**Where Does Value Lie in Peer Support? An Exploratory Discussion of the Theories and Methods Underpinning Effective Research in Peer Support**

Christine Walker and Chris L Peterson

ABSTRACT

*A literature review was undertaken in 2019 to review research into the effectiveness of peer support in chronic disease self-management. As with an earlier literature review, we found the results disappointing due to poor reporting and poor research design. Lack of information on training of peer supporters, unrealistically short timeframes to produce changes in health behaviors, and lack of any theoretical underpinning of the research design contributed to rating randomized controlled trials as poor to medium quality evidence. At the same time, systematic reviews considerpeer support as effective, arguing that improved research design and evaluation would demonstrate this. This article*

*discusses the need to examine more closely the contribution of peer support to chronic disease care as well as considering how research methods might more closely reflect that contribution and provide better evidence of the value of peer support to both participants and the health system.*

**Keywords**

peer support; randomized controlled trials; systematic reviews; research methods; qualitative; Australia

INTRODUCTION

Over the past four decades support groups, also known as peer support, have become recognised as an important adjunct to chronic disease management, where they contribute to treatment adherence, life-style changes and rehabilitation management (Thom et al., 2013; Stubbs et al., 2016; Houlihan et al., 2017). This is particularly the case in cancers, cardiovascular conditions and mental health care (DeMello et al., 2018; Patil et al., 2018; Fuhr et al., 2014; Johnson et al., 2018). As with all procedures in chronic disease care, support groups have become the subject of research into their evidence base.

In 2011, The Chronic Illness Alliance conducted a literature review to explore the effectiveness of support groups and concluded poor research design impeded the establishment of a good evidence base (Chronic Illness Alliance, 2011). However, many systematic reviews (SR) considered peer support to be valuable to people with chronic illnesses and deserved further research. In 2019 another literature review was conducted with the aim of examining whether further research employed better research designs and produced more robust evidence regarding peer support’s effectiveness (Chronic Illness Alliance, 2019). This review explored literature published since June 2011 for new evidence on which aspects of peer support are most effective; the outcomes of peer support interventions; cost-effectiveness of peer support; the sustainability of peer support programs; how peer support links to sub-acute and primary healthcare settings; and the costs and benefits of peer support, peer support workers, recipients and funders.

While the 2019 update revealed more RCTs were conducted, analysis demonstrated little improvement since 2011. Short timeframes, often low numbers, sometimes poor results, lack of definition and theoretical underpinning as well as poor reporting on the training of support group facilitators and no long-term evaluations of health outcomes meant that the evidence base remained poor. Given that research into support groups and peer support generally aims to explore their value in changing individuals’ behaviours in chronic disease care, the poor results led us to question current research designs to research the effectiveness of support groups and peer support generally:

* are we researching the wrong aspects of peer support?
* are we expecting outcomes that are not, in fact, the province of peer support such as changes in biomarkers for the severity of chronic health conditions?
* is the randomised controlled trial the correct methodology to apply since it removes variables that might provide useful information about components of peer support?
* if the randomised controlled trial is to be retained, are there more appropriate indicators to measure effectiveness of peer support than measures of clinical outcomes?
* are there more appropriate research designs that will generate robust outcomes; and capture important information about the journeys of ill people who access peer support?

In this article we focus on questions the literature reviews raised for us about appropriate research methods to demonstrate the contributions of support groups to chronic disease health care.

METHODS

Search terms:

The following terms were used to search health-related databases Medline, CINAHL, PsycINFO, PubMed and Cochrane Library, using the following terms:

|  |
| --- |
| Peer support + technology broad |
| Peer support +PAM (Patient Activation Measures) |
| PAM (general) RCT and Systematic Reviews |
| Peer support + RCT and systematic reviews |
| Peer support and technology (RCT and systematic reviews) |

Key words

|  |
| --- |
| Chronic, complex, peer support, mentor, cancer, asthma, arthritis, musculoskeletal, heart disease, cardiovascular, stroke, diabetes, rural/remote, homeless, social isolation, mental health, mental illness. |

Additionally, a hand search was conducted to identify qualitative research into peer support, reports and discussion papers. This was done through ResearchGate, Google Scholar and sites such as NICE UK, US-based Peers for Progress and the Canadian Agency for Drugs and Technologies in Health (CADTH).

Inclusion criteria:

The strategy was to include articles on randomised controlled trials (RCTs) and systematic reviews (SRs) from January 2011 to July 2018 in English. Specifically, articles covering research projects undertaken with people who attended peer support groups for chronic and complex conditions were sought. Peer support delivered through social media and other technologies (mobile phone apps, interactive online programs) were included. The initial search delivered 284 peer-reviewed articles.

Selection strategy:

After removal of duplicate results, all abstracts were read independently by CW and a research assistant. Articles on single or small projects, those only marginally concerned with peer support issues or no evidence on effectiveness, such as protocol papers were excluded. The result was 34 articles to review in full. Eighteen of these were RCTs; additionally, there was one rapid review; a qualitative study, and two reports. The remaining were 11 SRs.

Another facet of the 2019 project was to explore other methods of evaluating peer support effectiveness in long-term behaviour change that do not rely solely on clinical outcomes such as HbA1c or weight-loss. The above search strategy did not find these alternative methods of evaluation so following reflection the reviewers targeted Patient Activation Measures (PAM) to test their potential to evaluate the effectiveness of peer support in changing health behaviours. Methods involved in longitudinal studies were also considered since effectiveness of peer support may be better gauged over longer timeframes. Finally, Grading of Recommendations, Assessment, Development and Evaluations (GRADE) was used assist in estimating the effectiveness of RCTs.

Analysis:

Complete published copies of those articles meeting the inclusion criteria were obtained and read with key attributes summarised. Reviewers (CW and a research assistant) applied GRADE to the RCTs estimating the levels of evidence including bias, limitation in research design and reporting.

We compared the results of this literature review with those of the 2011 literature review to estimate if more recent research showed methodological improvement.

RESULTS 2019: the implications for future research.

The full results are reported elsewhere (Chronic Illness Alliance, 2019). Here we discuss how RCTs contribute to our understanding of support groups’ roles to produce behaviour change in chronic disease care.

*Implications for researching effective behaviour change*

Research of this nature is generally undertaken to demonstrate effectiveness of a support program in order to replicate it in the broader community. Accordingly, sample sizes are important to detect differences between control and intervention groups, but this aspect was rarely discussed and numbers appeared to relate to availability. They varied from the lowest of 30 participants divided between intervention and control groups and the highest of 400 divided between intervention and control.

Studies reported general differences between the intervention and control groups, though these differences could have been associated with influences other than peer support. Only five studies reported blinding of researchers involved in data collection and analysis. Few RCTs had numbers calculated, possibly relying on self-selection. Small sample sizes can restrict the power of the study: it can also affect the variability and therefore reliability of results.

Similarly, timeframes for the delivery of a program, or dosage required to show an effect varied from 4 weeks to 12 months. The time required for effectiveness was rarely discussed. It is likely that time spent in delivering an intervention was dependent on funding. In a few cases there was follow-up at 6 or 12 months. Outcome measures were often clinical such as HbA1c, but also treatment adherence, wellbeing and readmissions or ED use. The value of such measures is undermined, when there is inadequate baseline data collected on each person in the trial regarding stage of disease, social supports and activity levels (Krauss, 2018). Of the17 RCTs six reported significant changes though changes were not always evenly distributed across all measures. Seven other RCTs reported no or marginally significant improvements with several more reporting that both intervention and control arms improved. Only one (Houlihan et al., 2017) had a design demonstrating outcomes that could be attributed to peer support.

Peer support was delivered either in face-to-face groups or via Internet platforms. Peer supporters were generally volunteers. Training of peer supporters to deliver a program is integral to a peer support program and an important variable to be detailed in research. The curriculum and delivery methods were not reported in 5 RCTs and in 3 other RCTs were mentioned but not described.

Problems with RCT design are compounded when we consider the shortcomings in design of RCTs in peer support including ineffective blinding, small numbers and short timeframes. The extent of methodological problems is demonstrated when only one RCT (Houlihan et al., 2017) had a design that effectively demonstrated outcomes that could be attributed to peer support.

Articles lacked sufficient detail to assess if the length of time, the training or other factors across the RCTs influenced the outcomes. There were no reports of evaluations of the contributions of training to outcomes of RCTs, suggesting that its role as an influencing variable was undervalued. As well, the impact of the training on support group participants, including their views on its value was not evaluated.

More cost effectiveness studies have been undertaken since 2011 but much of the evidence relies on inference rather than modelling and measures such as DALYs. Burton et al., (2018) found six studies mentioning cost-effectiveness, only one of which provided evidence that peer-led programs were as effective as professionally led programs. CADTH (2013) found only one cost-effectiveness study but it did not include all risk factors related to Type 2 Diabetes.

The systematic reviews made greater attempts at defining their terms. Haines et al., (2018) cited Pfeiffer et al., (2011), defining peer support as “bringing together non-professionals with similar stressors or health problems for mutual support or unidirectional support from an experienced to novice peer”. Mead et al., (2001, p.135) defined peer support as a “System of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful…”. The importance of definitions is demonstrated as the first definition limits peer support to non-professionals with the same or similar experiences of health conditions, while the second suggests that health professionals may be included.

The 11 systematic reviews pointed to methodological problems or poor evidence. There are recommendations for better designed RCTs such as better blinding or more adequate powering (Stubbs et al., 2016), and fuller reporting of results. A number report the need for better outcome measures (Shilling et al., 2013), or a need to focus on what peer support does best (Barker & Maguire, 2017). Some authors speculated on the disappointing results and suggested that there were other aspects of peer support that might be more rewarding to investigate, for example, who most benefits from peer support (Furh et al., 2014), why it is popular with people with chronic illnesses, and which aspects are popular (De Mello et al., 2018; Small et al., 2013), and concentrating on overall improvement in wellbeing, possibly including improved health literacy, reduced isolation, increased personal control rather than clinical physical outcomes. Shilling et al. (2013 p. 608) in their SR articulate the need for theory to relate to outcome measures, timeframes, and comparators to strengthen evidence. They consider measures of health outcomes should be consistent with theories of peer support as an intervention; that the timeframes chosen to deliver per support should be appropriate to show health outcomes and greater attention paid to choosing appropriate control groups. With regard to control groups they suggest it is not ethical to prevent people from seeking support.

DISCUSSION

The results of the above literature review combined with the continuing popularity of peer support amongst consumers and many health professionals lead us to ask a number of questions, including: is the RCT the appropriate method to explore peer support; are outcome measures that focus on changes in health behaviours appropriate to what peer support actually provides health consumers; is the poor evidence of effectiveness of peer support due to not understanding what peer support actually is.

*Improving research design*

Some of the inadequacies of the research may relate to poor design at the outset. The lack of definitions and theoretical underpinning of methodologies contribute to this inadequacy.

Definitions are important because they name the essence of the thing to be researched. Without this, it leaves others to make their own inferences. In peer support there is no one accepted definition, its meaning may vary from one researcher to another. Some of this problem is exemplified in the RCTs. Thom et al., (2013) distinguish between peer support, peer health coaches and peer educators, arguing that peer health coaches are more flexible than peer educators, though these differences were not explained. Barker and Maguire (2017) defined peer support as ‘experts by experience’ though experience is not specified. While some definitions assume that peer support is integral to personal experience of illness and recovery others relate it to observable outcomes or applications of training and education. Commencing with a defined account of what peer support is, will assist in moving towards some internal consistency and establish better what is being researched. Additionally, it assists developing hypotheses and theories.

A theory of peer support makes clear how and by what mechanisms peer support may benefit the participants. This may then be applied as a working hypothesis in the different situations where peer support is employed. While some articles referred to theories most often these were only nominal and were not integrated in the research design. There was little evidence of theory driving the research design and providing the framework (Noar & Zimmerman, 2005). Often, theories of peer support relate to individual behaviour change, though the focus on clinical indicators as measures of changes in behaviours in both physical and mental health conditions may not fully represent this form of change. No article provided a detailed, theoretically derived description of peer support, hypothesised methods of effect, or the relationship between delivery, outcomes and the theoretical basis. Similarly, Davis et al., (2015) consider the evidence regarding the abilities of programs to change health behaviours is mixed and may be due to poor application of theory or employment of an inappropriate theory. They suggest theories including social and environmental factors should be considered when research involves health behaviours.

The design of training is best related to accompanying definitions and theories. While the importance of training those delivering peer support was demonstrated in the development of resources such as a training manual, didactic sessions to ensure information was consistently presented, communication skills and role plays, lack of reporting means it is not possible to evaluate if training was consistent with any definitions or theories. However, Cane et al. (2012 p.7) argue that there “is some evidence that behaviour change interventions informed by theory are more effective than those that are not” they maintain that in reality, designs of such training are more likely to be based on “common-sense models of behaviour.” Self-management programs offer an insight into the value of evaluations. Kennedy et al. (2014) undertook a process evaluation of a self-management program in UK primary care. This evaluation used a multi-method approach in line with the UK Medical Research Council recommendations to explore what worked and did not work for organisations, the staff, and patients. Normalisation Process Theory (NPT) was used as the basis of design and the results of the evaluation were included in the results of the main trial.

*Critiques of the RCT*

RCTs, as they are now employed in peer support research, are essentially reductionist, in this case reducing peer support, to pre-determined component parts (Hawe et al., 2004). Greene and Loscalzo (2017) explored the limits of reductionism regarding the complex interrelationships between genetics and environments, arguing for a more nuanced ‘network’ approach. Deaton and Cartwright (2017) argue that RCTs in economic research have advantages in convincing sceptical audiences that an intervention works but will only advance scientific progress as a part of a whole cumulative process that includes understanding why it works. What works with RCTs needs to be couched in the circumstances it works under and describe what these may be. Boon et al., (2006) made a similar argument with regard to understanding complementary medicines in healthcare.

Even earlier, Pawson and Tilley (1997) were sceptical of the use of RCTs to research complex interventions involving human behaviour. They argued for ‘realist’ evaluations, which avoid assumptions of direct causal links between interventions and outcomes and argue for examining the contexts of “what works for whom and when”. Thus, they argue for exploring what works for whom and in what contexts rather than simply determining that something does work. Hawe et al. (2004) suggest that the researchers’ job does not stop there but process evaluations and the use of mixed methods are necessary to build a complete picture.

These critiques have relevance to researching the relationship of peer support to healthcare and health outcomes.

Current designs of RCTs in peer support discount variables that may play a part in the success or failure of a program at the outset so do not figure in the results. Randomisation, which is meant to produce intervention and control groups that are identical at the outset of a research project, may involve purposive or convenience samples and be based on clinical and demographic factors (diagnosis, age, medical interventions and clinical results). They will ignore personalities, beliefs and behaviours, motivations and expectations for participating in peer support and the contexts such as impact on significant others (e.g. partners and family) all of which will impact on results.

Hawe et al. (2004) suggest that, instead of trying to create laboratory conditions, it would be better to start by examining all the variables present to understand the complexity of a system in order to understand how an intervention will work. Similarly, the UK Medical Research Council Developing and evaluating complex intervention (2019) recommends a thorough understanding of the contexts and the various parts of a complex intervention, as well as starting from a theoretical base. This gives coherence to the intervention and allows for replication. Piloting is important as well as building in a process evaluation. It is only after much preparatory work that a researcher considers which research design to adopt. Other recommendations include mixed methods studies to ensure that both quantitative and qualitative data are captured. Interviews of significant people to the study may uncover additional important variables to factor into the study. Bonnell et al. (2012) critique the use of RCTs in complex public health interventions arguing they may be modified to become ‘realist trials’ that account for how components of interventions interact and the circumstances that assist interventions to work. ‘Realist trials’ aim to demonstrate how components work in a trial and explore what aspects contribute to health changes. They use both qualitative and quantitative methods and contribute towards determining “*the validity of program theory rather than only examining 'what works' to better inform policy and practice in the long-term.*”

Bonnell et al. (2012 p.1).

In practical terms, this would include multiple groups receiving interventions as well as a group acting as a control and then comparing the results. It would also include examining more immediate impacts such as improvement in knowledge or self-efficacy rather than changes to health behaviours which might be the goal. This has the advantage of identifying effective ‘ingredients’ of an intervention. Another inclusion might be conducting research across different contexts, using consistent measures in order to assess how the intervention results vary with context.

*The value of considering peer support as a complex intervention*

These critiques of RCTs and the UK MRC recommendations suggest that peer support is best viewed as a complex intervention. Complexity can be portrayed as a system of multiple components that are dynamic, sometimes emergent processes and people interacting with one another (Hawe, 2015; Braithwaite et al., 2017; Mannell &Davis, 2019). Complex systems are portrayed as alternating between stability and chaos and therefore inherently unpredictable and this has implications for research into them (Khan et al., 2018).

Peer support for people who have experienced illness is itself a complex system operating within the complex contexts of healthcare systems and the broader social structures. Members of a support group bring their various beliefs, judgments, experiences, personalities social relationships and health statuses into the group, making it a replica of the broader complexity.

Hawe (2015) considers that applying complexity thinking will change how interventions are designed and evaluated. One of those changes in thinking relates to evaluating ‘real-world’ interventions such as behaviour change (Schoen et al., 2019). Greenhalgh and Papoutsi (2018) agreeing with Khan et al. (2018) that by embracing complexity rather than attempting to control for it, as do reductionist methods, interventions will be tailored to work within local contexts while recognising change takes time.

Further, applying reductionist methods such as the RCT to complex systems may relegate possibly important variables to background ‘error’ so they are not evaluated for their influence on the outcomes. Additionally, reductionist methods in an RCT may overestimate the role of the intervention (Hawe, 2015). Greenhalgh and Papoutsi (2018) point out that dependence and interdependence of components in complex interventions make it difficult to identify the ‘active ingredient’ required in RCTs. This has led to recognition of the value of mixed methods and process evaluations, or a ‘paradigm shift’.

In 2006 an international group examined four approaches to complex systems which began with establishing a theoretical framework, observation of interactions within the system, an intermediate RCT, followed by assessing the project for broader adoption and any potential adverse impacts (Boon et al., 2007).

Paul et al. (2007) adopted the UK Medical Research Council 2001 five phase framework to test complex interventions. In their study of peer support in diabetes self-management they argued that this framework allowed them to explore and pilot the key components of peer support before proceeding to a cluster RCT. This article discussed the first three phases only, with phases 1 and 2 using qualitative work which assisted in designing a flexible program where peer supporter training was designed in association with those being trained and the inclusion of process evaluation. Results of the process evaluation would then inform the implementation phase. This evaluation was another RCT, conducted over a two-year period and resulted in little change in the clinical indicators, though participants reported valuing the groups (Smith et al., 2011). The authors note the limitations of conducting a clustered randomised controlled trial in general practice, including difficulty of blinding and poor attendance of participants. They also report there was a decrease in well-being among participants at one point.

More recently, Deaton and Cartwright (2017) critiqued the use of the RCT where social context is ignored. Complexity theory and the poor RCT results already mentioned, suggests that the role of peer support should be researched in a far wider context than the health system (Rooghenas et al., 2019). Deaton and Cartwright (2017) argue that social context is important regarding the relevance of an RCT to wider populations and support that view that observational studies are important in ensuring context is understood. On this basis we argue it is important to understand peer support from the participants’ points of view, their motivations and what they derive from participation.

This includes the point at which people decide to participate. While an illness will impact individuals differently, the impact may be a life-changing moment in each person’s life. Frank in *The Wounded Storyteller* (2013) discussed the effect that an illness can have on a person’s identity and he portrays the need to tell one’s own story as a quest towards healing oneself and arriving at a new point where the illness is integrated into one’s identity. Personal journeys are highly variable and acknowledge that life changing events may be stressful and affect physical health and functioning (Rios et al., 2014). Seeking social support including peer support may be one part of these personal journeys towards new identities and will influence health outcomes.

Social support in health (e.g. Wilkinson & Marmot, 2003) also plays an important role in individuals’ abilities to participate in peer support. Social connectedness (being married, having family, friends, neighbours, community memberships, and employment) contributes to better health outcomes (Walker, 2010). Health outcomes variations may be influenced for example by partner and family attitudes to peer support and its effects, and hence be important influences to understand.

Kingod et al. (2017 p.95) effectively summarise the interplay between the personal, social and health system:

“*Through their online interactions, individuals with chronic illness animated illness associated identities, sought and provided social support and connectivity, shared experiential knowledge only available from those living with particular chronic illnesses, while also mobilizing collective voices for the purposes of promoting otherwise neglected perspectives concerning life with chronic illness.”*

A key finding is that the longing for mutual solidarity and emotional support in relation to the day-to-day management of illness motivatespeople with a chronic illness to seek advice and inspiration among peers with the same condition. (Kingod et al., 2017). This suggests that research aimed at exploring how peer support improves knowledge, self-efficacy, engagement in one’s own health care, and its role in personal change would reveal the effectiveness of peer support in healthcare.

*Consider other measures and methodologies*

While we do not see that the RCT will be abandoned in the foreseeable future these measures can be applied in other research designs, for example longitudinal studies where change can be measured over time within a cohort or panel (Tse et al., 2017; Young et al., 2005; Caruana et al., 2015).

Longitudinal studies can also be qualitative. Tse et al. (2017) collected views on peer support from health-professionals, co-workers and participants over 12 months, which demonstrated that peer support improved relationships between health professionals and their patients.

In some instances, longitudinal studies can be as equally limited as many RCTs. For example, Batenburg and Das (2014) ran a longitudinal study with a small number of breast cancer patients that had 2 reporting points: one at the beginning and then at 6 months. In this study numbers declined over the period studied and there was little information on the intervention itself.

Mixed methods research combining qualitative and quantitative methods is a comprehensive approach to collecting data on health outcomes as an initial qualitative collection can inform about the context and meanings that surround a health issue and inform the collection of quantitative data. Or qualitative collections can precede quantitative methods. Thompson and Balaam (2019) collected data on neonatal peer support using an online survey followed up by interviews of a purposive sample to inform on the management and supervision of peer support workers in their wider context. Another study using mixed methods supplemented an RCT with semi – structured interviews comparing peer support with other service supports for people with mental health issues (Wrobleski et al., 2015). Another used focus groups as well as quantitative data collections to analyse peer support for psychological problems (Aschbrenner et al., 2016). In addition an RCT was supplemented with a final interview program for peer support for people with brain injury, showing that other factors beyond the RCT needed investigation (Munce et al., 2019) These studies demonstrate that quantitative and qualitative data collection can be used to overcomes one of the chief criticisms of RCTs by Deaton and Cartwright (2017) that many lack an understanding of the context of outcomes of interventions.

Process evaluations, both quantitative and qualitative, are important to pursue as they provide detailed analysis of the content of peer support programs, including training of peer supporters, delivery of the curriculum, the responses of the participants and documentation of adverse events, plus where the strengths and limitations of the program occur. A process evaluation needs to be designed at the outset and to operate either continuously or at certain points identified as delivering outcomes. Those conducting the process evaluation should be separate from those delivering an intervention.

Given that participants may have different goals, motivations and be on differing journeys measuring peer support needs reconsideration. The question becomes whether to measure the components participants consider their own goals or to track changes in health behaviours and associated behaviours within a peer support group or program. If it is to be changes in health behaviours, clinical outcomes such as HbA1C or using the 6 Minute Walking Test (6MWT) or weight loss the question to next arise relates to a realistic timeframe for specific participants.

As we have seen, changes in clinical outcomes may require long timeframes to demonstrate effectiveness, while clinical measures may not capture the full complexity of the intervention and the context. Here, Patient Activation Measures (PAM) have capacity to measure the complex interrelationships with support groups. Rather than capturing clinical outcomes, their application can measure behaviour change that indicates progress towards potentially effective health outcomes (Hibbart & Gilburt, 2014).

Additionally, measures of self-efficacy and health literacy especially if performed pre- and post- intervention might be better indications of a person’s progress in a journey towards improved health outcomes (Bandura, 2005). Depression and anxiety scales will also yield valuable information on participants’ ability to accept new information and make changes.

Demographic information including employment, income, educational level and social networks measured with the Lubben Social Network Scale will also contribute to interpreting results (Lubben et al., 2006).

CONCLUSION

Peer support remains an important, popular adjunct in chronic disease self-management across the world. As such, it is being researched to establish its value in maintaining healthy behaviour change in many conditions.

A literature review was conducted in 2019 to assess if research since 2011 had established better evidence regarding the effectiveness of peer support programs. While research and systematic reviews continued, the results were generally disappointing. Research articles did not provide enough detail on the RCT or they demonstrated methodological shortcomings.

This led some authors of systematic reviews to suggest that research into peer support needs to be re-thought, possibly considering different research methods, different outcomes measures or measuring different components of peer support. Reliance on outcomes measures has, so far, not produced reliable or translatable results.

In line with this approach we have argued here that peer support operates within a complex system comprising the person’s response to illness, the community, the health system, and the wider social structure. Peer support is itself a complex intervention which takes place within a personal journey of health and illness. As such, it appears that RCTs as they are currently conducted are too limited in scope to operate within such complexity. They cannot control all possible variables or isolate an ‘active ingredient’.

While we do not expect that the RCT will be abandoned altogether, some appreciation of complexity should lead to better research design, possibly commencing with an understanding of people’s motivations in attending peer support, what they value by the attendance and how they relate peer support to their own health-illness journeys. Commencing with such a qualitative approach would assist in removing researchers’ own assumptions and anchoring a RCT within the complex system.   
Additionally, process evaluations conducted alongside a RCT can assist in making the research more reflexive and identify why a particular peer support intervention works, or does not, in this specific situation. Similarly, such mixed methods approaches should mean the adoption of outcomes measures that take account of what takes place in peer support.

Peer support is an intervention that health consumers value and will continue to pursue. The poor results from RCTs conducted over the last 20 years suggest that there is a strong need to adopt the paradigm shift that Greenhalgh and Papoutsi (2018) and others consider will produce results that reflect its contributions to health and wellbeing.

5205 words

REFERENCES

* Aschbrenner, K. A., Naslund, J. A., & [Bartels, S. J.](https://psycnet.apa.org/search/results?term=Bartels,%20Stephen%20J.&latSearchType=a) (2016). A mixed methods study of peer-to-peer support in a group-based lifestyle intervention for adults with serious mental illness. *Psychiatric Rehabilitation Journal*, *39*(4), 328-34. doi:[10.1037/prj0000219](https://doi.org/10.1037/prj0000219)

Bandura, A. (1977). Social Learning Theory. Englewood Cliffs, NJ. Prentice Hall.

Barker, S., & Maguire, N. (2017). Experts by experience: peer support and its use with the homeless. Community Mental Health Journal*,* *53*(5), 598-612. [doi:10.1007/s10597-017-0102-2](http://dx.doi.org/10.1007/s10597-017-0102-2).

Batenburg, A., & Das, E. (2014). Emotional approach coping and the effects of online peer-led support group participation among patients with breast cancer: A longitudinal study. *Journal of Medical Internet Research, 16*(11), e256. doi:[10.2196/jmir.3517](https://doi.org/10.2196/jmir.3517)

# Bonnell, C., Fletcher, A., Morton, M., Lorenc, T., & Moore, L. (2012). Realist randomised controlled trials: a new approach to evaluating complex public health interventions. *Social Science and Medicine 75*(12), 2299-306. doi: 10.1016/j.soc scimed.2012.08.032.

* Boon, H. S., Olatunde, F., & Zick, S. M. (2007). Trends in complementary/alternative medicine use by breast cancer survivors: Comparing survey data from 1998 and 2005. *BMC Women’s Health, 7.* doi:[10.1186/1472-6874-7-4](https://doi.org/10.1186/1472-6874-7-4)..

# Braithwaite, J., Churruca, K., Ellis, L. A., Long, J., Clay-Williams, R., Damen, N., Herkes, J., Pomare, C., Ludlow, K. (2017). Complexity science in healthcare–aspirations, approaches, applications and accomplishments: A white paper. Australian Institute of Health Innovation, Macquarie University: Sydney, Australia.

# Burton, E., Farrier, K., Hill, K., Coddie, J., Airey, P., & Hill, A-M. (2018). Effectiveness of peers in delivering programs or motivating older people to increase their participation in physical activity: Systematic review and meta-analysis. Journal of Sports Sciences, 36(6), 666-78. doi:10.1080/02640414.2017.1329549

# Canadian Agency for Drugs and Technology in Health (CADTH) (2013). Peer support for mental health disorder management: A review of the clinical effectiveness, cost-effectiveness, and guidelines. Project Number: RC0493 000. Retrieved from<https://www.cadth.ca/peer-support-mental-health-disorder-management-review-clinical-effectiveness-cost-effectiveness-and>

# Cane, J., O’Connor, D., & Michie, S. (2012). Validation of the theoretical domains framework for use in behaviour change and implementation research, *Implementation Science* ***7***(37). [doi:10.1186/1748-5908-7-37](https://doi.org/10.1186/1748-5908-7-37)

Caruana, E., Roman, M., Hernandez-Sanchez, J., & Solli P. (2015) Longitudinal Studies. *Journal of Thoracic Disease 7(*11), E537-40. doi: 10.3978/j.issn.2072-1439.2015.10.63

Chronic Illness Alliance. (2011) Peer support for chronic and complex conditions: a literature review. April 2011.Retrieved from <http://www.chronicillness.org.au/wp-content/uploads/2015/09/PeerSupportforChronicandComplexConditionsLitRevMay2011Final.pdf>

Chronic Illness Alliance (2019) Peer support for chronic and complex conditions: a literature review. March 2019. Retrieved from

<http://www.chronicillness.org.au/wp-content/uploads/2019/05/Peer-Support-for-Chronic-and-Complex-Conditions-Lit-Rev-Feb-2019-FINAL.-docx.pdf>

Davis, R., Campbell, R., Hildon, Z., & Michie, S., (2015) Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. [*Health Psychology Review,*](https://www.ncbi.nlm.nih.gov/pubmed/25104107) *9*(3), 323-44. doi: 10.1080/17437199.2014.941722.

Deaton, A. & Cartwright, N. (2017) Understanding and misunderstanding randomised controlled trials. Retrieved from <https://www.princeton.edu/~deaton/downloads/Deaton_Cartwright_RCTs_Oct-1-2017.pdf>

DeMello, M., Pinto, B., Mitchell, S., Dunsiger, S., & Stein K. (2018) Peer support for physical activity adoption among breast cancer survivors: Do the helped resemble the helpers? *European Journal of Cancer Care. 27*, e12849. https://doi.org/10.1111/ecc.12849

Frank, A. (2013) *The Wounded Storyteller: body, illness and ethics*. 2nd ed. Chicago, University of Chicago Press.

Fuhr, D. C., Salisbury, T. T., De Silva, M. J., Atif, N., van Ginneken, N., Rahman, A., & Patel, V. (2014). Effectiveness of peer-delivered interventions for severe mental illness and depression on clinical and psychosocial outcomes: a systematic review and meta-analysis. *Social Psychiatry and Psychiatric Epidemiology*. *49*(11), 1691-1702. doi:[10.1007/s00127-014-0857-5](https://dx.doi.org/10.1007%2Fs00127-014-0857-5)

Greene, J., & Loscalzo, J. (2017) Putting the patient back together-social medicine, network medicine and the limits of reductionism. *New England Journal of Medicine*, *377*, 2493-9.  
doi: 10.1056/NEJMms1706744

Greenhalgh, T., & Papoutsi, C. (2018) Studying complexity in health services research: desperately seeking an overdue paradigm shift. *Medicine.16*(95),  
doi:10.1186/s12916-018-1089-4

Haines, K., Beesley, S., Hopkins, R., McPeake, J., Quasim, T., Ritchie, K., & Iwashyna, T. (2018) Peer support in critical care: a systematic review. *Critical Care Medicine 46*(9), 1522-31. doi: 10.1097/CCM.0000000000003293\

Hawe, P., Shiell, A., & Riley T. (2004) Complex interventions: how “out of control” can a randomised controlled trial be? *British Medical Journal* *328*, doi:[10.1136/bmj.328.7455.1561](https://doi.org/10.1136/bmj.328.7455.1561)

Hawe, P. (2015) Lessons from complex interventions to improve health. *Annual Review of Public Health* *36*, 307-23.  doi:[10.1146/annurev-publhealth-031912-114421](https://doi.org/10.1146/annurev-publhealth-031912-114421)

Hibbart J., & Gilburt, H. (2014). Supporting people to manage their health; an introduction to patient activation. The King’s Fund UK. Retrieved from

[*file://I:/Projects/HCSG/HCSG%202018-2019/supporting-people-manage-health-patient-activation-may14.pdf*](file://I:/Projects/HCSG/HCSG%202018-2019/supporting-people-manage-health-patient-activation-may14.pdf)

Houlihan, B., Brody, M., Everhart-Skeels, S., Purnigotti, D., Burnett, S., & Jette, A. (2017) Randomized trial of a peer-led, telephone-based empowerment intervention for persons with chronic spinal cord injury improves health self-management. *Archives of Physical Medicine and Rehabilitation* *98*(6), doi:10.1016/j.apmr.2017.02.005

Johnson, S., Lamb, D., Marston, D., Osborn, D., Mason, O., Henderson, C., Ambler, G., Milton, A., Davidson, M., Christophorou, M., Sullivan, S., Hunter, R., Hindle, D., Paterson, B., Leverton, M., Piotrowski, J., Forsyth, R., Mosse, L., Goater, N.,...Lloyd-Evans, B. (2018) Peer-supported self-management for people discharged from a mental health crisis team: a randomised controlled trial. *Lancet*, *392*, 409-18. [doi:10.1016/S0140-6736(18)31470-3](https://doi.org/10.1016/S0140-6736(18)31470-3)

Kennedy, A., Rogers, A., Chew-Graham, C., Blakeman, T., Bowen, R., Gardner, C., Lee, V., Morris, R., & Protheroe, J. (2014) Implementation of a self-management support approach (WISE) across a health system: a process evaluation explaining what did and did not work for organisations, clinicians and patients. *Implementation Science,* ***9***, 129, [doi:10.1186/s13012-014-0129-5](https://doi.org/10.1186/s13012-014-0129-5)

# Khan, S., Vandermorris, A., Shepherd, J., Begun, J. W., Lanham., Uhl – Bien., M., & Berta, W. (2018) Embracing uncertainty, managing complexity: Applying complexity thinking principles to transformation efforts in healthcare systems. *BMC Health Services Research, 18,* doi: [10.1186/s12913-018-2994-0](https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-2994-0)

# Kingod. N., Cleal, B., Wahlberg, A., & Husted, G. (2017) Online peer-to-peer communities in the daily lives of people with chronic illness: a qualitative systematic review. *Qualitative Health Reearch*, *7*(1), 89-99. http[s://doi.org/10.1177/1049732316680203](https://doi.org/10.1177%2F1049732316680203)

# Krauss, A. (2018) Why all randomised trials produce biased results. *Annals of Medicine*, *50*, 312-22. <https://doi.org/10.1080/07853890.2018.1453233>

Mannell, J., & Davis, K. Evaluating complex health interventions with randomized controlled trials: how do we improve the use of qualitative methods? *Qualitative Health Research*,2019, Apr;29(5), 623-631.doi: 10.1177/1049732319831032.

Mead, S., Hilton, D., & Curtis, L. (2001) Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal 25*(2), 134-41. doi:[10.1037/h0095032](https://doi.org/10.1037/h0095032)

Medical Research Council (2019) Developing and evaluating complex interventions. UK. Retrieved from <https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/>p

Munce, S. E. P., Jaglal, S., Kastner, M., Nelson, M. L. A., Salbach, N. M., Shepherd, J., Sweet, S, N., Wilcock, R., Thoms, C., & Bayley, M, T. (2019). Ontario Brain Injury Association Peer Support Program: a mixed methods protocol for a pilot randomised controlled trial. *BMJ Open,* *9,* e023367 doi:[10.1136/bmjopen-2018-023367](https://doi.org/10.1136/bmjopen-2018-023367)

Noar, S. M., & Zimmerman, R. S. (2005) Health Behavior Theory and cumulative knowledge regarding health behaviors: are we moving in the right direction? *Health Education and Research*, *20*(3), 275–90. doi:[10.1093/her/cyg113](https://doi.org/10.1093/her/cyg113)

Patil, S., Ruppar, T., Koopman, R., Lindbloom, E. J., Elliott, S. G., Mehr, D. R., & Conn, V. S. (2018) Effect of peer support interventions on cardiovascular disease risk factors in adults with diabetes: a systematic review and meta-analysis. *BMC Public Health* *18*, 398, <https://doi.org/10.1186/s12889-018-5326-8>

Paul, G. M., Smith, S. M., Whitford, D. F., O’Shea, F., O’Kelly, F., & O’Dowd, T. (2007) Peer support min type 2 diabetes: A randomised controlled trial in primary care with parallel economic and qualitative analysis: Pilot study and protocol. *BMC Family Practice, 8,* doi: [10.1186/1471-2296-8-45](https://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-8-45)

Pawson, R., & Tilley, N. (1997) *Realistic Evaluation*. UK, Sage Publishing.

Pfeiffer, P. N., Heisler, H. M., Piette, J. D., Rogers, M. A., & Valenstein, M. (2011) Efficiency of peer support interventions for depression. *General Hospital Psychiatry, 33*(1), 29-36. doi:[10.1016/j.genhosppsych.2010.10.002](https://doi.org/10.1016/j.genhosppsych.2010.10.002)

Rios, R.M., Hjemdal, O., Martinez Uribe. P., & Corveleyn, J. (2014) Life stress as a determinant of emotional well-being: development and validation of a Spanish-Language Checklist of Stressful Life Events. *Health Psychology and Behavioral Medicine*, *2*(1), 390-411.doi:[10.1080/21642850.2014.897624](https://doi.org/10.1080/21642850.2014.897624)

Rooghenas, L., Paramasivan, S., Jepson, M., & Donovan, J, L. Intensive triangulation of qualitative research and quantitative data to improve recruitment to randomized trials: The QuinteT Approach. *Qualitative Health Research 29(*5), 672-679. doi:10.1177/1049732319828693

Schoenau, M. N., Hansen, M., & Ulvestad, S. (2020) The lived experiences, perceptions, and considerations of patients after operable lung cancer concerning nonparticipation in a randomized clinical rehabilitation trial**.** *Qualitative Health Research**30*(5),760-771. doi: 10.1177/1049732319886564.

# Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M., & Logan, S. (2013) Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine and Child Neurology*

# [doi:10.1111/dmcn.12091](https://doi.org/10.1111/dmcn.12091)

Small, N., Blicken, C., Blakeman, T., Panagioti, M., Chew-Graham, C. A., & Bower, P. (2013) Telephone based self-management support by ‘lay health workers’ and ‘peer support workers’ to prevent and manage vascular diseases: a systematic review and meta-analysis. *BMC Health Services Research* 13, 533 doi: 10.1186/1472-6963-13-533

Smith, S. M., Paul, G., Kelly, A., Whitford, D. L., & O’Dowd, T. (2011) Peer support for patients with type 2 diabetes: Cluster randomised controlled trial. *BMJ, 342*, doi:10.1136/bmj.d715.

Stubbs, B., Williams, J., & Shannon, J. (2016) Peer support interventions seeking to improve physical health and lifestyle behaviours among people with serious mental illness: A systematic review. *International Journal of Mental Health Nursing* *25*, 484–95. doi: 10.1111/inm.12256

Thom, F., Ghorob, A., Hessler, D., De Vore. D., Chen, E., & Bodenheimer, T. A. (2013) Impact of peer health coaching on glycemic control in low-income patients with diabetes: a randomized controlled trial. *Annals of Family Medicine* *11(*2), 137-44. doi: 10.1370/afm.1443.

Thomson, G., & Balaam, M-C. (2019) International insights into peer support in a neonatal context: A mixed-methods study. *PLoS ONE* 14(7), e0219743 doi.org/10.137/ journal pone 0219743.

Trachtenberg, M., Parsonage., M., Shepherd, G., & Boardman, J. (2013) Peer support in mental health care: Is it good value for money? Report Centre for Mental Health. Retrieved from <http://eprints.lse.ac.uk/60793/1/Trachtenberg_etal_Report-Peer-support-in-mental-health-care-is-it-good-value-for-money_2013.pdf>

Tse, S., Mak, W.W.S., Lo, I.W.K., Kiu, L.L., Yuen, W.W.Y., Yau, S.,. & Wong, S. (2017) A one year longitudinal qualitative study of peer support services in a non-Western context: The perspectives of peer support workers, service users and co-workers. *Psychiatry Research*, *255*, 27-35. doi: 10.1016/j.psychres.2017.05.007

Walker, C. (2010). Ruptured identities: leaving work because of chronic illness. *International Journal of Health Services* *40*(4), 629–43.

Wilkinson, R., & Marmot, M. eds. (2003) Social determinants of health; the solid facts. Second Edition. World Health Organisation Europe. Retrieved from

<http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf>

# Wrobleski, T., Walker, G., Jarus-Hakak, A., & Suto, M.J. (2015) Peer support as a catalyst for recovery: a mixed-methods approach *Canadian Journal of Occupational Therapy 82(*1), 64-73. doi: 10.1177/0008417414551784

Young, J.F., Berenson, K., Cohen, P., & Garcia, J. (2005) The role of parent and peer support in predicting adolescent depression: A longitudinal community study, *Journal of Research on Adolescence,* [doi:10.1111/j.1532-7795.2005.00105.x](https://doi.org/10.1111/j.1532-7795.2005.00105.x)