

# Sisyphus and self-management: the chronic condition self-management paradox

Peter W Harvey and Barbara M Docherty

## Abstract

Chronic condition self-management is promoted internationally as not only a possible solution to the health problems of our increasingly chronically ill and ageing population, but as part of a new wave of consumer-led and volunteer-managed health care initiatives. Consumers are now indicating that they want to be more involved in the management of their lives and their health care options, while, especially in rural and smaller communities in Australia, a shortage of clinicians means that health care is rapidly changing. This emphasis on self-management raises crucial questions about where consumer action and control in health care should end and where clinical and medical intervention might begin. Hence, as in the case of Sisyphus and his rock, the self-management process is a difficult and demanding one that poses major challenges and loads for health system reformers and represents a struggle in which new difficulties are constantly emerging.

This paper examines some implications of new self-management approaches to chronic illness from an ideological perspective and highlights key elements that underpin the effort to promote health-related lifestyle change. While peer-led self-management programs may assist certain individuals to live engaged and meaningful lives, the essential social and economic determinants of health and wellbeing mean that these programs are not the answer to our urgent need for major reform in the health care arena. Rather, self-management, from an ideological perspective, represents a minor adjustment to the fabric of our health system.

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THERE HAS BEEN MUCH DISCUSSION about the efficacy of chronic illness management programs, care planning, regular health assessments, preventive primary health care and the

## What is known about the topic?

Self-management has been considered to be an effective approach to the management of chronic conditions.

## What does this paper add?

This paper questions some of the basic premises of self-management in health care using the analogy of Sisyphus, who was condemned to continually roll a rock up a hill. Concern is expressed that self-management that is solely focused on the involvement of people in the management of their lives and their chronic conditions equates to “rock rolling” as it does not address a more revolutionary community approach to health system reform and development.

## What are the implications for practitioners?

The authors suggest that through system-level consumer collaboration and cooperation it is possible for health professionals, consumers and carers to develop a comprehensive team to enable the translation of medical approaches to care into more holistic approaches. In these approaches a wider range of factors impacting on consumer health and wellbeing would be considered in illness management and treatment.

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role of self-management in these processes overseas and in Australia. This discussion advances the idea that the adverse impacts of chronic illness can be mitigated through individuals assuming more responsible and healthy approaches to their lifestyle and to the management of their health and wellbeing generally.<sup>1</sup> That is, we can improve wellbeing, and reduce the financial impact of illness upon the health system through educating people about positive and constructive approaches to healthy living and developing their skills for managing their care.<sup>2-5</sup> Such efforts, however, remain focused on people with existing chronic illness and are yet to grapple with the longer term earlier intervention and prevention of illness that appears to be necessary if we are to create improvements in overall health and wellbeing in future generations. We are faced with the immediate challenge of dealing with people who already have chronic diseases, but in the long term we can't simply wait until chronic illness becomes evident and then learn to manage it. We will need to prevent much of this illness burden from occurring in the first instance as well as resourcing the management of existing chronic conditions if we are to improve the long-term outcomes of our health care system.<sup>6</sup>

Although self-management appears to be a wholesome idea, Wilson argues that we need to examine more carefully the motivation behind the self-management trend in health care. Changes in consumer empowerment and involvement in health care need to be placed within the context of personal and institutional power relations, and health professionals must, accordingly, examine whether such trends are about saving resources, reinforcing the social construction of chronic illness or facilitating a real shift of power to the consumer.<sup>7</sup> Others argue that the empowerment of consumers within the health care system might drive up demand as consumers learn more about their needs, and as their expectations for their health and wellbeing rise.<sup>8</sup> This appears to be the case for the baby boomer generation in the United States, which may be indicative of trends in Australia.<sup>3,6</sup>

The nation's [US] 65-year-and-older population will swell from 35 million in 2000 to 53 million in 2020 as the baby-boomer generation reaches the age of increased chronic disease prevalence. Many baby boomers bring to the health care system a high level of sophistication. In the view of one analyst, baby-boomers 'will accelerate the movement and awareness of self-care and wellness and will irreversibly alter the traditional doctor-consumer relationship'.<sup>3</sup> (p. 2469)

Therefore the self-management phenomenon embodies paradox — for generations consumers have been increasingly alienated from the complex process of maintaining health and wellbeing, and health care has become more and more the preserve of highly trained professionals. Consumers have been persuaded to abrogate their responsibility<sup>9</sup> for their lives generally, some say brainwashed, as they are trained in numerous ways to be passive consumers of everything from education to motorcycle maintenance and the way they manage their health. Conway suggests, "We are confronted with an Orwellian nightmare of entire societies debauched by childish oral-narcissistic and anal-acquisitive appetites which are justified by the scientific jargon of economists and made to seem sober and ethical by the use of statistics."<sup>9</sup> (p. 203)

What chance do discerning consumers and self-managers have against such overwhelming forces of social conditioning and control? The creation of passive consumers has been central to the development of the wider consumer society upon which much wealth and economic growth is currently predicated in the West. Growth depends on consumption, but consumption can sometimes be bad for our health!

The orchestrated alienation of consumers may be economically detrimental to both the individual and society generally, and better-informed, participating consumers might make for healthier and more functional communities.<sup>10</sup> Blind consumerism, at least in the case of health care, is undesirable from a systems perspective. People are encouraged to become "responsible consumers" and "partners" in the system rather than

mindless consumers of health care. When it comes to fast food we may be encouraged to consume and up-size blindly, but in relation to expensive health care, which is necessarily capped at a predetermined level of gross domestic product, we must be parsimonious in the interests of the health of the whole community and, of course, in our own wellbeing.

This presents a paradox — trained consumers must become retrained and mindful partners in the provision of health care. The challenge of self-management programs in health is therefore, in the first instance at least, to assist consumers to lessen the load of Sisyphus's rock and resolve this paradox by learning to take back some control. Ironically, this is the very control that we have all been encouraged hitherto to hand over to others without so much as a second thought.

## **Behaviour change**

Mechanic, as early as 1979, questioned the wisdom of a general approach to behaviour change, suggesting that there was little correlation between patterns of behaviour and the idea of responsibility for actions generally, or for health specifically.<sup>11</sup> He suggested that rather than focusing on educating for generally responsible behaviour we should concentrate on specific problem areas like smoking, exercise and diet so we can change behaviours known to correlate with adverse health outcomes. The idea of general responsibility for health is a broad concept and the psychological and social factors that motivate human behaviours (eg, smoking and high-risk activity) are implicit in powerful, deep-seated causes of human behaviour within society of which we have only a primitive understanding.<sup>11</sup> This is to say nothing of the inherent contradictions, as outlined above, in socially “trained consumers” encouraged to become “retrained partners” in health care, but not in relation to other aspects of their lives as economically and socially constructed consumers.

Others argue that the task of changing entrenched health-related behaviours is too difficult, and chronic disease self-management

approaches are dismissed on the grounds that these methods are not based on sound medical practices and that consumers may suffer from medical complications requiring professional management<sup>12</sup> to help them live more empowered lives. This may be misrepresenting the idea of self-management somewhat, at least as it is defined by Von Korff,<sup>13</sup> where self-management

involves [the person with the chronic disease] engaging in activities that protect and promote health, monitoring and management of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment.<sup>14</sup> (p. 43)

The criticism stands, however, that whatever social or behavioural aspects of chronic illness management we employ, there can be no substitute for the proper and timely medical intervention required to manage the clinical complications of chronic illness. Perhaps a more useful way of conceptualising the self-management phenomenon, therefore, is as a partnership between the consumer and the health professional in which each takes control of the elements of health care and daily living that are directly relevant to and best managed by them.<sup>15-17</sup>

Broad-based behaviour change strategies are not always effective at all levels of the community. The good health and prevention message reaches only certain population profiles.<sup>18</sup> We have evidence that some groups in Western society are becoming sicker<sup>19</sup> in spite of the good health messages that abound. Training as passive consumers may have become so deeply a part of our consciousness that retraining or reconditioning for prudent consumption in relation to health and wellbeing is really a contradiction too difficult, if not impossible, for some people to resolve. Another common assumption is that consumer concern about health is a prime motivating factor in behaviour change. This is not the case, as smoking messages, alcohol advertisements, healthy food pyramids and gambling text messages attest.<sup>20</sup> Simply hearing a message doesn't equate to an effective stimulus for change; infor-

mation alone is not sufficient to motivate and maintain behaviour change.<sup>21</sup>

This view of the deep-seated nature of human health-related behaviour challenges initiatives like chronic illness self-management programs that are predicated upon consumers accepting greater responsibility for their health in an environment where they are conditioned to neglect responsibility for their actions. They will be unable to take responsibility for their own health until they know it matters, and carrying on destructive behaviour is often far less debilitating for people in the short-term than attempting to initiate lifestyle change.<sup>22</sup>

To add further complexity, such responsibility is expected to manifest itself after a lifetime of adverse social and environmental influences or, at least, of less than optimal health-related behaviour. This is a simplistic view of cause and effect and does not fully accommodate notions of social and economic determinism in health.<sup>23-26</sup> In short, the desired end of self-management programs for some groups in society might be nothing less than an archetypal conversion; Paul on the road to Damascus or Saint Augustine after a life of debauchery.<sup>27</sup>

That self-management programs might be worthwhile weapons in the health management armoury is not questioned. However, without tackling the larger ideological drivers of poor health, self-management can only really be one alternative solution, and an alternative that may not be suited to large numbers of people who, for various reasons, may never be effectively engaged in the process. We might be better to concentrate on other methods of reducing risk-related behaviours that are not required to appeal to a hitherto absent sense of goodness and compliance. This appeal, presumably, is designed to miraculously kindle a sudden bout of responsible self-management in spite of the other powerfully contradictory social messages that may be influencing behaviour. We are primarily social creatures and our state of wellbeing is generally created out of a social environment.

It is probably more likely that the “Lorig approach” to self-management<sup>28-30</sup> might be less

about the vagaries of human goodness and more about reducing the impact of chronic illness upon a flagging health care system. Self-management in this context is really about managing at the level of the self, rather than systems-level approaches to reducing the social and economic causes of chronic and complex illness. It is about promulgating an ideology of individual control and causation rather than accepting the domination of the larger systems influences over behaviour and quality of life: a stance, which, as outlined above, is essentially problematic.

The Australian Government chose self-management as a key plank in the chronic illness management strategy rather than reform the health system (as was intended at the time of the COAG flirtation with managed care models).<sup>31</sup> This is indicative of the tendency to choose less costly strategies over more significant and wide ranging attempts at reform. Most people in the health business still think of the Australian Coordinated Care trials simply as a method of coordinating consumer care rather than as a strategy for transforming the health system by fundamentally restructuring the service purchasing and delivery arrangements to improve outcomes and efficiencies across the whole health care system.<sup>32-39</sup>

Our current preoccupation with self-management ignores wider community health ideologies and determinants. Instead of major systems reform the focus is on developing the ability and skill of individuals to make a difference to their health — even though health status is clearly the result of numerous social, political and economic determinants and antecedents which are beyond the control of most people.<sup>40</sup> This suggests that it is simpler and easier to focus on the individual than the system.

There are many varied factors that influence consumer behaviour and we may be naïve in thinking that we can convince those who carry with them a lifetime of bad habits suddenly to manage their conditions more responsibly, avoid unnecessary hospital admissions and reduce their use of costly medicines and other health services. Some argue that such changes in behaviour, if possible at all, may actually be engineered for

social and political expediency.<sup>7</sup> All of this effort, because of the imperative for concentrating on our current and burgeoning problems, may also be missing the next wave of health problems. New health problems are emerging as a result of high-risk behaviours such as drug and alcohol use and sedentary lifestyles for which we are yet to see the long-term physical and psychological consequences. How are we planning to self-manage this emerging juggernaut?

The issues and contradictions notwithstanding, the following discussion provides an outline of some of the key elements of self-management and determines which components may be achievable and which are more politically motivated and perhaps more fanciful. It may be instructive to turn to education for insight on self-management and participation.

### **The ideal of self-management**

There are parallels between concepts of self-management in health and many of the collaborative teaching and learning processes employed in education today. Participation and involvement within education implies ownership of the processes and outcomes of education by students and families and schools. It implies joint responsibilities for outcomes and a social contract between families and school communities through which greater outcomes can be achieved than if families abrogate their responsibility for the education of their children and leave schools to work in isolation towards student learning outcomes. Students who work in partnership with the education system achieve more. Common goals and agreed values that underpin the curriculum and structure of the education system are more likely to achieve common ends. Such benefits are achievable, in spite of what may be seen as a less than perfect ideological framework of teaching and learning through which our young people must pass.

In health there may be real gains to be made through improved self-management in spite of the many opposing and negating messages discussed above and through which the perceptions

and behaviours of consumers are constructed. The issue of self-management is now squarely on the health system agenda as suggested by Bodenheimer: "The question is not whether consumers with chronic conditions manage their illness, but how they manage."<sup>3</sup> (p. 2470)

Self-management in health, as in the education context, is also about partnerships and collaboration and about consumers working with the system as partners rather than as passive recipients of end-point treatments and health care services. This does not imply that consumers must be solely responsible for their wellbeing. Self-management in health, as in education, requires shared understanding between stakeholders and common purposes, goals and processes for achieving those goals.

In the following sections the key elements of the self-management social contract are explored and an attempt is made to put to rest some of the more cynical misconceptions about the ultimate motivation behind self-management in health promotion activities. The defeat of cynicism about self-management programs, particularly in view of the obvious ideological slant towards individual responsibility and behaviour change, is not a simple task. Even though, as one consumer says, "Overall it is my responsibility to look after my health, my body and my medication",<sup>41</sup> (p. 26) there is a need for preventive health care programs to be used to intervene earlier in the cycle of illness at the systems level to prevent the onset of much chronic illness in the first place. This however, at least in the context of chronic illness self-management, is another task that must be addressed along with our efforts to improve the management of those who are already living with chronic conditions.

### **Partnerships**

#### ***Systems level partnerships and health service reform***

The idea of self-management in the context of chronic illness implies cooperation and partnership among the various service agencies working with consumers with chronic conditions. Provid-

ers with sometimes contradictory and antagonistic approaches to health service provision, and to each other, are encouraged to work together collectively and cooperatively in loosely formed primary health care teams. This is required through processes such as the Medicare Benefits Schedule (MBS) Enhanced Primary Care (EPC) funding system in Australia, community care planning, and coordination of services around individual consumer need.<sup>34,42</sup>

Under these arrangements funding is tied to specific health outcome criteria facilitated through teamwork and planning, and requiring that certain levels of collaboration and accountability are evident before payment for services. To date, the majority of EPC funds have been channelled through general practices where practice nurses liaise with allied health teams, pharmacists and private providers to construct care plans to address social, emotional and clinical needs of eligible consumers.<sup>43</sup>

The chronic disease self-management (CDSM) approach links to this care planning process through the development of goal setting and behaviour change strategies that encourage and support consumers to participate in the care planning process and to set goals with which they are more likely to comply than extraneous goals set by health service providers. In addition, chronic disease self-management approaches introduce generic education programs to assist consumers to learn to cope with the symptoms of their illness and live more effectively with chronic illness.<sup>15,16</sup>

### ***Consumer level partnerships — health service access***

As well as the partnerships and relationships that are required at a system level to support the self-management and care planning approach, consumers also form partnerships with their principal carers, their nurse coordinators and their GP with a view to taking more control of the management of their condition. Through these partnerships consumers work with health service teams and other consumers in “support and self-help” groups to learn about how best to manage their

condition and how to access more effectively the services they need, when they need them.<sup>44-46</sup>

Through these two levels of collaboration and cooperation (system level and consumer service level) it is possible for health professionals, consumers and carers to develop a more comprehensive and supportive team approach to understanding the social, emotional and medical conditions with which consumers are faced. Importantly, the consumer-centred goals, set in the process of consumers learning about how to self-manage, enable the translation of medical approaches to care into more holistic approaches in which a wider range of factors impacting on consumer health and wellbeing are considered in illness management and treatment.<sup>15</sup>

In many ways this translation of problems from a medical to a personal level of analysis is crucial in gaining consumer adherence to and compliance with the elements of the care plan through which they can pursue health improvements.<sup>15,47,48</sup> Through this process consumers are able to develop a more personal understanding of how their illness impacts on their lives. This understanding, together with the process of direct consumer involvement in goal setting and planning, supports their ongoing commitment to working with and managing their symptoms. Commitment comes from participation and understanding rather than from being told what to do, or through passing responsibility for the management of personal wellbeing to others.

The self-management strategy being developed for the CDSM program through goal setting and care planning consists of six clear premises for consumers to follow to help them manage their condition.<sup>47</sup> Consumers are encouraged to:

- learn about and understand their condition
- take an active part in decision making with the GPs and health professionals
- follow an agreed treatment plan (ie, care plan)
- monitor symptoms associated with the condition(s) and take appropriate action to manage and cope with the symptoms
- manage the physical, emotional and social impact of the condition(s) on the life of consumers and carers

- adopt a lifestyle that promotes health and does not worsen the symptoms or the impact of their condition.

## Conclusion

Chronic condition self-management implies that consumers are supported to become more involved in the management of their lives and their health. In the past, some aspects of care have been taken out of the hands of the consumers and monopolised by professionals, perhaps to the detriment of the consumer. Some critics suggest that the self-management process is individually focused, and has the implication that individuals are responsible for the state of their wellbeing in the first instance. Such a view of health management, it is argued, does not address the larger social and economic determinants of wellbeing or acknowledge that individual existence is determined by factors outside of the individual's direct sphere of influence and control.

Self-management is about consumer-level empowerment and involvement of people in the management of their lives and their chronic conditions. This approach does not grapple with larger social and political health care issues, but takes as its starting point the fact that people have chronic conditions and that improvements can be made in their quality of life through a structured learning and self-management program, irrespective of the origins or causes of those conditions.

For the ideologically concerned who want to see a more revolutionary community approach to health system reform and development, the argument for self-management may not be convincing as it ignores much of the fabric of our culture that contributes to the development of chronic illness. However, if we acknowledge that people will develop chronic conditions, a process that can assist them to achieve improved quality of life while living with such conditions can make a significant contribution to improving community health and wellbeing.

The financial benefits of such approaches for individuals and community may also be signifi-

cant, although we are yet to produce sufficient data to confirm this outcome. It may well be, as others argue, improved health outcomes and quality of life come at a cost<sup>49-53</sup> and that we cannot expect to reduce the cost of health care through such processes, but merely to moderate the rate of increase in demand. There will always be upward pressure on demand for services within a system with a finite capacity to meet such demand.<sup>7</sup>

It is more likely that other wider social, economic and political factors will impact on the overall health system demand before these relatively minor (in the scheme of things) CDSM initiatives. Along with other chronic illness strategies and population health approaches, CDSM programs may serve to improve health service efficiency and contribute to an improvement in overall consumer wellbeing. It is unlikely that we can look to these strategies, given the nature of our health system, to reduce costs or save money per se. These programs are about improving the quality of outcomes that can be achieved for consumers in collaboration with the various elements of the health care system.

Whether self-management will lead to improved longevity and result in increased health care costs is yet to be determined.<sup>54</sup> Given the nature of our health system, we may be more inclined to look to these new programs as a means of improving quality of care for consumers rather than for them to generate cost savings and profits for investors and health care systems.

## Competing interests

The authors declare that they have no competing interests.

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