**A Sociological Approach to Resilience in Health and Illness**

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***Abstract***

*Work on resilience in health and illness has been approached from a number of perspectives. These are the biological and psychosocial with a focus on the individual’s responses to cope and adapt to changing circumstances wrought by changing physical health states. This we argue has a place but is far too narrow emphasising the neoliberal view that the sick or imperfect individual is ultimately responsible for their own health outcomes. In this perspective the individual’s failure to cope or adapt may be seen as a personal failure to interact with the health system on offer. A broader sociological approach focusses on the overarching socio-political system within which health and illness occur and looks at the role of concepts such as growing social and economic inequity and the process by which neoliberalism establishes the framework of unequal opportunity and life chances. At this broader level resilience relates to interplay between the socio-political and health systems and the individual. It is the role of the health system to provide opportunities, supports and to reduce inequities to promote healthy lifestyle and beneficial coping approaches. We aim to understand and describe the mechanisms and opportunities afforded to individuals by their place in the social structure and to argue for health reform that makes a health system that assists all individuals be resilient. Longitudinal data from the Australian Epilepsy Longitudinal Survey is used to understand how income, inequity and social isolation affect resilience over time.*

**A Sociological Approach to Resilience**

**Biological, psychosocial and sociological approaches to resilience**

Biological and biophysiological models were the first to be developed in a scientific health care system. Stress, coping and resilience were initially shaped by an understanding of biological processes. 1 However approaches to resilience using biological processes and based solely on the medical model can be used to shift responsibility of stress, coping and health outcomes to the individual patient, seeing them fall short of resilience needed for healthy living. The purely biological approach is based on narrow conceptualisations and testing and on simplified cause– effect relationships.

In the development of the concept and processes of stress and later resilience the works of Hans Selye 2 and Walter Cannon 3 were seminal, providing the basis of far reaching models of physical and psychological processes which could be linked to other systems an individual was engaged in.

Psychosocial approaches to stress, coping and resilience emerged in the mid-20th Century and became the basis of psychological approaches to resilience. More recently however this approach has led to individualising people’s problems and identifying traits which make patients having poor resilience, something they could have overcome themselves. Lazarus 4 was one of the psychologists to have a large input into understanding stress and consequent resilience from a psychosocial perspective. He largely expanded on Selye’s idea that a person actively perceives a situation as stressful and then mobilises psychological resources to deal with the threat. The development of coping approaches leads to the growth of a strong personal resilience.

Southwick et al 5 take an American Psychological Association (APA) definition of resilience and extend its application. The APA defines resilience as how well trauma, adversity, threats, tragedy and significant types of stress are dealt with. This does not adequately explain how responses describe complexities of resilience which include psychological, biological, cultural and social factors interact with stressful situations 5.

More recently, new perspectives have developed following ‘natural’ disasters such as Cyclone Katrina 6. Vulnerability science explores disasters as functions of locality, societal conditions, political and economic forces that expose some social groups to potential harm and limits their ability to cope. It is also concerned with factors that make different social groups and individuals more resilient, meaning they either avoid or withstand the impacts of disasters and have strategies to recover from such events. With the growth of globalisation and neoliberalism over the past 3- 4 decades there has been an exponential growth of inequity in many developed societies. This has been manifest in a greater disparity in wages/salaries, increased unemployment and reliance on welfare of those in lower socioeconomic groups, and increased life stresses for the more marginalised sectors. There is an extensive literature on the life and work stresses faced by those in more vulnerable, powerless positions. Currently in Australia there has been a reasonable level of economic growth, accompanied however by an unprecedented low level of wages growth, coupled with the removal of some penalty rates. For those reliant on the more precarious types of employment and casualised work, this has greater ramifications for inequality.7

Socioeconomic disadvantage and its accompanying inequity of access to vital social and personal resources can lead to health and illness vulnerabilities. This can work through increased stresses and inadequate coping skills and resources to deal with economic, employment, social and health hardships. Pearlin, Menaghan, Leiberman and Mullan 8 refer to depression as a proxy for stress and they and other authors discuss its prevalence in the context of vulnerability and powerlessness. This can also be related to lower quality of life.

Ongoing research indicates that a person’s position in the social and economic structure and opportunity predisposes some people to have greater environmental and biological risk factors. In sum the psychosocial approach to stress, coping and resilience has added substantially to the biological approach but fails to offer a multidimensional perspective to address the underlying causes of such vulnerability in the first place and ignores the point that those groups of people who are most vulnerable occupy vulnerable positions in society 9. While health care and access to it is not as dramatic a disaster as Hurricane Katrina, in terms of unnecessary mortality and morbidity it is a continuing disaster. In this article we adopt this perspective to explore the role of inequality in creating health vulnerabilities and to use the solutions it offers to improve resilience at both an individual and societal level.

The relationship between health and social inequality is well documented by those concerned with the social determinants of health 10. Wilkinson and Marmot 11 present evidence on the role of social and psychosocial disadvantage in health. Summarising their work in this area they argue that when people are disadvantaged in terms of material assets, education, income and employment, poor housing and inadequate retirement incomes the effects of these disadvantage accumulate over a lifetime and contribute to early morbidity and mortality. “They are less likely to enjoy a healthy old age”11. In the social gradient of health this means that the further down the ‘social ladder’ the greater the vulnerability to poorer health outcomes for whole groups of people.

Australia, listed as one of the top wealthiest countries by the OECD 12 provides an instructive example of the relationship between the social gradient and health outcomes.

Australia as a whole has become much wealthier since 1970, with the total stock of capital growing about twice as fast as national income during the years since then. But inequality has markedly increased during this same period, and continues to increase. Currently the poorest 40% of Australian households have effectively no wealth at all: about half of them actually have negative net wealth because of their personal debts. At the opposite pole, the wealthiest 10% of Australian households have more than half the nation's total wealth. The Top 1% of households alone has at least 15 per cent of the nation's wealth. This affluent elite-the Top 10% and especially the Top 1% is getting cumulatively richer, not only relative to poor households but also, significantly, in relation to the next 50% of households 12. Rates of mortality are indicators of health inequalities as well as indicators of health and well-being. Mortality based on the Index of Relative Socioeconomic Disadvantage (IRSD) shows that across all age groups mortality rates were significantly higher in the most disadvantaged areas than in the least disadvantaged areas. For example, the relative difference for females between the least and most disadvantaged areas was largest among children aged 0–14 years (62%), which equates to 22 more deaths per 100,000 for females living in the most disadvantaged areas; and smallest for those aged 75 years and over (4%), which equates to 3 more deaths per 1,000 for females living in the most disadvantaged areas 13.

Another comparative example of inequality relates to Australian aboriginal population , where Aboriginal people can expect to live 17 years less than non-Aboriginal Australians .14 For all Aboriginal people in age groups below 65 years, the age-specific death rates are at least twice those experienced by the non-Aboriginal population. It is now acknowledged that these differences in mortality rates are related to access to education, employment, income, poor housing, the effects of discrimination including rates of incarceration and access to health care. 15 In each of these areas Aboriginal populations fare far worse than non-Aboriginal Australians.

**What is the role of the health system in reproducing vulnerability or improving resilience?**

A health system is not isolated from the political, economic and social structures though it is very often treated as such. Health systems can be strengthened and system made more resilient by concentrating on making health systems more responsive to delivering safe services that also improve outcomes of populations 16 17. Those who treat it thus, will argue that health system improvements within it will deliver improved outcomes to the populations the system serves. However these services may only be delivered to those who can access them.

Currently some health systems may make people with health conditions more vulnerable and create obstacles to becoming resilient. This may be seen from comparisons of health systems. 18 Most importantly these international comparisons demonstrate that the political ideologies of various nations play an important role in the way the health system functions impacting on equality and access to make people more or less vulnerable.

The Australian health system offers an example of the role of political ideology which also governs economic policy. Created as a system of national insurance funded by the tax payer in the 1970s, successive governments have introduced a “user pays” function which has increased out of pocket costs for medicines and medical services for health consumer.19 At the same time private health insurance has been supported by governments through tax payer funded subsidies that encourage higher income health consumers to take out PHI (John Menadue as below in the conclusion. 20 While “user pays” increases out of pocket costs the political ideology in which user pays is situated is integrated into the broader Australian economic structure so that welfare payments are low, if not impossible to access and wages are kept at low levels. At this present time full time work is hard to access and utility costs have escalated. 7 Recent research demonstrates that this policy of user pays has meant that nearly one third of the Australian population is made financially vulnerable by the co-payments on prescription medicines. 21

The authors consider that this economic policy approach does not support Australia’s National Medicines Policy of equality of access and equity to medicines.

To illustrate how economic policy creates vulnerable groups of people’s access to healthcare we present data on a cohort of people with epilepsy in Australian communities.

**Epilepsy: A sample of a vulnerable population.**

In the context of low incomes and lack of opportunities people with epilepsy experience socioeconomic disadvantage and the health care system is not sufficiently resilient to deal with these inequities. Referred to in an earlier paper 22 we discuss that the epilepsy sample has close to 85 per cent below the weekly average family income in Australia, with close to half living below the poverty line. This represents about four times the rate of individuals in Australia living below the poverty line. Also many were on disability pensions with many not being able to work due to their epilepsy.

They, like many chronic illness groups have people with multiple comorbidities, have reliance in many cases on multiple antiepileptic drugs 23 many of which have both physical and mental side effects. Many also have difficulties due to their condition in finding suitable work, and a high proportion is in receipt of Centrelink benefits. Overarchingly the prospect of having seizures has very strong self-esteem effects, impacts strongly on personal, family and work relationships and can lead to being stigmatised.

**A study of people with epilepsy**

Data on the social impact of epilepsy are collected by survey from the Australian Epilepsy Research Register (AERR) for all Waves of the Australian Epilepsy Longitudinal Study (AELS). It is a community sample of people with epilepsy. The Wave 3 (2013) survey tools used validated questions on education, income and employment, stigma, comfort with talking about epilepsy, personal control and economic hardship. Wave 3 had a response rate of 36.7% with 324 respondents out of a total of 883.

The personal control scale7 and economic hardship scale was compared with another longitudinal study representing the Australian household population, the Household, Income and Labour Dynamics in Australia Survey (HILDA). Wave 11 (2011) of the HILDA longitudinal study was used as it contained a relatively recent version of both scales and was used as a benchmark. Epilepsy results are also compared with a sub-sample of the representative HILDA Wave 11, people with long – term health conditions, disability or impairment.

*Note: The HILDA project was initiated and is funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and is managed by the Melbourne Institute of Applied Economic and Social Research (Melbourne Institute). The findings and views reported in this report, however, are those of the authors and should not be attributed to either FaHCSIA or the Melbourne Institute. These data are derived from Wave 11 (2011) of the HILDA survey.*

Pearlin’s Sense of Personal Control and Mastery over external events scale has seven question. 24  Good reliability and convergent validity have been reported. The scale is often used as two sub-scales but only its individual items are used in this study. Inequality and social context influence health. What is required is more of the social context and therefore socioeconomic data in the Australian context are discussed. 25 In addition an Economic Hardship set of items has been used from HILDA Wave 11. Only individual items are used for comparing the epilepsy sample to HILDA Wave 11 total sample and sub - sample.

***Personal control***

Wave 3 of the AELS has been used to demonstrate differences in the epilepsy sample’s personal control scores to a random sample of an Australian long-term condition, disability and impairment sample. In a previous paper (Walker and Peterson) 22 we have presented Wave 3 personal control scores compared to those of the whole sample of HILDA Wave 11 personal control. In this paper we are presenting Wave 3 results specifically compared to the HILDA long-term condition, disability and impairment sample.

In the previous paper we showed that Wave 3 responses on all of the personal control items were very much poorer than those of the HILDA Australian Household sample. As shown below when compared to the HILDA long-term condition, disability or impairment sample these differences between the epilepsy sample and the HILDA disability sample were of a lesser magnitude but in all the epilepsy personal control items were poorer than the long-term condition, disability and impairment sample.

**Table 1 Personal control**

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|  | **HILDA Disability\*** |  | **Epilepsy** |  | **Difference** |
| **Personal control** | **Mean (SD)** | **n** | **Mean (SD)** | **n** |  |
| There is no way I can solve the problems I have | 3.11 (1.93) | 3534 | 4.28 (2.21) | 274 | +1.17 |
| Sometimes I feel I am being pushed around in life | 2.86 (1.86) | 3524 | 4.05 (1.99) | 277 | +1.19 |
| I have little control over things that happen to me | 3.14 (1.90) | 3539 | 3.85 (1.99) | 275 | +0.75 |
| I can do just about anything I set my mind to | 4.85 (1.73) | 3539 | 4.76 (1.73) | 276 | -0.09 |
| I often feel helpless dealing with problems in life | 2.96 (1.87) | 3542 | 3.87 (1.93) | 274 | +0.91 |
| What happens to me in future mostly depends on me | 5.20 (1.18) | 3539 | 5.33 (1.71) | 273 | +0.13 |
| There is little I can do to change many important things in my life | 3.19 (1.88) | 3538 | 3.52 (1.93) | 275 | +0.33 |

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\*Long-term condition, disability or impairment

All items above are scored negative for negative statements and positive for positive statements.

Each of the items is scored from 1 – 7. ‘There is no way I can solve the problems I have’ and ‘sometimes I feel I am being pushed around in life’ were the two items comparing least favourably with the HILDA long-term condition, disability or impairment sample. ‘I can do just about anything I set my mind to’ and ‘what happens to me in future mostly depends on me’ are the two items closest to the HILDA responses. Three of the items were 0.91 or more showing less control on the scale of 1 – 7. Only ‘what happens to me in future mostly depends on me’ for the epilepsy sample was similar, representing only slightly poorer control, to the HILDA long-term condition, disability or impairment respondents.

***Financial hardship***

**Table 2 Financial hardship**

|  |  |  |  |
| --- | --- | --- | --- |
| **Hardship** | **Wave 3 Epilepsy** | **HILDA Disability** | **HILDA ALL** |
|  | **n (%)** | **n (%)** | **n (%)** |
| **Could not pay electricity, gas or telephone bills on time** | 66 (23.2%) | 606 (17.1%) | 2117 (14.0% |
| **Could not pay the mortgage or rent on time** | 38 (13.6%) | 281 (8.0%) | 1036 (6.9%) |
| **Pawned or sold something** | 46 (16.2%) | 280 (7.4%) | 837 (5.5%) |
| **Went without meals** | 34 (12.0%) | 231 (6.5%) | 581 (3.8%) |
| **Was unable to heat the home** | 21 (7.6%) | 274 (7.8%) | 606 (4.0%) |
| **Asked for financial help from friends or family** | 75 (26.1%) | 542 (15.3%) | 2076 (13.7%) |
| **Asked for help from welfare/community organisations** | 32 (11.3%) | 258 (7.3%) | 642 (4.2%) |

On each level of hardship experienced over the preceding 3 years the epilepsy sample had about twice or more the proportion of people experiencing hardships compared to all people in the HILDA sample. They were also substantially higher proportions than HILDA people with a long-term condition, disability or impairment. The greatest proportion of the epilepsy sample asked for financial help from friends or family and could not pay electricity, gas or telephone bills on time. They were much more likely to have pawned or sold something, gone without a meal or asked for help from welfare/community organisations than the random selection of Australian households, as well as those with a long-term condition, disability or impairment.

**Implications; how epilepsy disadvantage is related to inequity**

The results presented here show that personal control is well below the level of HILDA, a random sample of the Australian household population, and below those in HILDA who have a long-term condition, disability or impairment. We have also reported previously that being in employment provides a significantly better level of personal control. 22 Further, it showed with a specific epilepsy condition, that having seizures frequently compared to no seizures over for the past 12 months substantially reduces control.

The epilepsy sample faces about twice or more the level of economic hardship compared to the HILDA ALL sample and substantially more than the HILDA disability sample. In addition those who cannot work due to epilepsy, or due to illness or a disability have poorer psychosocial health than those who do not have those constraints. 26

Epilepsy literature reports stigma as a particular problem for people with epilepsy.27, 28 Stigma can be seen as a personal state experienced and also as a result of systemic influences of the socio-political system. People need to draw on psychosocial resources for coping with stigma, but their stigma results in a large degree from their social position, labelling that has taken place and inequity experienced as a result of having a chronic illness that is not well understood in the community and fewer material and social capital resources. Personal control is influenced by position in the social structure and coping approaches and strategies that some wealth, education and position afford. It has been associated with education, position and life changes and has been shown to be poorest for those in low socioeconomic and socio-political situations. 29, 30

Low levels of personal control which is a key component of personal resilience, is largely due to the social and economic vulnerability of the epilepsy population, its level is well below a random sample (HILDA) of the Australian population. Consequently the personal resource important in coping with stressful situations (note Peterson) is markedly weakened. 9 Personal control is more a product of life chances and place in the social structure and opportunities afforded than the physical and mental ‘toughness” of individuals, often seen in a vacuum rather than in their socio-political context.

Anxiety and depression have been reported to be higher in epilepsy samples than in the general community 31 and most notably more in those in lower socio-economic positions. This has been established in the Marmot studies 32 of differences in stress and adjustment between high and low positions in the British civil services. Being psychosocial concepts, anxiety and depression are deeply rooted in socioeconomic and socio-political structures with evidence that they exist to greater degrees at lower socioeconomic groups. 33 34

**Concluding comments: What are the best forms of health systems to achieve resilience?**

There are some interventions in the social structure that can positively impact on health, including antismoking campaigns. However one criticism of some of these interventions is that they imply that a middle class life style is the most appropriate. But without adequate socioeconomic resources that underpin it, it impossible to succeed and this may lead to increased stress and poorer health. We argue that in the context of growing inequality in society a health care system needs to increase resilience of its users by reducing inequities in access, treatment, care and support. Internationally there are wide differences in the way that diverse health systems work. Schneider et al., 18 analyse health system performance for eleven developed countries including Australia, UK, US, Canada and other European countries. The UK, Australia and the Netherlands were top ranked in overall performance and the US was poorest in Access, Administrative Efficiency, Equity and Health Care Outcomes.

In terms of equity which refers to such things as differences in access between high and low income consumers UK, the Netherlands and Sweden ranked highest while the US, France and Canada had very big differences between high and low incomes related to issues such as financial barriers and skipping doctors’ visits when needed, For Australia the poorest ranked indicator of the health system functioning was equity, so that even though it has a highly performing health care system the main area of concern is related to issue such as differences in access between those with high and low incomes.

Increasing equity will make the Australian health system more accessible to those who most need the services. Duckett & Breadon 35 argue that increases to out -of - pocket costs for visiting a doctor and getting prescription medicine s and tests make many Australians more vulnerable and that while health care costs can be reduced this should not be done by shifting costs through regressive taxation measures and charging co-payments, but could be achieved by lower drug prices, making medical specialists’ fees more transparent and updating workforce roles.

Taxpayer subsidisation of private health insurance effectively means a redistribution of funds via government budgets of $6.565 billion, the outcome of which is to increase health inequalities, as those who receive these rebates for taking out private health insurance benefit from $1.6 billion, tax-free income. The money saved by abolishing this subsidy would effectively mean redistribution to the broader population and for example could be spent on either preventive health or dental care which many Australians on low wages cannot afford at present. 20

Another aspect of health care rarely discussed is that under the current Australian health system allocation of health care relates to those who can afford it, as well as those who are seen as priorities by the government, with the medical profession acting as gatekeepers to health services. 36 The example of people with epilepsy discussed demonstrates that this approach contributes to inequality by limiting services based on diagnosis rather than actual need amongst all ill people.

However much more needs to be addressed. The example of indigenous health demonstrates that relying solely on health system reform does not work. Money spent on health has been slow to improve health outcomes because of lack of jobs, income, housing and education and this requires rethinking at the political level, where the social, welfare and health systems are all seen as interlinked and working towards the health of the whole population. Much could be gained from this approach benefiting people and the economy.

The findings of The Cost of Inaction on the Social Determinants of Health37appear to suggest that if the World Health Organisation’s recommendations were adopted within Australia:

“500,000 Australians could avoid suffering a chronic illness; 170,000 extra Australians could enter the workforce, generating $8 billion in extra earnings; annual savings of $4 billion in welfare support payments could be made; 60,000 fewer people would need to be admitted to hospital annually, resulting in savings of $2.3 billion in hospital expenditure; 5.5 million fewer Medicare services would be needed each year, resulting in annual savings of $273 million; 5.3 million fewer Pharmaceutical Benefit Scheme scripts would be filled each year, resulting in annual savings of $184.5 million each year. “

These remarkable economic gains are only part of the equation. The real opportunity for action on social determinants is the improvements that can be made to people’s health and well-being.

**Conclusion**

While individual resilience is problematic for health and health care, the key to its enhancement lies in broader social and structural issues that promote inequity and consequently vulnerability. For chronic illness groups such as those with epilepsy there are systemic disadvantages which occur in the health care system. If a health system is developed to promote and enhance resilience in those needing health care important inroads would be made into the issue of strengthening personal resilience.

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