifier and registry name. If not yet registered, name of intended registry	18
	2b	All items from the World Health Organization Trial Registration Data Set	18
Protocol version	3	Date and version identifier	N/A
Funding	4	Sources and types of financial, material, and other support	19
Roles and responsibilities	5a	Names, affiliations, and roles of protocol contributors	19
	5b	Name and contact information for the trial sponsor	19
	5c	Role of study sponsor and funders, if any, in study design; collection, management, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication, including whether they will have ultimate authority over any of these activities	19
	5d	Composition, roles, and responsibilities of the coordinating centre, steering committee, endpoint adjudication committee, data management team, and other individuals or groups overseeing the trial, if applicable (see Item 21a for data monitoring committee)	6,19
<b>Introduction</b>			
Background and rationale	6a	Description of research question and justification for undertaking the trial, including summary of relevant studies (published and unpublished) examining benefits and harms for each intervention	3-5
	6b	Explanation for choice of comparators	4-6

Objectives	7	Specific objectives or hypotheses	5
Trial design	8	Description of trial design including type of trial (eg, parallel group, crossover, factorial, single group), allocation ratio, and framework (eg, superiority, equivalence, noninferiority, exploratory)	5-6

### **Methods: Participants, interventions, and outcomes**

Study setting	9	Description of study settings (eg, community clinic, academic hospital) and list of countries where data will be collected. Reference to where list of study sites can be obtained	7
Eligibility criteria	10	Inclusion and exclusion criteria for participants. If applicable, eligibility criteria for study centres and individuals who will perform the interventions (eg, surgeons, psychotherapists)	8, 10
Interventions	11a	Interventions for each group with sufficient detail to allow replication, including how and when they will be administered	11-14
	11b	Criteria for discontinuing or modifying allocated interventions for a given trial participant (eg, drug dose change in response to harms, participant request, or improving/worsening disease)	10
	11c	Strategies to improve adherence to intervention protocols, and any procedures for monitoring adherence (eg, drug tablet return, laboratory tests)	12
	11d	Relevant concomitant care and interventions that are permitted or prohibited during the trial	13
Outcomes	12	Primary, secondary, and other outcomes, including the specific measurement variable (eg, systolic blood pressure), analysis metric (eg, change from baseline, final value, time to event), method of aggregation (eg, median, proportion), and time point for each outcome. Explanation of the clinical relevance of chosen efficacy and harm outcomes is strongly recommended	15-17
Participant timeline	13	Time schedule of enrolment, interventions (including any run-ins and washouts), assessments, and visits for participants. A schematic diagram is highly recommended (see Figure)	14

Sample size	14	Estimated number of participants needed to achieve study objectives and how it was determined, including clinical and statistical assumptions supporting any sample size calculations	10-11
Recruitment	15	Strategies for achieving adequate participant enrolment to reach target sample size	7-9

### **Methods: Assignment of interventions (for controlled trials)**

Allocation:			N/A
Sequence generation	16a	Method of generating the allocation sequence (eg, computer-generated random numbers), and list of any factors for stratification. To reduce predictability of a random sequence, details of any planned restriction (eg, blocking) should be provided in a separate document that is unavailable to those who enrol participants or assign interventions	N/A
Allocation concealment mechanism	16b	Mechanism of implementing the allocation sequence (eg, central telephone; sequentially numbered, opaque, sealed envelopes), describing any steps to conceal the sequence until interventions are assigned	N/A
Implementation	16c	Who will generate the allocation sequence, who will enrol participants, and who will assign participants to interventions	N/A
Blinding (masking)	17a	Who will be blinded after assignment to interventions (eg, trial participants, care providers, outcome assessors, data analysts), and how	N/A
	17b	If blinded, circumstances under which unblinding is permissible, and procedure for revealing a participant's allocated intervention during the trial	N/A

### **Methods: Data collection, management, and analysis**

Data collection methods	18a	Plans for assessment and collection of outcome, baseline, and other trial data, including any related processes to promote data quality (eg, duplicate measurements, training of assessors) and a description of study instruments (eg, questionnaires, laboratory tests) along with their reliability and validity, if known. Reference to where data collection forms can be found, if not in the protocol	15-17
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	18b	Plans to promote participant retention and complete follow-up, including list of any outcome data to be collected for participants who discontinue or deviate from intervention protocols	
Data management	19	Plans for data entry, coding, security, and storage, including any related processes to promote data quality (eg, double data entry; range checks for data values). Reference to where details of data management procedures can be found, if not in the protocol	17
Statistical methods	20a	Statistical methods for analysing primary and secondary outcomes. Reference to where other details of the statistical analysis plan can be found, if not in the protocol	17
	20b	Methods for any additional analyses (eg, subgroup and adjusted analyses)	15-17
	20c	Definition of analysis population relating to protocol non-adherence (eg, as randomised analysis), and any statistical methods to handle missing data (eg, multiple imputation)	N/A

### Methods: Monitoring

Data monitoring	21a	Composition of data monitoring committee (DMC); summary of its role and reporting structure; statement of whether it is independent from the sponsor and competing interests; and reference to where further details about its charter can be found, if not in the protocol. Alternatively, an explanation of why a DMC is not needed	later
	21b	Description of any interim analyses and stopping guidelines, including who will have access to these interim results and make the final decision to terminate the trial	N/A
Harms	22	Plans for collecting, assessing, reporting, and managing solicited and spontaneously reported adverse events and other unintended effects of trial interventions or trial conduct	N/A
Auditing	23	Frequency and procedures for auditing trial conduct, if any, and whether the process will be independent from investigators and the sponsor	later

### Ethics and dissemination

Research ethics approval	24	Plans for seeking research ethics committee/institutional review board (REC/IRB) approval	18
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Protocol amendments	25	Plans for communicating important protocol modifications (eg, changes to eligibility criteria, outcomes, analyses) to relevant parties (eg, investigators, REC/IRBs, trial participants, trial registries, journals, regulators)	6,16
Consent or assent	26a	Who will obtain informed consent or assent from potential trial participants or authorised surrogates, and how (see Item 32)	9
	26b	Additional consent provisions for collection and use of participant data and biological specimens in ancillary studies, if applicable	N/A
Confidentiality	27	How personal information about potential and enrolled participants will be collected, shared, and maintained in order to protect confidentiality before, during, and after the trial	18
Declaration of interests	28	Financial and other competing interests for principal investigators for the overall trial and each study site	19
Access to data	29	Statement of who will have access to the final trial dataset, and disclosure of contractual agreements that limit such access for investigators	19
Ancillary and post-trial care	30	Provisions, if any, for ancillary and post-trial care, and for compensation to those who suffer harm from trial participation	N/A
Dissemination policy	31a	Plans for investigators and sponsor to communicate trial results to participants, healthcare professionals, the public, and other relevant groups (eg, via publication, reporting in results databases, or other data sharing arrangements), including any publication restrictions	18-19
	31b	Authorship eligibility guidelines and any intended use of professional writers	later
	31c	Plans, if any, for granting public access to the full protocol, participant-level dataset, and statistical code	19

## Appendices

Informed consent materials	32	Model consent form and other related documentation given to participants and authorised surrogates	
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Biological specimens	33	Plans for collection, laboratory evaluation, and storage of biological specimens for genetic or molecular analysis in the current trial and for future use in ancillary studies, if applicable	N/A
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\*It is strongly recommended that this checklist be read in conjunction with the SPIRIT 2013 Explanation & Elaboration for important clarification on the items. Amendments to the protocol should be tracked and dated. The SPIRIT checklist is copyrighted by the SPIRIT Group under the Creative Commons "[Attribution-NonCommercial-NoDerivs 3.0 Unported](#)" license.

## **Appendix K: Publication Permission Details**

- b. BMC Health Services Research (Chapter 2)
- c. BMC Family Practice (Chapter 4)
- d. PLOS One (Chapter 5)
- e. Chronic Illness (Chapter 6)
- f. Request for revisions BMC Public Health (Chapter 7)

**Ruth Hardman**

---

**From:** Springer <SpringerAlerts@springeronline.com>  
**Sent:** Sunday, 1 March 2020 10:38 AM  
**To:** Ruth Hardman  
**Subject:** Your article published in BMC Health Services Research is now online



Publication of your article

2020-03-01

Dear Author,

We are pleased to inform you that your open access article has now been published:



*BMC Health Services Research*

**What impact do chronic disease self-management support interventions have on health inequity gaps related to socioeconomic status: a systematic review**

Ruth Hardman, Stephen Begg, Evelien Spelten

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Best regards,  
 Rachel Burley  
 Publishing Director, BMC

**Ruth Hardman**

---

**From:** Springer <SpringerAlerts@springeronline.com>  
**Sent:** Friday, 12 March 2021 10:28 AM  
**To:** Ruth Hardman  
**Subject:** Your article published in BMC Family Practice is now online



Publication of your article

2021-03-12

Dear Author,

We are pleased to inform you that your open access article has now been published:



*BMC Family Practice*

**Healthcare professionals' perspective  
on treatment burden and patient  
capacity in low-income rural  
populations: challenges and  
opportunities**

Ruth Hardman, Stephen Begg, Evelien Spelten

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**Ruth Hardman**

---


**From:** No Reply <noreply@plos.org>  
**Sent:** Tuesday, 10 August 2021 5:21 PM  
**To:** Ruth Hardman  
**Subject:** Your article is published in PLOS ONE - Multimorbidity and its effect on perceived burden, capacity and the ability to self-manage in a low-income rural primary care population: a qualitative study.




**PLOS ONE**

Dear Ruth Hardman,

I'm excited to share that your article, [Multimorbidity and its effect on perceived burden, capacity and the ability to self-manage in a low-income rural primary care population: a qualitative study](#), is now published in *PLOS ONE*. Let me be the first to congratulate you! Your article is now freely available for anyone around the world to read, cite and reuse under an Open Access license.

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Emily Chenette, Editor-in-Chief, *PLOS ONE*  
 ORCID: [0000-0003-0393-395X](#)

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**Ruth Hardman**

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 Cc: sage.eprints@sagepub.com  
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## Ruth Hardman

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From: BMC Public Health <bmcpublichealth@biomedcentral.com>  
 Sent: Thursday, 18 November 2021 8:48 PM  
 To: Ruth Hardman  
 Subject: BMC Public Health: Decision on your manuscript

Ref: Submission ID 65646446-88b0-4500-b927-ad4fc64d5dc2

Dear Dr Hardman,

Re: "Relationships between different capacity domains and perceived treatment burden in chronic disease patients: a cross-sectional study"

We are pleased to let you know that your manuscript has now passed through the review stage and is ready for revision. Many manuscripts require a round of revisions, so this is a normal but important stage of the editorial process.

### Editor comments

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Based on two meaningful external peer reviews oen recommending rejection and anotehr major revision and my own Editorial insight I hereby render my Decision as:

### Major Revision

Awaiting your revised manuscript upload,

Sincerely,

Mihajlo (Michael) Jakovljevic M.D. Ph.D.  
 Full Professor, Head of Department Global Health Economics & Policy  
 University of Kragujevac Faculty of Medical Sciences, SERBIA  
 Full Professor, Institute of Comparative Economic Studies  
 Hosei University Faculty of Economics, Tokyo, JAPAN  
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