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Sisyphus and self-management: health care and the chronic condition self-management paradox!

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Sisyphus and self-management: health care and the chronic condition self-management paradox!

Abstract

Chronic condition self-management is popularly promoted internationally now 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 whilst, especially in rural and smaller communities in Australia, a shortage of clinicians means that health care as we once knew it is rapidly changing. This new emphasis on self-management however raises crucial questions about where consumer action and control in health care should end and where clinical and medical intervention might begin.

Recent work in chronic condition self-management has highlighted the fact that consumers of health services, patients in the system, are more likely to commit to making behavioural and health related lifestyle changes if they are led to these changes by their peers rather than by health professionals who are apt to confront patients with alien concepts and clinical demands. In this process, despite the health professionals' best intentions, they may actually restrict the patient learning and engagement processes that are necessary to effect lasting health related behaviour change.

This paper examines some ideological implications of the new wave of self-management approaches to chronic illness from an ideological perspective and highlights key elements that underpin a genuine effort to promote health related lifestyle change. The concept of patients or consumers of health services being assisted to enhance their self-management potential is a progressive one, especially in light of our existing professional monopoly on health care. We are now, for a range of reason that will be discussed, on the verge of a treatment paradigm change in which existing institutional models of care are being challenged. Can self-management overturn the institutionalisation of health care and allow consumers to take back some responsibility for the management of their behaviour and ultimately for a large part their fundamental wellbeing?

The literature review and discussion that follows will serve to inform this debate and examine our priorities in health care generally and in chronic illness management specifically.

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The context

There has been much discussion about the efficacy of chronic illness management programmes, care planning, regular health assessments, preventive primary health care and the role of self-management in these processes in recent times in Australia. More and more attention continues to be devoted to advancing the idea that the adverse impacts of illness and disease can be mitigated successfully through individuals with chronic conditions assuming more responsible and healthy approaches to their lifestyle and to the management of their health and wellbeing (1). That is, we can improve wellbeing and reduce the financial impact of illness upon the health system through educating people about more positive and constructive approaches to healthy living and by developing their skills for participating positively and constructively in the management of their care (2-5).

Such efforts, however, remain focused on people with chronic illness currently and are yet to grapple with the longer-term earlier intervention and prevention of illness that will be necessary if we are to create improvements in overall health and wellbeing in future generations. For the present, however, 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 eventually need to prevent much of this illness burden from occurring in the first instance *as well as* putting resources into managing existing chronic conditions if we are to improve the long-term outcomes of our healthcare system (6).

Although self-management appears to be a wholesome idea, Wilson argues that we need to examine more carefully the motivation behind movements such as the self-management trend in health care. Changes in patient empowerment and level of 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 (7,p 141). Others argue that the empowerment of patients and consumers within the health care system might even drive up demand as consumers learn more about their needs and as their

expectations for their health and wellbeing rise (8). This appears to be especially the case in relation to the baby boomer generation (3, 6).

“The nation’s (USA) 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-patient relationship” (3)

It would therefore appear that the self-management phenomenon embodies a degree of paradox in that 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, some say brainwashed (9, p202), for their lives generally 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. In the end, 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 (9, p203).

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!

Interestingly, we now appear to be more cognisant as a culture that the orchestrated alienation of consumers may be economically detrimental to both the individual and society generally and that better-informed, participating consumers might make for healthier and more functional communities (10). Blind consumerism, at least in the case of health care, is becoming undesirable from a systems perspective. People are being encouraged to become ‘responsible consumers’ and ‘partners’ in the system rather

than mindless consumers of everything they can get their hands on when it comes to health care. When it comes to KFC, however, they may be encouraged to consume and up-size blindly, but in relation to expensive health care, which is necessarily capped at a pre-determined level of GDP, they are encouraged to be parsimonious in the interests of the health of the whole community and, of course, in the interests of their own wellbeing.

This presents a very difficult paradox for people to resolve and indeed a difficult contradiction with which to grapple; trained consumers must become re-trained and mindful partners when it comes to their health care! The essential challenge of self-management programmes in health is therefore, in the first instance at least, to assist consumers and health professionals to resolve this paradox by learning to take back some control over the essential conditions of their existence. Ironically, this is the very control that they have been schooled and encouraged 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 is little correlation between patterns of behaviour and the idea of responsibility for actions generally or for health specifically (11). He suggested that rather than focusing on educating for generally responsible behaviour per se 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 far too broad a 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 very 'primitive' understanding (11, p1144). This is to say nothing of the inherent contradictions, as outlined above, in socially 'trained consumers' being encouraged to become 're-trained partners' when it comes to their health care, but not in relation to other aspects of their lives as economically and socially constructed consumers!

Others agree that the task of changing entrenched health related behaviours is too difficult and they oppose chronic disease self-management approaches on the grounds

that these methods are not based on sound medical practices and that patients may suffer from too many medical complications requiring professional management for them to be allowed to rely on self-management techniques (12) 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 (13), when he says that 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.’ (14)

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 of the partners takes control of the elements of health care and daily living that are relevant to and best managed by them.

Also, broad-based behaviour change strategies that encourage generally sound approaches to health and wellbeing are not effective across whole communities. The good health and prevention message reaches only certain population profiles (15). At the same time we have evidence suggesting that some groups in western society are becoming sicker (16) rather than healthier in spite of the good health messages that abound. Their training as passive consumers may be making them sick and this training has become so deeply a part of their consciousness that re-training or re-conditioning for prudent consumption in relation to health and wellbeing is a contradiction too difficult, if not impossible for some people to resolve. Another common assumption is that a patient’s concern about their 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 (17). Simply hearing a message doesn’t equate to an effective stimulus for change.

This view of the deep-seated nature of causation of human health-linked behaviour challenges the motivation of initiatives like chronic illness self-management

programmes that are predicated upon patients accepting greater responsibility for their health in an environment where they are conditioned generally 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 change their behaviour (18, p5).

To add further complexity, such responsibility is expected to manifest itself, in most cases of chronic and complex illness, after a lifetime of adverse social and environmental influences or, at least, of less than optimal health related behaviour. In short, the desired end of self-management programmes 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 (19, p56).

Applying Mechanic's version of human motivation and behaviour, as is the case for many an experienced physician, we might be better to concentrate on other methods of reducing risk related behaviours; methods other than simply appealing to everyone's better nature and their 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 their behaviour. We are primarily social creatures and our state of wellbeing is generally created out of a social environment, which determines our behaviour, or as McMurray has it, 'health is a sociological construct' (20, p29).

That self-management programmes might be worthwhile weapons in the health management armoury is not questioned here. However, without our tackling the larger ideological drivers of poor health, self-management can only really be one alternative solution to our problems; an alternative that may not be suited to large numbers of people who, for various reasons, may never be effectively engaged in the process.

It is probably more likely, therefore, that in Australia, as in the US, the 'Lorig approach' to self-management (21-23) might be less about the vagaries of human goodness and more about reducing the impact of chronic illness upon a flagging health care system whether it be a private or public system. Self-management in this context is really about managing at the level of the self rather than about access to systems level approaches to managing and reducing the overall social and economic causes of chronic

and complex illness in the first instance. 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! Self-management processes may therefore be ignoring the wider community health ideologies and health care determinants and focusing, instead, on developing the ability and skill of individuals to make a difference to their health even though their health status might be the result of numerous social, political and economic determinants and antecedents (24).

Although we know there are many and varied factors that influence consumer behaviour we may be naïve in thinking that we can somehow convince those who carry with them the reification of a lifetime of adverse habits suddenly to ‘take it on the chin’, 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 may actually be engineered for social and political expediency as patients are coerced into behaving in this new, ‘third way’ approach to illness management which ‘both liberates and subjugates at the same time’ (7).

All of this effort, because of the present imperative for concentrating on our current and burgeoning problems associated with chronic illness, may also be missing the next wave of health problems; those emerging as a result of new ‘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 manifestations. How are we planning to self-manage this emerging juggernaut?

A person may well know that certain behaviour is ‘risky’, maybe even fatal, but they will still indulge in the behaviour because the forces driving it are more immediate than the fear of any potential adverse outcomes that may result from the behaviour. People will indulge in such behaviours irrationally and without concern for the potential consequences of their actions as these consequences are still too far removed from present consciousness to be relevant to the individuals concerned.

The above issues and contradictions notwithstanding, the following discussion provides an analysis 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. In the process, it is perhaps instructive to turn to the education

community for insight on self-management and participation as a way of seeing just how consumer responsibilities are affecting life outcomes for whole communities in this sector.

The idea of self-management

Participation and involvement within the education community today 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 learning outcomes for students. Students left in this one-sided situation do poorly in schools, but those who work in partnership with the education system achieve more. The parties have common goals and agreed values that underpin the curriculum and the structure of the education system and they are in the system for common ends. Such benefits are actually 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 the health arena, there may be real gains to be made through improved self-management in spite of the many other opposing and negating messages through which the perceptions and behaviours of consumers are constructed. The issue of self-management is now squarely on the health system agenda for many reasons and as suggested by Bodenheimer...

“The question is not whether patients with chronic conditions manage their illness, but how they manage.” (3, p2470).

Self-management in the health context is also about partnerships and collaboration and about patients working with the system as partners rather than as passive recipients of end point treatments and health care services. This does not imply that patients are left to their own devices to become responsible in isolation for their wellbeing. Self-management in health, as in education, consists in the establishment of shared understanding between stakeholders and the development of a common agreement about purposes, goals and processes for achieving those goals.

In the following sections some of 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 the recent preoccupation with the idea of self-management in health promotion activities. The defeat of rising elements of cynicism about self-management programmes, particularly in view of the obvious ideological slant towards individual responsibility and behaviour change, however, may not be a simple task. Even though, as one patient says, 'Overall it is my responsibility to look after my health, my body and my medication' (25, p26) and self-management does help patients with chronic conditions, there is also a wider agenda in health prevention to intervene earlier in the cycle of illness and at a systems level to prevent individuals from developing chronic conditions in the first place. This however, at least in the context of chronic illness self-management, is another task altogether 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 & health service reform

The idea of self-management in the context of chronic illness implies cooperation and partnership between the various service agencies working with patients with chronic conditions. Providers 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 being effected through the application of processes such as the Medical Benefits Schedule (MBS) Enhanced Primary Care (EPC) funding system in Australia, community care planning and coordination of services around individual patient need (26, 27).

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 can be generated. To date, the majority of funds (EPC funding) have been channelled through GP practices where practice nurses are employed to liaise with allied health teams, pharmacists and private

providers to construct a care plan to address the social, emotional and clinical needs of eligible patients.

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 patients to participate in the care planning process and to set patient-centred goals for themselves with which they are more likely to comply than extraneous goals set for them by health service providers. In addition, chronic disease self-management approaches introduce generic education programmes to assist patients to learn to cope with the symptoms of their illness and live more effectively with chronic illness generally (28, 29).

patient 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, patients 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 patients work with health service teams and other patients 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.

Collaboration and service integration

Through these two levels of collaboration and cooperation (system level and patient service level) it is possible for patients and carers to develop a more comprehensive and supportive team approach to understanding the social, emotional and medical conditions with which patients are faced. Importantly, the patient centred goals, set in the process of patients learning about how to self-manage, enable the translation of hitherto medical approaches to care into more holistic approaches in which a wider range of factors impacting on patient health and wellbeing are considered in illness management and treatment (29).

Self-management

In many ways, this translation of problems from a medical to a personal level of analysis is crucial in gaining patient adherence to and compliance with the elements of the care plan through which they can pursue health improvements (29, 30). Through this process patients are able to develop a more personal understanding of how their illness impacts on their lives. This understanding, together with the process of direct patient involvement in goal setting and planning, supports their ongoing commitment to working with and managing their symptoms. Commitment comes from participation and understanding, not from being told what to do or through passing responsibility for managing their wellbeing to other people such as health professionals, carers and friends.

The key elements of realistic self-management

The self-management strategy being developed for the CDSM programme through goal setting and care planning consists of six clear premises for patients to follow in the adoption of a self-management approach to their condition (30). Patients are encouraged to...

- learn about and understand their condition
- take an active part in decision making with the GPs and health professionals when managing their condition(s)
- 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 patients 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 patients are being supported to become more involved in the management of their lives. 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 patient. Some critics also 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.

However, these ideological criticisms notwithstanding, it appears fair to conclude that these arguments are not particularly relevant to the self-management process that is emerging in practice and which is described here. Rather, self-management is more about patient level empowerment and involvement in the management of their lives and their chronic conditions. This approach does not attempt to grapple with larger social and political issues in the health care debate, but takes as its starting point the fact that people do have chronic conditions and that improvements can be made in their quality of life through a structured learning and self-management programme 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 above 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 in the first place. However, if we acknowledge that, for whatever reason, people will develop chronic conditions, a process that can assist them to achieve improved quality of life whilst 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 significant, although we are yet to produce sufficient data over long enough periods of time to confirm this thesis. It may well be, as others argue, improved health outcomes and quality of life all come at a cost (31-35) 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 (7, p140).

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 programmes may serve to improve health service efficiency and contribute to an improvement in overall patient wellbeing. It is unlikely that we can look to these strategies, given the nature of our health system, to really reduce costs or save money per se! These programmes are more about improving the quality of the outcomes that can be achieved for patients in collaboration with the various elements of the health care system.

Whether improved self-management and patient responsibility for managing their health leads to extended longevity and even *increased* health care costs associated with more and more people living longer and more independent lives with chronic illness is yet to be determined. Possibly the cost factor will need to be played down in Australia and improved quality of life emphasised, since our system is not driven by private insurance programmes to the extent of the American system, for example! With a 'universal access' system, we are therefore more inclined to look to these new programmes as a means of improving quality of care for patients rather than for them to generate cost savings and profits for investors.

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