

Empowerment, patient centred care and self-management

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Abstract

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Background Patient or person centred care is widely accepted as the philosophy and practice that underpins quality care. An examination of the Australian National Chronic Disease Strategy and literature in the field highlights assumptions about the self-manager as patient and a focus on clinical settings.

Objective and Conclusion This paper considers patient or person centred care in the light of empowerment as it is understood in the health promotion charters first established in Alma Ata in 1977. We argue that patient or person centred care can be reconfigured within a social justice and rights framework and that doing so supports the creation of conditions for well-being in the broader context, one that impacts strongly on individuals. These arguments have broader implications for the practice of patient centred care as it occurs between patient and health professional and for creating shared responsibility for management of the self. It also has implications for those who manage their health outside of the health sector.

Introduction

Patient or person centred care is often taken to be an ethical panacea; it is perceived to be the solution to excessive paternalism in clinical medicine and the lack of genuine concern for people's values and needs. So, it is unsurprising that self-management care planning considers it a fundamental principle for chronic care. This article questions whether patient or person centred care (PCC) is in fact sufficient as an underpinning philosophy for appropriate self-management support. We will show how, in the Australian context, our understanding of and perhaps ultimately the practice of PCC can

be enhanced by models of empowerment. We begin by examining what PCC means within the context of chronic condition self-management support provided by health practitioners and systems of care. Then, we move to a consideration of empowerment that explores whether it captures something important that a PCC focus does not. We conclude by showing how this kind of deliberation is important for dealing with assumptions behind both sets of thinking and their impact on health-care practice. Our aim is to reconcile PCC with empowerment to highlight ways of talking about self-management that enables genuine empowerment.

Person centred care, Australia and the National Chronic Diseases Strategy

One way of understanding the concept of person centred care (PCC) is by analysing its use in policy about chronic conditions and care planning. Care planning has influenced the restructuring of care for chronic illnesses across the world. Given the global burden of chronic illness and the importance of care being provided in an appropriate way that realistically acknowledges the long term, ongoing nature of chronic illness and its management, there are strong arguments in favour of planned care as opposed to ad hoc reactionary care centred around acute crisis-oriented health service systems. A central idea is that care planning for chronic illness should be person centred, given that it involves the person's day-to-day experience over time and the knowledge and action that they apply over the long term in managing their health. Person centred health care is argued to provide increased understanding, capacity, confidence in decision making and awareness of health, illnesses, options for treatment, symptoms and behaviours.¹⁻⁴ In addition, it is recommended as a strategy for 'empowering patients to effectively critique and provide feedback on the quality and appropriateness of health care services' (p. 42).¹

In 2002, the World Health Organization (WHO) released a document entitled *Innovative Care for Chronic Conditions: Building Blocks for Action*.⁵ This document drew global attention to the rise of chronic conditions and a path forward for tackling their impact on the populations of developed and developing countries.

The WHO's message strongly influenced the development of Australia's National Chronic Diseases Strategy (NCDS)⁶ that was released soon after another WHO report detailing the economic burden of chronic conditions and the need for *urgent* action (p. 84).⁷ The National Strategy has been very influential in Australia, particularly in the way that it is underpinned by PCC. This idea is taken to be central to the rationale and success of the National Strategy so it is important that there is clarity about both

what this idea means and that it does not make unjustifiable assumptions.

The six primary NCDS objectives as they are listed in the Strategy are:

1. Prevent and/or delay the onset of chronic disease for individuals and population groups;
2. Reduce the progression and complications of chronic disease;
3. Maximise the wellbeing and quality of life of individuals living with chronic disease and their families and carers;
4. Reduce avoidable hospital admissions and health procedures;
5. Implement best practice in the prevention, detection and management of chronic disease;
6. Enhance the capacity of the health workforce to meet population demand for chronic disease prevention and care into the future (p. 8).⁶

While these are the central aims of the NCDS, the Strategy is also careful to articulate how it is that these objectives should be realized. The Strategy is guided by seven principles:

1. Adopt a population health approach and reduce health inequalities.
2. Prioritize health promotion and illness prevention.
3. Achieve person centred care and optimize self-management.
4. Provide the most effective care.
5. Facilitate coordinated and integrated multi-disciplinary care across services, settings and sectors.
6. Achieve significant and sustainable change.
7. Monitor progress (p. 9).⁶

The NCDS asks that when we approach chronic disease management, we should take into account growing a person's control over their health (Principle 2) an aim mirrored in Principle 3, achieving PCC. The Strategy describes PCC as putting 'people at the forefront and centre of their own health care' (p. 9).⁶ PCC implies that a person's experience of the health system would be 'oriented towards making a positive difference as determined by the person him/herself', and that 'the health system' would

be 'driven by outcomes relevant to the person and their family and carers' (p. 9).⁶ PCC requires the health system to support individuals in achieving self-management (p. 10).⁶

Multidisciplinary care is seen as pivotal to care for people with chronic conditions. It is the focus of Principle 5 in the NCDS. The approach to it 'must be person centred' and 'responsive to changing patient needs' (p. 10).⁶ The PCC approach is echoed in the Action Areas (prevention across the continuum, early detection and early treatment, integration and continuity of prevention and care and self-management).

Chronic condition self-management and PCC are closely linked in other supporting documents. The briefing report on self-management submitted to government to support development of the NCDS describes chronic condition self-management as being about,

... how the person, the workers and the system share responsibility and work together to support the achievement of better health and wellbeing *as defined by the person*, not the professional, acknowledging the social, psychological, biological and spiritual aspects that impact on self-management ability, set within a cultural context that recognises and respects the beliefs and values of the *person* (p xiii, Italics added).⁴

Person centre care and patient centred care

While in the context of chronic illness, it is usual to refer to '*person* centred care' and in other areas of health care, this term is often used interchangeably with '*patient* centred care', '*client* centred care' and '*consumer* centred care'. There are many different accounts of what this means.

The Australian Diabetes Educators Association (ADEA) has a position statement on Client Centred Care (CCC).⁸ In it, they summarize three bodies of literature to explain what CCC is. They conclude that there is no consensus in the literature and that there are 'multiple definitions and descriptions' (p. 3).⁸ Basing their statement on consultations with over 150 educators, they set out CCC as being about educators supporting, facilitating and encour-

aging individuals to make informed decisions about the management of their disease (p. 2).⁸

For Bauman *et al.*⁹, the more commonly used PCC is about interactions and partnerships between health practitioner and patient, based on communication and 'a focus beyond specific conditions, on health promotion and healthy lifestyles' (p. 254).⁹ They argue the key is developing a 'common ground' for 'integrated management' (p. 255).⁹ Not unlike the ADEA statement, the aim is to encourage informed decision making in the patient. This requires a shift in the health sector to nurture changes in the relationship between practitioner and patient.

For Rogers *et al.*¹⁰, patient centredness can either be a way of viewing an individual's health or a process of empowerment of patients.¹¹ In their view, patient centredness is about the doctor-patient 'encounter' (p. 266).¹⁰ According to Little *et al.*¹², there are several elements to models of patient centred approaches based on changed relationships and communication between health professionals and patient, focussing on 'exploring', 'understanding', 'finding' and 'enhancing' (p. 1).¹² Their research concluded that for patients, the key components were 'communication, partnership, and health promotion' (p. 5).¹²

Stewart *et al.*¹¹ work on 'patient centred medicine' is an example of PCC being put into practice in a clinical setting and provides insight into how PCC is understood. Their 'patient-centred clinical method' is made up of six 'interactive components' including validating the patient's experiences, considering the broader context in which the illness is experienced, working towards mutual understandings between doctor and patient, engaging in health promotion, taking a partnership approach to the doctor-patient relationship and being realistic about goals.¹¹

McWilliam (p. 279)¹³ lists additional elements from other approaches based on health promotion, accessibility of services, continuity of care and motivation of the patient. The aims are to encourage, enable and support patients to take responsibility for control of management of

their conditions and growing patient autonomy in decision making to become 'expert' patients (p. 279).¹³ McWilliam¹³ sees the achievement of empowerment of patients to self-manage as an assumption of PCC approaches (p. 280) a point we have also made elsewhere.¹⁴ In the clinical frame, power is conceived of as something that is transferred from the 'expert' to the patient (p. 280).¹³ This assumes that 'receipt' of the power (which takes the form of knowledge and support) is all that is required to impact self-management. As an alternative, she offers the 'empowering partnering' approach. This, the author argues, develops meaningful, productive interactions in the clinical setting through forging a relationship built on mutual reflection. McWilliam¹³ believes that empowerment for the patient is achieved when there is an 'equitable or *fair* sharing of knowledge, status and decision-making authority' plus opportunities for the patient to be involved as they so choose (p. 282 original Italics). This still focuses attention (necessarily, if the task is to improve effectiveness of clinical interactions) on the patient–doctor relationship. It leaves begging the question of how to empower those who are not 'in' the health system.

McWilliam¹³ herself acknowledges that empowerment partnering is a 'micro-level strategy' (p. 284) but what the WHO Charters guide us towards, and what research has shown, is that a focus on the practitioner–patient relationship is not enough.^{5,7,15,16} McWilliams¹³ offers us a way of seeing empowerment as potentially having a positive impact on the limitations of the illness or medical model that dominates the health system. But the imperative to look beyond the clinic is established and until patient centredness becomes wholly *person centred*, as opposed to *patient centred*, and directs energy to those managing their conditions in their own way, as it were 'outside' the health system, then empowerment and the health equity it is meant to address cannot be achieved.

According to Greenhalg (p. 630)¹⁷, this argument is reflected in 'whole systems' models that acknowledge that 'interventions must go beyond the clinic and into the community'. Individuals

are pivotal to creating change in the wider environment including around cultural norms, community ethos and policies (p. 631).¹⁷ Within critical public health, this change is understood to be a highly political process: 'the focus for living positively shifts from individual self-management to challenging political preconditions for poverty and health inequalities' (p. 631).¹⁷ Empowerment understood in this frame may offer something quite new to PCC approaches.

Thus, three key concerns remain unaddressed in the literature. First, the assumption throughout much work in the chronic conditions and self-management area that for many the self-manager is a patient. This obviates the fact that people who have chronic conditions may not be 'active' patients, in the sense that although they are or indeed are *not*, seeing a health professional for the care of their chronic condition, they are still self-managing. For this reason, 'person' centred care is a more accurate concept and term for an approach that puts the person with the condition at the 'centre'. Second, given that PCC is more often than not discussed and reflected on within the context of clinical settings, the broader context is left unacknowledged – 'If any individual's capacity for health and involvement in self-care management is to be optimized, then society at large, healthcare policy, healthcare infrastructures and health care professionals alike all have to both reflect and promote this orientation' (p. 284),¹³ that is, structural change needs to occur. Finally, the question remains whether the concept of empowerment can make more, different or better room for a self-determining, self-managing individual.

Empowerment

Those who articulate a social determinants approach to public health have distinguished a number of senses of 'empowerment' and suggested that this is an idea that should underpin our approach to health.^{18,19}

There is general agreement that empowerment as a concept grew in the 1950s from Paolo Fri-

ere's work with poor people in Brazil, then during the civil rights movements of the 1960s. It was further developed and used by the self-help movement in the 1980s and has continued to grow since then.^{20,21} There is also recognition of the importance of empowerment being stated in the Charters embedding health promotion on the global health agenda.

The imperative to advocate for and practice empowerment in public health comes from the principles that underpin the global health promotion charters, initiated by the Alma-Ata in 1978.^{22,23} These Charters moved public health towards a focus on health as a human right involving multi-sectoral collaborations, health promotion, social justice and a focus on reducing inequities in health. Empowerment approaches linked to Comprehensive Primary Health Care (CPHC) are not only a matter for the individual. Rather, practicing empowerment within the CPHC frame means reducing or ameliorating 'inequitable social conditions' (p. 254).²⁴ It is also considered to be an approach to health promotion involving patient autonomy, ensuring the patient is actively involved in their care, relying on an achievement of self-efficacy or having a sense of control in one's life. Empowerment is seen to involve a change in the power relations that currently generally exist between the patient/person and the health professional. This can be understood as a human rights or social justice approach to empowerment.²⁵

What we want to explore here is if empowerment understood in this way has something to offer PCC and self-management, what does empowerment 'do' differently to PCC and what lessons for PCC are there in these differences?

Despite some agreement that the term empowerment is poorly defined,²⁰ it is common to see definitions incorporating an element of self-efficacy or being in control of one's life.²⁶ This can be understood as an individual being able to see a 'relationship between their efforts and the outcomes thereof' (p. S12).²⁷ It is also understood as 'an enabling process' for decision making to 'achieve change'.²⁸ It was Labonte²⁴ who pointed out that empowerment could be interpreted as a process of 'assuming power' or a

process of power being 'given'. This is what is considered to be the key to the contested nature of this concept.²¹

Keleher²⁹ develops principles of empowerment-based health teaching for well-being. These principles suggest a number of important elements that are missing from PCC and ways in which this concept, and the policies informed by it, can be enriched. These principles are as follows:

1. Respect for culture: a necessary prerequisite for all people involved in learning for health and wellbeing.
2. Cultural and local sensitivity of programs.
3. Education materials and opportunities examined for their underlying assumptions about race and culture.
4. A sense of community and local bonding.
5. Reinforcement of authentic participation.
6. Increase people's skills and control over resources.
7. Use of lay leaders and helpers.
8. Fostering of advocacy and leadership development.
9. Time and space to identify structural barriers and facilitators to empowerment interventions.
10. Mechanisms to overcome structural barriers and facilitators to empowerment interventions.
11. Understanding of the role of material and social forces that underpin constraints to good health conditions or personal health skills (p. 147).²⁹

Broadly these principles refer to the social context in which people self-manage, the value of people's knowledge and experience of their health and ill-health and the structural barriers that impact on their self-management. While the practice of these principles requires action from health professionals, they also require systemic changes.

PCC approaches are, not surprisingly, focussed on the individual, whereas empowerment, especially within the context of health promotion, gives centrality to the social environment the individual lives within it. The individual is considered within a broader com-

munity context, beyond even carers and family. This means respecting culture, acknowledging the family and community context and the need to address structural barriers to achieving well-being.²⁹

There is a particular sense of autonomy that is implicit in empowerment. The reference to 'authentic participation' requires something more of practitioners and the people they see. Empowerment is about individual clients and patients participating in the health system. This is a different *kind*, a different *level* of participation and action to that required of patients in PCC. This type of participation gives more credibility to what the individual has to offer, not just their personal care but to the system they encounter in the process of self-care. So, essentially, the difference is about the value placed on the individual's knowledge and experience. This is reflected in the recognition that they have something to contribute to the system as a whole, not just to their own care. In the light of this, it is possible that the autonomy expected of an individual in PCC is distinctly different to the autonomy expected of an individual through the process of empowerment.

This kind of approach has the potential to impact a key assumption for PCC and behaviour-change approaches to empowerment, which assume the individual whose health is a concern is necessarily the patient – an individual engaged directly with the health system through contact with health professionals. That is, while PCC has grown within the context of self-management for patients of health professionals, empowerment is focused on individuals who may or may not be patients. This makes room for an acknowledgement that individuals with chronic conditions are always self-managing regardless of their contact with the health systems and especially health professionals within it. In essence, 'power' rests with the individual regardless of health systems' perceptions that *they* may hold the majority of knowledge and power in relation to the management of chronic conditions.

The process of empowerment is in part about enabling use of resources. But most important is

attention to structural barriers. These barriers need to be identified and included, so that a mandate to find mechanisms needed to deal with them is an explicit part of the process. Attention can then be paid to the structural 'forces' that affect the conditions of health and an individual's skills in caring for themselves.

Empowerment and PCC

While empowerment approaches can be mobilized as strategies for both community and individual behaviour change,²⁶ personal and psychological empowerment is driven by achieving change in power relations, with the reasoning that as a consequence of those changed power relations, concomitant changes in the (social and economic for example) determinants of health will create improved health outcomes. This is what lies at the heart of Comprehensive Primary Health Care approaches to health wherein empowerment is a key strategy.

There is room for caution, however. While there are good reasons for supposing that 'empowerment' is a better aim than PCC, or indeed that person centred care is a means of achieving empowerment for individuals, this concept runs the risk of making assumptions about the needs of those with chronic illnesses too. Empowerment approaches presuppose a disempowered individual. Within the context of self-management, empowerment approaches assume then that all individuals wish to be empowered to self-manage in specific ways and that individuals and health professionals want to change and have the capacity, drive and skills to change their relationship. For example, Lorig (p. 11),³⁰ one of the leading researchers in this area, sees self-management as enabling 'participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise'.

The empowerment currently embedded in PCC resembles what are considered to be uncritical definitions of health literacy that are concerned with 'people's capacity to obtain,

process and understand basic (written and oral) health information and services needed to make appropriate health decisions' (p. 285).³¹ Health literacy is being reconfigured to see it as an 'ability to critically analyse information, increase awareness and participate in action' (p. 288).³¹ Our call to action is that these developments in health literacy be mirrored in thinking around PCC, so the focus is on approaches that build self-efficacy, not only changes in relationships between health practitioner and patient. To conceive of empowerment as self-efficacy (as a sense of individual capacity), empowerment through PCC needs to be conceived as something beyond the patient, beyond the individual and beyond the clinical relationship. That kind of empowerment is a social justice, rights-based empowerment that requires broader change.

PCC reconfigured in this way has the potential to address three key limitations underpinning self-management. Firstly, all self-managers are patients. This would require some shift in focus away from the clinical setting. Secondly, individual patients are characterized as simultaneously and uniformly uninformed, but (with the right information) capable of autonomy. Finally, the individualistic approach in PCC focuses attention squarely on individuals and to some extent their families and carers but not on the wider community as if they are diametrically opposed.

Our review of PCC showed it to be understood variously as putting a person's needs at the heart of the system,⁶ supporting people to make informed decisions,^{8,9,13} a focus on the relationship between the practitioner-patient relationship,^{9,10} a partnership approach,^{11,13} a valuing of people's experiences^{11,13} and a process of empowerment.^{10,11} In reviewing understandings of empowerment, we asked whether it could make more, different or better room for a self-determining, self-managing individual. Our conclusion is that this can be achieved with a PCC informed by a social justice and rights-based approach to empowerment, an approach that would become a shared responsibility, beyond the practitioner and beyond the indi-

vidual. This PCC could go some way towards achieving the goals of the global health promotion charters. The call to action for health professionals then is that they assume the role of advocate and champion for a system that operationalizes an understanding of PCC. It also assumes and acknowledges the social context within which self-management takes place, the value of the self-manager's (patient or not) knowledge and experience of their health and ill-health and the impact of structural factors on self-management.

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