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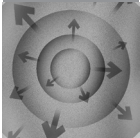
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The person's perspective of chronic condition self-management: Time to shift from rhetoric to reality

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This article argues for greater understanding, acknowledgement and inclusion of the person's perspective of chronic condition self-management as part of the development of health services. This is based on the belief that current debates and initiatives continue to be limited by knowledge that is largely vested within the health professional realm.

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Much has been written about chronic conditions, their management, and their self-management, particularly since the development of the Chronic Care Model (Wagner, Austin & Von Korff, 1996). A great deal of this literature comes from the perspective of service providers and discusses the many layers of service system organisation and responses. The ideas discussed and the way they are translated into practice make many assumptions about and for the person receiving support, yet health professionals within those services continue to say that they are working in a person-centred way. Health professionals often make assumptions about how people will respond to becoming and being clients of services.

An interesting exercise is to be on the receiving end of a system, with the potential to be judged, not listened to, or have your views dismissed as non-professional and therefore non-

expert. It is as if health professionals are claiming 'expertise' in the person's perspective, 'professionalising' it or confining it as if it is a box they can tick off as done. There is something fundamental about the person and their experience of their health and the receipt of support that is still largely missing from the literature and debates. Much of the chronic condition self-management (CCSM) literature contains sweeping statements about collaboration, partnership, engagement, and so on, but it has not been good at describing what that actually means from the person's perspective. It's largely one-sided still. The paucity of literature that addresses CCSM from the person's perspective illustrates the silo view of CCSM as one small ingredient of chronic health care, rather than it being central to the process. Its meaningful inclusion is, arguably, a first step to achieving real person-centred care on a broad level.

However, people's experience of managing their health and making choices about their health is vast. People are more than a string of symptoms to be managed with medications and behavioural adjustments. They have complex life histories that impact on their health behaviour in spite of knowing what is 'good for them'. Within the service provider driven interpretation of health, denial, non-compliance and lack of insight are deemed as being problems to be assertively addressed with education, treatment and behaviour change therapy. Yet, from a service user's perspective, their perceived non-compliant behaviour may sometimes be a wish to escape the rigours of chronic illness management and to escape being defined as the condition; that is, an act of trying to take back some control within a process that may be perceived to be out of control or a system that is controlling (Gabe, Bury & Elston, 2004, p. 111; Fincham, 2007, p. 160).

Within this 'healthism' realm, self-regulation is viewed as being the path to good health and those who choose not to self-regulate or who demonstrate some deviation from this are perceived as somehow lacking or lazy, morally responsible for their situation and blamed, shamed and stigmatised for their circumstances: "Under this paradigm, all behaviours, attitudes and emotions that are deemed to put individuals at risk of disease are medicalized and people become morally obliged to correct unhealthy habits" (Paterson & Hopgood, in preparation).

Corbin and Strauss (1988) said that "a tug of war goes on among the management needs of illness, everyday life, and biography" (p. 109). The prioritisation of one or two of these comes at costs to the other(s). Taylor (1979) defined it as diseases, illnesses and predicaments. What this shows is that self-management needs to be socially contextualised. It is not just about health, but about the whole person, and the person within the social, cultural, economic and political context. Much of the discussion in the CCSM area assumes that people are free to make the choices that health professionals say they 'should' be making to be responsible and self-disciplined. Yes, life is not really like that.

People rarely make decisions based on their own needs and preferences all the time. They exist within a social world ultimately. What they do every day is to try to balance all the decisions that fill up their lives. Many compromises must be made. The challenge is to manage all these competing influences, pressures and expectations. Sometimes they get the health ones right, and at other times such decisions have to take second place with all the other competing demands upon the person and their other obligations and 'responsibilities'. The process is not a simple linear one. Little wonder some people find it difficult to know where to start, to get started at all, or to make choices that health professionals and others may perceive as unhelpful or self-destructive.

In order to address the growing burden of chronic conditions on the community, the notion of health care needs to be expanded to take account of the whole person within their community; one that fully acknowledges broader contexts for interaction and behaviour. This involves a health system that is built upon

people and communities with shared power and resources to manage their own health rather than being subject to provider and discipline hegemony, dominance and control. This need is apparent every day within health care systems where health professionals continue to tell people what they should be doing and where service users struggle to follow the 'good advice' of health care providers or simply do not access services in the first place. Interestingly, the predominant findings of a recent audit of the skills of the Australian primary health care workforce, commissioned by the Department of Health and Ageing, found that workers largely do not understand how to support behaviour change by service users, and service users continue to report that health workers largely do not listen (Battersby, Lawn et al., 2008).

Ultimately, CCSM is not just about the way people treat themselves and the individual choices they make, but the way they treat each other and are treated by others that influences their behaviour. Addressing social determinants of health, stigma, racism and other broad concerns are as important to effective CCSM as supporting the internal processes of behaviour change.

The chronic care model talks of the importance of activated informed patients, prepared proactive practice teams, and informed enlightened health policy. Yet little guidance exists in how to achieve these goals in practice. The lack of inclusion of the person's perspective and understanding is at the heart of the failed implementation of many initiatives; this must be addressed. It is not only unbelievably costly to health systems and communities, but to the people themselves. And there is still little understanding of how to support those people referred to as "pre-contemplators" of change (Prochaska & DiClemente, 1992).

A system that continues to specialise and dissect the person's issues and needs into silos and that fails to understand the whole person within their social context, and in which health is "managed" by health professionals, will continue to diminish incentives for the person to take control of their health, and, in turn, their life. Fortunately, there are many emerging examples of a positive shift within policy. The rhetoric is there; the practice now needs to follow.

References

- Battersby, M. W., Lawn, S., Wells, L., Morris, S., Lindner, H., Matthews, R., Litt, J., Reed, R. 2008, *An Analysis of Training and Information Options to Support Chronic Disease Prevention and Self-Management in Primary Health Care*, Flinders University, South Australia.
- Corbin, J.M. & Strauss, A. 1988, *Unending Work and Care: Managing Chronic Illness at Home*. Jossey-Bass Publishers, San Francisco.
- Fincham, J.E. 2007, *Patient Compliance with Medications: Issues and Opportunities*. Haworth Press, New York.
- Gabe, J., Bury, M. & Elston, M. 2004, *Key Concepts in Medical Sociology*. Sage, London.
- Paterson, B. & Hopwood, M. In preparation, 'Harm reduction as a frame for prevention of disease-related complications in chronic illness', Chapter 4 in *Translating chronic illness research into practice*, D. Kralik & B. Paterson (Eds.), Blackwell Synergy Press, London.
- Prochaska, J. & DiClemente, C. 1992, 'Criticisms and concerns of the trans theoretical model in the light of recent research', *British Journal of Addiction*, Vol.87, pp. 825-826.

Taylor, DC. 1979, 'The components of sickness: diseases, illnesses, and predicaments', *The Lancet*, Nov 10, pp. 1008–1010.

Wagner, E., Austin, B. & Von Korff M. 1996, 'Organizing care for patients with chronic illness', *Millbank Quarterly*, Vol. 74, pp. 511–542.

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