Archived at the Flinders Academic Commons:
http://dspace.flinders.edu.au/dspace/

This is the authors' version of an article published in *Patient Education and Counseling*. The original publication is available by subscription at:
http://www.sciencedirect.com/

doi: 10.1016/j.pec.2010.07.008

Please cite this article as:

Lawn S, McMillan J, Pulvirenti M. Chronic condition self-management: expectations of responsibility. Patient Education and Counseling. 2011 Aug;84(2):e5-8.

Title: Self-management and responsibility

Authors:

Dr Sharon Lawn

Flinders Human Behaviour and Health Research Unit

Flinders University, GPO Box 2100, Adelaide, SA, 5001

Phone: (61) 8 8404 2321,

Fax: (61) 8 404 2101

Email: sharon.lawn@health.sa.gov.au

Associate Professor John McMillan

Social Health Science / School of Medicine

Flinders University

Dr Mariastella Pulvirenti

Discipline of Public Health

Flinders University

1

Title: Chronic condition self-management: expectations of responsibility

Abstract

Objective

While self-management has been shown to be beneficial for many patients it assumes and encourages a particular conception of responsibility and self-management that may not fit with all patients' experience of their chronic conditions and their management. It therefore warrants further examination.

Methods

We examine the concept of self-management and responsibility from a range of standpoints.

Results

All attempts to meet people's needs run the risk of imposing specific conceptions of how people should live their lives. While self-management appears to be consistent with placing patient needs, values and priorities at the heart of health care, it might be more problematic for some patients.

Conclusions

The context in which patients seek self-management support from health services, and how their needs and preferences are listened to by health professionals, are critical if the collaborative self-management partnership between them is to be effectively realized.

Practice Implications

Providing services without reflecting on the meaning of self-management for the person with chronic conditions creates unintended assumptions about responsibility, engagement and care provision which may serve to alienate and further stigmatise some patients. Often, these are the very patients with complex needs who need such service support the most.

2

1 Introduction

> "There is not just one good human life, but many. Who is to say what humans need to accomplish all the finest purposes they can set for themselves?" Ignatieff p11 [1]

Michael Ignatieff describes the difficulty of accommodating and reconciling the multitude of ways in which people live their lives with support from the State. All attempts to meet people's needs run the risk of imposing, even in subtle ways, specific conceptions of how it is that people should live their lives. This tension is important for ethics and politics and raises issues for those involved in providing services.

While this tension is important in all areas of life where the State attempts to meet the needs of its citizens it's particularly so in health care. A failure to meet health care needs can have significant consequences, but attempts to meet needs that are overtly or subtly prescriptive can have the effect of excluding or alienating some people. Further tensions and unintended consequences often lie at the heart of how health services are structured and delivered.

In this paper we argue that self management assumes and encourages a particular conception of what a 'self-managing' patient is. While this conception is one that appears to be consistent with placing patient needs, values and priorities at the heart of health care and is a concept that will be appropriate for many patients, it might be more problematic for those who do not wish to or can't exercise the same degree of control over their care. The concept of the 'self managing' patient does not account for patients engaging in the process of learning to become 'good self-managers'. Patients are at risk of getting caught up in systems and service- driven processes that do not always acknowledge the skills patients bring to the encounter. The service-driven processes do not

3

necessarily facilitate understanding or listening to patients needs, nor do they necessarily value preferences and identification of the problems or solutions from the patient's perspective

The expectation that patients should become 'effective self-managers' is the central issue of this paper. We do not, by considering this issue, intend to undermine self management; instead our hope is to alert practitioners to some of the subtleties and assumptions that it embodies. We base our stance on the belief that respect for patient choice is central to encounters with services and that we need to work towards structuring services so that this is facilitated. We also base our stance on the belief that, through reflective practice, the underlying ethical and value base for our practice and those of the systems in which we work, are better understood so patient centred care is more likely to be realized.

2 Self management

Self management is a process that individuals engage in. It exists within a collaborative system of care involving a range of professionals in partnership with patients [2,3]. Self-management support is a collection of health care services' attempts to enable those, particularly with chronic conditions, to take greater control of their own care. Self-management attempts to articulate and shift some of the decision making focus to the patient. This has major implications for the professions and their systems of care.

There is more than one way of defining 'self management', but in an Australian context the most common understanding of its aims and principles is articulated by the National Health Priority Action Council in their National Chronic Disease Strategy. They describe self management as involving a range of 'attitudes, behaviours and skills' and suggest that the following are key features of successful self management for chronic conditions.

1 Having knowledge of the condition and/or its management

2 Adopting a self-management care plan agreed and negotiated in partnership with health professionals, significant others and/or carers and other supporters

3 Actively sharing in decision-making with health professionals, significant others and/or carers and other supporters

4 Monitoring and managing signs and symptoms of the condition

5 Managing the impact of the condition on physical, emotional, occupational and social functioning

6 Adopting lifestyles that address risk factors and promote health by focusing on prevention and early intervention

7 Having access to, and confidence in the ability to use support services.

This definition of self-management represents an attempt to address paternalistic values inherent in more traditional approaches to healthcare provision and the growing burden of chronic disease [4].

3 Patient-centred care

Encouraging and facilitating patients to take control of and manage their illnesses is a significant step toward patient centred health care. Rogers et al define patient centred care as "responsiveness to patient needs and preferences, using the patient's knowledge to guide actively the interaction and information giving, and shared decision-making"(p.226) [5]. When patients are genuinely involved in the management of their condition this should place them at the centre of their care, decisions about care and treatment, and ensure that they own and take responsibility for their illness.

When viewed in this light, self management is profoundly important in developing care for chronic illnesses that meets the needs of patients without imposing upon them an external conception of how they ought to live their lives. While there's no doubt that for many patients, self management

does meet patients' needs, are there any ways in which it could subtly impose a conception of how one should live upon patients?

4 Health Worker - patient relationship

The evidence-based medicine movement is one example where the tension between objective and subjective language within the patient/worker encounter is yet to be resolved. Taylor describes the tension as, "the conflict between the subjective, undifferentiated experience of the patient and the need of the doctor to objectify, code and structure this information"(p.152) [6]. Within such tensions, the patient's account is often medicalised and their expert experience of living with their health condition is minimized or ignored altogether [4].

The ideal of 'patient centred care' can be seen as an attempt to remedy these concerns: when health care places patient preferences, needs and values at the heart of care then it should be inclusive and consistent with the different ways that people want to live their lives [7]. Yet, genuine sharing of expertise and power across the divide of patient and health worker needs more than general ideals and intentions. Many patients expect health workers to be 'the expert' and many health workers believe they include patients in decisions about care, even when patients' feedback is that they do not always do so [8]. Hence, some structured rules for engagement seem to be needed; some means of operationalizing the ideals of patient-centred care that will satisfy both patients and health professionals. Taylor notes this concern when he states, "If doctors surrender their legacy of scientific rationalism completely, the consultation is left floundering in a post-modern void where neither person is sure of the others expertise"(p.153) [6].

We think that the features or principles of self management listed above, can all be viewed as ways of helping patients 'own' or 'take responsibility' for their care, but what does being responsible for one's care imply? Does this presume anything about the kind of patients, chronic care patients

should be? Are there limits to responsibility? How is the knowledge that defines the parameters of what is to be undertaken responsibly defined and by whom? What value base underlies this knowledge? Grappling with these questions involves giving some thought to what it is to take or be held responsible.

5 Responsibility: knowledge and control

One way to unpack what's involved in 'taking responsibility' is to think about cases where we excuse someone of responsibility. When people are made to do things or when they don't know what it is that they're doing we're likely to excuse them or not hold them responsible for good or bad effects that result [9,10]. So if someone was compelled to live in housing that lacked an adequate water supply because they had no other option, then they should not be held responsible if they or they family contract a waterborne illness such as giardia. Likewise, if a family had no reason to suspect that their water supply had become contaminated with giardia then it would be wrong to hold them responsible if they become infected.

On the other hand, if parents knowingly gave water that was infected with giardia to their children, when they were free to do otherwise, our attitude would be different. In this case the parents would have to 'take responsibility', at least to some extent, for their children's illness.

These twin conditions of knowledge and control are implicit within the principles of self management [4]. The seven principles aim at enabling patients to become better informed about their condition and by sharing in its management they thereby take a degree of control over its management. Of course this doesn't imply that that they are responsible for having that chronic condition, but it does suggest that patients should take responsibility for the management of their condition and be fully engaged and active in using and accepting self-management support from health service providers and other supports where indicated.

7

It is unlikely to be a coincidence that self management has been born and thrives in neo-liberal states battling to manage increasing demand on state services previously offered as citizen rights. The shift currently underway, Clark argues, is towards 'self regulating subjects' (p.452) [11]. Importantly the choices consumers make are based not on individual interests but on 'responsible behaviour' so that what are considered to be 'bad choices', "result from the wilfulness of irresponsible people, rather that the structural distribution of resources, capacities and opportunities" (p.451) [11]. This has significant implications for expectations on patients to be responsible.

For many patients, self-management and self-management support are likely to provide an empowering experience but are there patients who don't experience it in a positive way? Clearly, an important point to realise is that self-management is a process, not an event. A person can manage one health condition well yet struggle with another condition. Gaining mastery over managing one's day to day life with a chronic condition often involved a long experience and period of learning. This learning also occurs within specific contexts over time that only the person experiencing the condition can truly know.

Within these specific contexts, there are many internal and external forces at play that impact on a person's ability to learn, know and take action. There are entrenched forces at a population level involving political, economic and social factors that create social determinants of health that require responsibility and action beyond the mere individual and their capacity to take responsibility. For Greenhalgh [12], "Responsibility for preventing and managing illness lies at many levels' including 'wider society' which she says' 'should create healthy environments and remove structural and cultural barriers to individual lifestyle choices' (p.630). People with chronic conditions and their families have many accommodations, choices and decisions to make about how they will manage

their overall health and wellbeing and how they will adhere to health professional advice, not solely based on 'knowing what is good for them' [13].

There are also significant potential negative consequences of entering into systems of care and seeking help. Richards [14] describes the danger of the person being rendered invisible, labelled, judged or stigmatized within the systems in which they attempt to tell their individual story of managing chronic illness (their autoethnography), becoming the object of interventions and therefore vulnerable. Our stories, "tell others who we are but they also tell us. And more than this, they can make us who we are" (p.1722). This has clear implications for the importance of power sharing within the self-management dialogue and interaction between patient and health worker and how workers and systems respond to patients' needs and preferences.

In a large multicentre trial involving self-management of chronic disease Rogers et al [5] highlight the threats to patient centred interactions where health professionals largely interpreted self-management as compliance with medical instructions and where patients' self-management strategies were marginalized by doctors. Patients tended to, "rely on the knowledge and experience of their bodies when deciding whether to adhere" (p. 232) to treatment advice and they rarely shared this information with their health professionals. They also found that an increased focus on self-management did not equate to a shift towards shared decision-making. In effect, there appeared to be a process of 'responsibilizing' without power sharing, one that disregarded the patients' experience.

6 Not being responsible

Many or perhaps most patients want a better understanding of their condition but there are some who do not. Do patients have a right to not understand their condition and what would exercising that right imply about them as a person in a context where 'self management support' is offered?

9

In other medical contexts, for example when giving consent to surgery, it's not unknown for patients to say that don't want to know the details of, or options for their operation, and for the surgeon to simply tell them what they should agree to. While most of us would want to be involved when making decisions of this kind, those who do not, place their trust in the ability and judgment of those treating them. Relying on 'expert' opinion could in and of itself be viewed as a conscious relinquishing of responsibility to the expert.

In some respects the reasoning underlying this decision is the same as a patient not wanting to take responsibility for the management of their chronic illness, but the latter incurs a moral penalty. In that instance, the patient risks being judged within the self-management system as not responsible. This is because consent to surgery is an event, an intervention and not an ongoing process and part of treatment. Opting out of self management is in effect opting out of an approach to treatment and a particular orientation to one's own health. When viewed in this light, opting out of self management has implications for how some patients view themselves and their illnesses, particularly where power for rule making rests with the health professional and health systems and where patients may be required to engage with those services over many months or even years.

Here we mean opting out of self management as it is defined by the sector. Does any one with a chronic condition truly opt out of managing their health? Whatever choices a person with chronic conditions makes, they are still making some choices every day. In a qualitative study of people living with rheumatoid arthritis Stamm et al. [15] highlight the dichotomy of mastery of one's conditions (often the person's view) versus the concept of suffering (often the health professional's view of the person). This relates to who is defining the rules for self-management and acknowledges that patients often challenge being passive recipients of medical advice, either

actively or by omission or non-engagement. Patients are doing something to self-manage in some form every day, and this is rarely acknowledged by health professionals.

Self-management is in danger of becoming bound up in the wave of healthism in which peoples' choices have become enmeshed within value-laden speak and focus on the individual as making good or bad, responsible of irresponsible choices about what and how much they eat, drink, exercise, and so on. Cheek [16] describes this as the emergence of a 'bounded autonomy' in which we are individually blamed for our acts and omissions. "The individual has the freedom to make choices but then can be held accountable for the consequences of those choices, or even for making them in the first place" (p.980).

While self management assistance from health workers is intended to be offered in a supportive manner, would opting out of this way of managing one's health imply that you were in some way a less responsible person? If self management is the predominant or gold standard approach to care for a particular chronic condition might this, in effect, imply that patients should be a particular kind of patient, a "self manager"? Are we, as Cheek [16] asks, "not seeing the health care system and powerful groups within it abandon control as much as we are seeing the establishment of new and different form of control" (p.981) through notions of bounded or delimited autonomy?

7 Structural Control

McKnight (1977) talks of the manufacture of needs in order to rationalize the service economy and the layers of professional bodies embedded within it. Within such a system, individualized need is separated out from its social context and the person becomes 'the problem' (p.113). A process of 'effective clienthood' develops involving a process of assuming that people need professional input to define and solve their problems (p.115). Within the self-management area, the health professional and the system in which they exist are seen as the answer to need, with the chronic care team

perceived as central to support provision, even though only a very small percentage of support comes from this sector in the larger scheme of how the person lives with their condition. Is an old problem simply wearing a new suit? Such concerns bring us back to the central concern about the expectation that patients 'should' become 'effective self managers'. The questions that remain are who defines what this means and how do these definitions fits with the larger purposes that people live by, beyond the management of their health.

8 Conclusions

Michael Ignatieff draws our attention to the difficulties that surround attempts to meet the care needs of citizens while also paying due respect to their right to determine how they should live their lives. The context in which patients seek self-management support from health services, and how their needs and preferences are listened to by health professionals, are critical if the collaborative self-management partnership between them is to be effectively realized.

9 Practice Implications

Providing services without reflecting on the meaning of self-management for the person with chronic conditions creates unintended assumptions about responsibility, engagement and care provision which may serve to alienate and further stigmatise some patients. Often, these are the very patients with complex needs who need such service support the most.

12

References

[1] Ignatieff M. The Needs of Strangers. London: Vintage, 1994.

[2] Wagner E, Austin B, Von Korff M. Organising care for patients with chronic illness. Millbank Q 1996; 74: 511–42.

[3] World Health Organization. Innovative care for chronic diseases. Building blocks for action. Global Report. Geneva: WHO, 2002.

[4] National Health Priority Action Council (NHPAC). National chronic disease strategy, Canberra: Australian Government Department of Health and Ageing, 2006.

[5] Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the limits of patient-centredness: Implementing a self-management trial for chronic illness. Qual Health Res, 2005; 15: 224-39.

[6] Taylor K. Paternalism, participation and partnership: The evolution of patient centredness in the consultation. Patient Educ Couns 2009; 74: 150-5.

[7] The Kings Fund. Patient centred Care

http://www.kingsfund.org.uk/research/topics/patientcentred_care/ [last accessed 21/1/2010]

[8] Lawn, S., Battersby, M., Lindner, H., Mathews, R., Morris, S., Wells, L., et al. What skills do primary health care professionals need to provide effective self-management support?: A consumer perspective. Aust J Primary Health 2009; 15: 37-44.

[9] Aristotle. Nichomachean Ethics. Trans W.D. Ross. London: Oxford University Press, 1954.

13

[10] Fischer M, Ravizza P. Responsibility and Control: A theory of moral responsibility. Cambridge: Cambridge University Press, 1998.

[11] Clark J. New labour's citizens: activated, empowered, responsibilized, abandoned? Critical Social Policy 2005; 25: 447-63.

[12] Greenhalgh, T (2009) Chronic illness: beyond the expert patient. BMJ 2009; 338: 629-31.

[13] Corbin JM. Strauss A. Unending Work and Care: Managing Chronic Illness at Home. San Francisco: Jossey-Bass Publishing Co, 1988.

[14] Richards R. Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability. Qual Health Res 2008; 18: 1717-28.

[15] Stamm T, Lovelock L, Stew G, Nell V, Smolen J, Johnsson H, Sadio G, Machold K. I have mastered the challenge of living with a chronic disease: Life stories of people with rheumatoid arthritis. Qual Health Res 2008; 18: 658-69.

[16] Cheek J. Healthism: A new conservatism? Qual Health Res 2008; 18: 974-82.

[17] McKnight J. The professional service business. Soc Pol, 1977; Nov/Dec: 110-16.