

Human infrastructure in health: a commentary on networks of supports

Heidi Muenchberger^{1,2} PhD, MCLinPsych (Neuro), BBehSc(Hons), Senior Research Fellow

Elizabeth Kendall¹ PhD, BArts(Hons), Professor

Hoon Han¹ PhD, Research Fellow

¹Griffith Health Institute, Griffith University, Meadowbrook, QLD 4131, Australia.

Emails: e.kendall@griffith.edu.au; h.han@griffith.edu.au

²Corresponding author. Email: h.muenchberger@griffith.edu.au

The move towards community health settings and health partnership initiatives in managing chronic disease have inadvertently created a renewed focus on the social economy in Australia, particularly the informal human structures of support and significance (people, professionals and partnerships) that can contribute to health. Although these initiatives have also pointed to the need for greater flexibility of service delivery and trans-disciplinarity of health professionals, their ultimate success rests on the quality of the underlying human infrastructure to support these changes. Over the past two decades, a confluence of observations and research studies have confirmed the existence of, and need for, a social construction of health and chronic disease management (see e.g. Gallant,¹ Israel² and Norris *et al.*³). Undoubtedly, chronic conditions may precipitate a process of deep introspection, identity change, and extreme modification of day-to-day activities for the individual or 'self' (see Charmaz⁴ and Muenchberger *et al.*⁵). However, the role and significance that others play in lessening the impact of chronic disease on the individual although often mentioned, remains vastly underestimated and even less well understood. In the absence of a comprehensive understanding of the human infrastructure that is expected to support the shift towards prevention and coordination in the community, the burden of disease will continue to damage social networks, maintaining inappropriate, unsustainable and costly dependencies on health services.

The social construction of health and wellbeing can be best understood when considering the concept of self-management. The idea that self-management in chronic disease is solely an individual's responsibility is a tempting, but fundamental error of understanding. Self-management courses are often delivered to individuals (within a group context) by a trained peer or health professional, and the goals and outcomes specified are largely individually focussed (e.g. individual gains in knowledge, skills and health utilisation).³ The information on 'managing self' in chronic disease is usually disseminated by way of an individual workbook, and goals are documented in response to individual priorities, needs and capacities. There is also a component focussed on locating effective support and linking with healthcare providers.⁶ Even though there is an implied assumption, if not expectation, that including family members or significant others

will somehow facilitate self-management goals over time, what is not often clear is the nature or quality of the role that family members or significant others must assume in order to facilitate this change in health behaviour.

A comprehensive review conducted by Gallant¹ explicated the particular importance of emotional support in self-management (especially perceived support). Gallant argued that effective self-management relies on the facilitated relationships between family, peers and healthcare professionals (see also Kendall *et al.*⁷). Although there is increasing focus and resources dedicated to optimising the patient–health professional partnership in chronic disease, the same cannot be said for family and friendship networks where the impost may be much greater. Without in-depth studies documenting the quantity and quality of the social infrastructure and how it is used by people with chronic conditions, it is difficult to determine actual social and financial implications. For instance, in Australia between 1998 and 2003, 93 900 people with severe (including chronic) conditions required daily assistance with core activities.⁸ Presumably, most of this daily assistance came from family or friends. Indeed, almost half of disability services delivered to people with chronic conditions have been found to be provided through informal support sources.⁹ A major question, therefore, becomes how the health service system can support, maintain and partner with this significant social network to improve the health of people with chronic conditions.

Although people with chronic conditions may know whom in their informal social network they can turn to for help or advice at crucial points in their lives, they are usually less well equipped to select and mobilise appropriate primary care providers who can interact successfully with their natural support systems. Current knowledge about the structure and quality (rather than quantity) of social support for people with chronic conditions is developing, but gaps remain. For instance, health professionals know relatively little about how to engage the specific social supports that exist for individuals, and what interventions and decision processes are required to maintain the long term involvement of important natural or informal supports in people's lives. As researchers and clinicians, we are even less well equipped to develop and adjust our methods of practice to incorporate the natural social infrastructure.

Unequivocal evidence supports the interdependence between people and their social environments. Indeed, social factors have been viewed as both a fundamental cause of major health problems, but also the best context in which to develop innovative solutions.¹⁰ Over a decade and a half ago, it was noted that ‘individuals with chronic or severe illnesses are more likely to employ strategies with friends or family members (in combination with physicians) than the physician directly’.¹¹ However, it seems that we have not advanced past this recognition in the subsequent years. In 2007, the World Health Organization (WHO) Commission on Social Determinants of Health confirmed the need to set solid benchmarks in societal relations and factors that influence health, so that health becomes a whole-of-community concern not just reserved for governments.¹² However, health policy in some countries has been slow to recognise the importance of the social context and its direct influence on wellbeing. In Australia on 25 February 2008, the ANZCOG (Australia and New Zealand Council of Governments) reported that the key to success in achieving social inclusion is having widespread networks of relationships. ANZCOG established that, although most people’s needs are currently met through the family or social networks and those without such networks are more likely to be excluded, adequate recognition of family and social networks have been missing from government policy and platforms.

To further highlight the current shortfalls in our understanding of social supports, in May 2008, the then Prime Minister of Australia, established the Australian Social Inclusion Board to address key areas of policy and development.¹³ Two explicitly stated aspirational principles for health reform involved the need to establish (a) social networks, and (b) strong relationship between all levels of government and services. The report stated that ‘people with well-established social networks and institutional connections are more likely to deal successfully with personal crisis and adversity’ (p. 1), and ‘Building effective partnerships to tackle shared priorities is essential to improving social inclusion over time’ (pp. 2–3). Despite acknowledging the protective benefits of social networks of support, there is a lack of comprehensive understanding of the nature of these networks and covert structures.

It is clear that we require more detailed and targeted attention to the nature of the social support infrastructure if we are to understand the pathways individuals travel in developing health habits and care choices, and develop socially-based preventative strategies. Attention must be given to both the processes (or quality) and structures of social support,¹⁴ with examination of key concepts such as exchange (i.e. reciprocity,¹⁵ equality), control (i.e. regulation) or conflict (i.e. negative support).^{14,15,16} Although it is clear that what individuals give to each other makes a difference to their social and health outcomes,¹⁷ the situation is far more complex than has been articulated by governments and policy-makers.

To illustrate this complexity, we return again to the concept of self-management. Effective self management depends on the ability of the individual to make use of his or her social supports and resources in a way that does not deplete the relationship, but facilitates a meaningful exchange of information, emotional support, skills and positive respect.¹⁸ Even the level of participation and involvement in self-management courses is dependent

on social factors for both individuals with chronic conditions as well as health professionals. For people with chronic conditions, whether or not they agree to participate in self-management courses in the first instance is dependent on their social situations and status,¹⁹ such as whether they have the support of their spouse to attend the course, if they live alone or if they are typically confronted by other culturally related challenges making attendance difficult. Health professionals who choose to deliver self-management support are likely to struggle with judgements relating to their social boundaries. The nature of the interaction between health professionals and consumers is altered during these interactions. For instance, researchers have questioned how much ‘support’ can be realistically provided by a health professional, given that this typically characterised by one-way exchanges (provider to patient) that are discordant with a self-management philosophy of practice. As documented in self-management and rehabilitation research (see Catalano *et al.*²⁰ and Kendall *et al.*²¹), community leaders of self-management courses may be torn between providing emotional support to participants, and offering proxy, ‘disaffected’ and sometimes superficial solutions to their support needs (e.g. information flyers, lists of service providers). The entire interaction depends on social networks that are developed, understood by all parties and negotiated successfully to produce positive outcomes. The role of the social network cannot be treated lightly in this context.

If we accept that primary healthcare is embedded within a wider social infrastructure and that this infrastructure is based partly on the self-motivation of the individual and partly on the structures of social opportunity (e.g. healthcare access, insurance policy, social position, neighbourhood capacity), then it is also necessary to incorporate the role of both micro and macro social determinants^{11,14,22} of health in all future policy. Micro level (i.e. individual and service) social determinants might include: employment, living arrangements, disease type and severity, hospital admissions and experiences, experience of a general practitioner, friendships, family cohesion and social roles. Macro level determinants (i.e. population and environment) might include transport and access to healthcare, socio-economic status, political and policy directives and interactions between health systems and natural social networks.²² All of these variables are relevant in determining the structural connectivity of an individual and the likely journey they will embark upon in controlling their chronic condition over time. Attention to these factors and sharing this knowledge in a meaningful way will facilitate our understanding of the broader social context in which health is created. For instance, important questions could be resolved: is a person who lives in a certain location with a certain disease, of certain age and cultural identity, and socio-economic status more likely to consult with their general practitioner, allied health provider, friends or family before making a health decision? Is there a predictive pattern of social exchange that individuals consider when determining their health choices? What aspects of these social connections can be used to optimise healthcare delivery and self-management goals? What are the gaps in an individual’s social support structure that might be targeted in future interventions? How do social networks and the social geography interact with public health systems? A series of fundamental questions related to quality and quantity can also be dealt with: do diverse (extensive network) or proximal (close

network) ties determine health status and health decision making? How do negative (harmful) or positive (helpful) network ties contribute to health status and health decision making?

Contemporary answers to these questions can be found in more sophisticated research designs incorporating the social determinants of health and chronic disease epidemiology. Innovative techniques for mapping and testing the integrity of the social support networks in chronic disease would be extremely useful, as would the application of meta-methods, where a collection of datasets from diverse origins are synthesised to produce new perspectives. To achieve this focus, we need to seek shared and standardised visions, measures and methods of studying social inclusion, social determinants of health and social support. It will be necessary to understand the 'human journey' of people with chronic conditions: who is in their support circle, what are the sensitivities associated with communicating medical information to significant others or including them in treatment, how does the patient access appropriate human supports and at what points in time and how can this process be supported both clinically and systematically. Cultural sensitivities are crucial in this context, as people with chronic conditions who come from some culturally diverse backgrounds rely even more heavily on their social connections given their mistrust of government systems. For these populations, the role of natural supports must be investigated and incorporated into responses.

Preventative management of chronic disease and promotion of self-management as a 'socially constructed' strategy will increasingly involve mapping the breadth and depth of human connectivity and supportive relationships. There are trends to suggest that we should tailor health strategies such as self-management to specific conditions. We argue here that, in addition, we must tailor research to the local social infrastructure and the supportive capacity of the social network that sits around each person. As clinicians and researchers, we need to find ways of optimising this support without placing extra burden on already stretched informal social resources. Doing so will ensure positive and sustainable outcomes not only for individuals with chronic disease, but also for entire communities.

Competing interests

The authors declare that no conflicts of interest exist.

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