Chapter 2

Promoting Self-Management and Patient Empowerment in Primary Care

Claire Collins and Andree Rochfort

Additional information is available at the end of the chapter

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Abstract

The complexity of health care is increasing, associated with several factors including aging populations and expanding comorbidities, growth in options for health interventions and patients' access to information from electronic and other media. Management of chronic conditions with high morbidity such as diabetes, cardiovascular disease, cancer, chronic pulmonary disease and depression constitutes a major burden of clinical care worldwide and an increasing problem for primary care because responsibility for chronic care shifts from hospitals to health professionals in primary care. Recently, there has been increasing attention focussed on another player/stakeholder in this quest to improve patient outcomes–the patient.

As of 9 September 2011, the new World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (WONCA) EU definition of general practice includes as its 12th characteristic "Promotion of patient empowerment and self-care", following evidence of its relevance and importance.[1, 2]

During the course of a systematic review of the literature on the impact of health professional training regarding patient self-management on patient outcomes, we created a repository of information around the topics of patient self-management and empowerment. In this chapter, we synthesise this literature.

The systematic review was performed for articles published in advance of 1 September, 2013 using PubMed, ERIC, EMBASE, CINAHL, PsycINFO, Web searches, Hand searches and Bibliographies employing 13 search terms.

In conclusion, we note that there is a need to explore and to clarify the various aspects of patient empowerment and the many sources influencing successful patient self-management. These concepts involve a complex interaction of patient factors, health professional factors, health system factors and multiple other influences that need to be harnessed effectively by all stakeholders.

Keywords: Self management, patient empowerment, general practice, primary care, chronic conditions

1. Introduction

The complexity of health care is increasing, associated with several factors including aging populations and expanding comorbidities,[3] growth in options for health interventions and patients' access to information from electronic and other media. Management of chronic conditions with high morbidity such as diabetes, cardiovascular disease, cancer, chronic pulmonary disease and depression constitutes a major burden of clinical care worldwide and an increasing problem for primary care as responsibility for chronic care shifts from hospitals to health professionals in primary care. Chronic diseases, often now referred to as non-communicable diseases, are of long duration and generally of slow progression.[4] Chronically ill individuals are more likely to have limitations in their daily living activity than others.[5] Chronic disease accounts for a significant proportion of the disease burden and an increasing workload for GPs, accounting for up to 60% of visits by patients 45 years and older.[6] The World Health Organisation (WHO) expects that chronic conditions will account for 73% of all deaths and 60% of morbidity and disability by 2020 and considers that one of the greatest challenges facing health care systems globally is the increasing burden of chronic diseases.[7] Multimorbidity, polypharmacy, complexity and increasing fragmentation of the management of chronic conditions are real challenges for GPs today. This complexity and fragmentation are reported by both patients [8, 9] and health care workers.[10, 11] Patients with multiple chronic diseases experience unfavourable health outcomes and give rise to challenges in patient care and medical costs.[12] It must be acknowledged that increasing demands and associated costs on health care system are not sustainable.

The availability of sufficient time for clinicians to manage a range of chronic conditions[13, 14] within the normal consultation time has been identified as a factor along with infrequent care coordination[15-17] and lack of active follow up.[10, 18-21] Furthermore, chronic illness requires a different approach from clinicians than acute illness.[22]

The WHO has suggested that the following skills are both useful and necessary to better manage chronic illness[23]:

a. Patient centred care — care needs to be organised to include patient involvement.

b. Quality improvement — measuring care and its outcomes, learning and adapting to change and translating evidence into practice.

c. Collaboration — partnering with patients, other health care workers/providers and communities.

d. Information and communication technology — designing and using patient registers, using computer technologies to support care and communicating with partners.

e. Public health perspective — health care workers need to broaden their perspective on health. This includes a better understanding of population-based care and the care continuum.

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Battersby and colleagues[22] have expanded this list of core factors influencing primary health care workers (HCWs) and listed them in three domains: general patient-centred capabilities, behaviour change capabilities and organisational infrastructure.

While most GPs describe their approach as patient-centred, the latter does include elements that are sometimes missing in the doctor–patient relationship. There are five domains to patient-centred care.[24-26] These include the following:

- a biopsychosocial perspective
- patient-as-person
- sharing power and responsibility
- therapeutic alliance (establishing common ground)
- doctor as person.

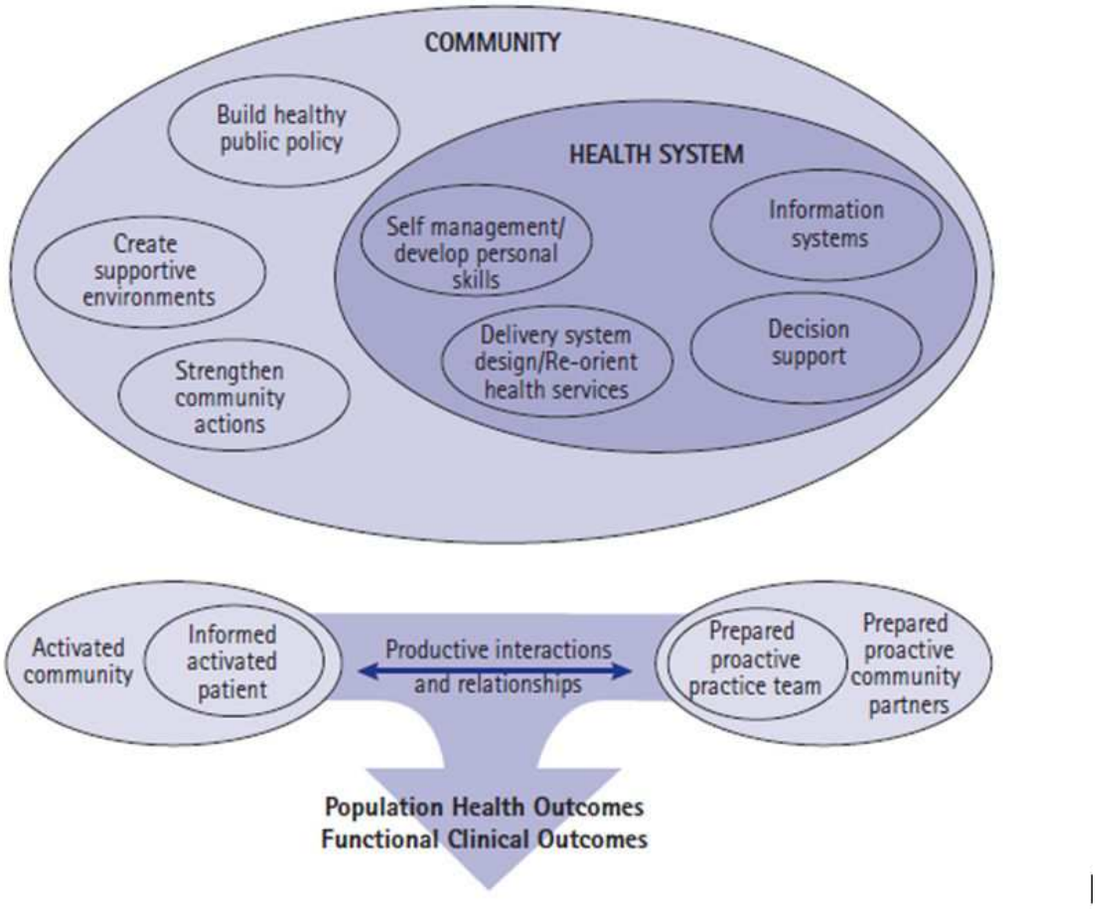
Teasing these concepts out, Stewart[27] summarised the key elements of patient-centred care that are desired by patients. These include the following:

- an exploration of the patient's main reason for the visit, including their concerns and need for information
- an integrated understanding of the patient's world–that is, their whole person, including their emotional and other needs and life issues
- an attempt to find common ground on what the problem is and mutually agree on what should happen
- a greater role for prevention and health promotion
- strategies that enhance the continuing relationship between the patient and the doctor.

Others have suggested the use of 'person-centred care' to emphasise the importance of the doctor–patient relationship, which includes more reflection and an acknowledgement of the patient in his/her individual context as a person, and not simply as a patient.[28]

Wagner and colleagues[29] first described the chronic care model (CCM).[29] The chronic care model (Figure 1) is designed to make patient-centered, evidence-based care easier to achieve. The aim of the CCM is to transform the daily care for patients with chronic illnesses from acute and reactive to proactive, planned and population-based. It is designed to accomplish these goals through a combination of effective team care and planned interactions: self-management support including more effective use of community resources; integrated decision support and patient registers and use of other information technology (IT) resources. These elements are designed to work together to strengthen the clinician–patient relationship and improve health outcomes. Patient focussed care needs to include outcomes that are meaningful and helpful for the patient.[30] A wide range of interventions to improve patient outcomes in chronic illness have been implemented at health policy level, organisational level and health professional level. Interventions are targeted at secondary prevention to minimise complications as there is no absolute 'cure' for chronic conditions once established. Recently, there has been

increasing attention focussed on another player in this quest to improve patient outcomes and that player or stakeholder is the patient. Patient participation in the management of their illness is now recognised as a factor that can improve patient outcomes and is a factor in implementing improvement in quality and safety of health care.[31]



Created by: Victoria Barr, Sylvia Robinson, Brenda Narin-Link, Anita Dotts and Dariana Ravensdale (2002). Adapted from R. Glasgow, C. Orleans, E. Wagner, S. Curry and L. Solberg (2001). Does the Chronic Care Model also serve as a template for improving prevention? The Millbank Quarterly, 79(4), and World Health Organisation, Health and Welfare Canada and Canadian Public Health Association (1986). Ottawa Charter of Health Promotion. (This diagram may be found in Barr, Robinson, Marin-Link, Underhill, Dotts, Ravensdale & Salivaras, 2003.)

Figure 1. The chronic care model.

As of 9 September 2011, the new WONCA (*World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians)* European definition of general practice includes "Promotion of patient empowerment and self-care" as its 12th characteristic, following evidence of its relevance and importance. [1, 2, 32-34] The literature search by Mola et al.[32] provides evidence to support the specific setting of family medicine/general practice within the primary care setting as the optimum health care environment above other health care environments for promotion of patient empowerment and

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self-care. This is the basis of this newly accepted characteristic of patient empowerment being adopted as a core characteristic of the discipline of general practice rather than hospital-based care (Figure 2). Following adoption of this new characteristic, WONCA, through it anniversary grant, funded a collaborative project comprising of a systematic review and the creation of a template e-learning module focussing on patient self-management, of which patient empowerment is a key factor.

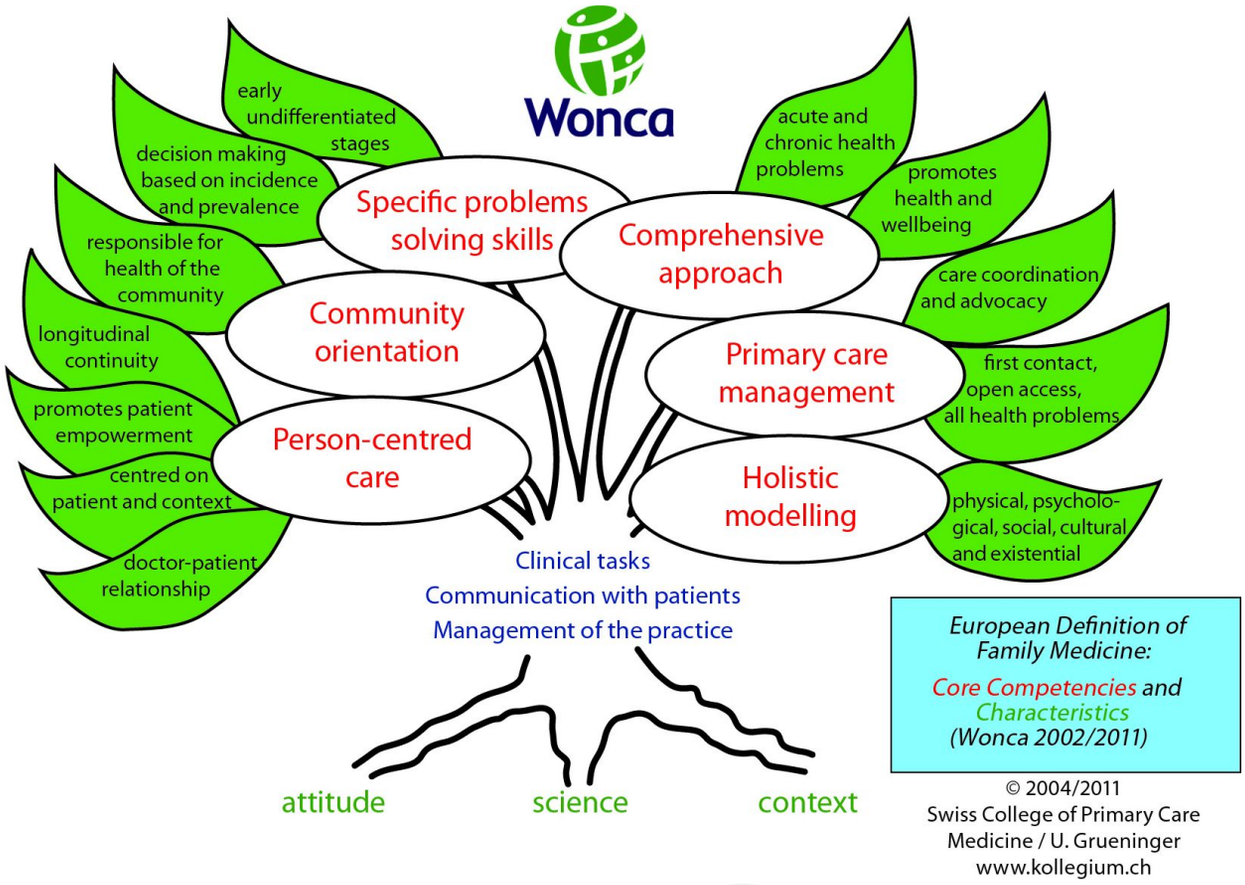

Figure 2. The WONCA tree.

While undertaking the systematic review, which focused on the impact of health professional training regarding patient self-management on patient outcomes (PROSPERO registration number: CRD42013004418), we created a repository of information around the topics of patient empowerment and self-management. In this chapter we synthesise this literature.

2. Methods

The systematic review was performed for articles published before 1 September 2013 using the following: PubMed, ERIC, EMBASE, CINAHL, PsycINFO, Web searches, Hand searches and Bibliographies employing the following search terms:

1. Primary healthcare
2. Physicians, primary
3. Physicians, Family
4. General Practitioners
5. #1 OR #2 OR #3 OR #4 NOT dental NOT pharma*
6. Education, continuing OR evidence-based medicine/education
7. Patient education as topic
8. Training
9. #6 OR #7 OR #8
10. "long term care"
11. Chronic disease
12. #10 OR #11
13. #5 AND #9 AND #12

All abstracts were reviewed using the RefWorks package to categorise the abstracts identified by the search. Articles not considered directly relevant to the systematic review where retained to populate a separate repository of information on subtopics. The key generic articles located from this search under the topics of patient self-management and patient empowerment and are synthesised in this chapter.

2.1. Self-management

Self-management, in the context of non-communicable disease, can be conceptualised as a set of tasks and processes that are used by a patient to maintain wellness in the presence of an ongoing illness.[35] Chronic condition self-management has been defined in numerous different ways; one example is: a process that includes a broad set of attitudes, behaviours and skills. It is directed toward managing the impact of the disease or condition on all aspects of living by the patient with a chronic condition. It includes, but is not limited to, self-care and it may also encompass prevention.[36]

A Cochrane Collaboration report[37] showed that improving patient self-management is one of the four categories of practice change that result in maximum impact on improving patient outcomes: the four categories being increasing clinicians' expertise and skill, educating and supporting patients, emphasis on team-based care delivery and making better use of IT-based patient registers.

Effective self-management skills can improve patient self-efficacy and reduce health care costs through fewer outpatient visits[38] and hospital admissions.[15, 39] Health professional training is associated with better uptake, implementation and effectiveness of self-management programs.[36, 40]

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Self-management support is defined as the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support.[41] Self-management support involves the application of collaborative goal setting and a range of self-efficacy strategies, for example, effective problem solving, monitoring his/her own condition, relapse prevention plans, patient education, group supports and shared decision making.[42]

Self-management support is the least implemented of the elements of the CCM[43] and has its own set of challenges, including developing and refining clinician skills in chronic care management, clinician self-efficacy and changing clinician behaviour. It is easy for clinicians to overlook the fact that many patients do not feel 'sick' with chronic conditions such as hypertension, diabetes or obesity.[44] Willcox and Gill[45] revealed uncertainty and a lack of understanding among health professionals regarding the concept of self-management support and its application. There is evidence available showing the efficacy of self-management support.[46-48]

Patient self-care affects health outcomes through numerous pathways,[49] such as follows:

- adherence to therapeutic regimens
- maintenance of health-related behaviours, e.g., lifestyle choices
- (self)-monitoring symptoms to inform treatment/self-care decisions
- monitoring and managing the emotional consequences of illness
- influencing the nature of communication between health care worker and patient to ensure that patients' needs are expressed and addressed
- using support networks to help achieve the above.

Self-management expands self-care with strategies to enhance the patient's own effectiveness and self-determination.[50] It requires greater collaboration with health care workers. An increasing number of patients are requesting a greater emphasis on shared care.[51-54]

Chronic care programmes that encourage self-management have been shown to be effective in a range of chronic diseases.[19, 20, 48, 55, 56-59] Improving specific patient and clinician behaviours (patient self-management and close monitoring of disease control parameters to achieve individualised goals) can improve disease control and quality of life among patients with multiple conditions and complex health care needs.[60]

Self-management methods promoted by primary care professionals should be based on best available evidence on effectiveness, safety and cost-effectiveness. Numerous system factors, patient factors and clinician factors influence effective patient self-management. System support for patient self-management (e.g., adequate time, training, IT, resources and support) is thought to contribute to an effective self-management process.[30]

Initiatives that both support patients and equip health professionals are required because each has a different function and both are required if self-management support is to be effective

and sustainable.[16, 61] In terms of patient factors, coordination of methods to address barriers to patients' behaviour change is also key to successful patient self-management.[22] Two clinician factors, which might adequately be addressed at the level of continuing medical education and post-graduate training, are guideline non-adherence and sharing decision making with the patient; both require patient participation and engagement.[60, 62] Skill development in shared decision making can be incorporated into post-graduate professional development programmes and has been recommended.[63]

The educational focus around self-management needs to extend to all health care professionals in both primary and secondary services to ensure patients receive consistent and effective messages appropriate for their condition across the sector.[15] In the United Kingdom, the WISE (Whole System Informing Self-management Engagement) model advocates at patient, health care professional and structure of health care levels to support self-management practices.[64]

2.2. Patient empowerment

The idea of empowerment was first introduced in the 1960s by the Brazilian pedagogue Paulo Freire[1] and, with health care, has been acknowledged as an alternative to compliance to guide the provider–patient relationship.[65] Most patient empowerment definitions focus on individuals' capacity to make decisions about their health (behaviour) and to have, or take control over, aspects of their lives that relate to health[66] with most incorporating some form of personal control and self-efficacy/self-mastery.[35, 65, 67-71] Empowerment occurs when the health care professional's goal is to increase patients' capacity to make autonomous, informed decisions, and patients are making these decisions and choosing personally meaningful, realistic goals.[72]

Patient empowerment suggests more collaborative models of clinician–patient interaction. McAllister et al.[66] compared the paternalist and empowerment paradigms and suggested that the concept of empowerment could be another conceptualisation of the capability paradigm suggested by Sen.[73] A key attribute of patient empowerment is that the patient is not a passive recipient of health care and is self-determining with some control of his/her own health and health care.[35, 65, 69-71] However, Anderson et al.[74] argued that patients who choose to hand over responsibility should still be considered empowered being responsible for their choice, if not for their treatment.

Studies of patient empowerment in general practice and primary care to improve management of chronic diseases have shown good results, increasing patient and health professionals' satisfaction, adherence to guidelines and treatment and improving clinical outcomes.[1] With regard to success, research has indicated that multifaceted interventions are more effective than simpler ones[75] and that enduring change requires a multilevel approach,[76] with interventions at different levels interlinked and mutually reinforcing. This requires a whole systems perspective that involves interventions at the patient, practitioner and service organisation levels in the delivery of self-management support.

Although many factors (such as culture, age and socio-economic resources) influence empowerment, it is argued that empowerment can be considered to be either a process or an outcome and that patients can be empowered by their health care providers.[77, 78] As the concept of

patient empowerment continues to be the subject of further exploration, we can expect more refinement of its definition and relevance to patient health outcomes in primary care in the future.

General practice/family medicine (GP/FM) has been shown to be a suitable setting for promoting patient empowerment, because many of the characteristics of GP/FM are already oriented towards encouraging patient empowerment longitudinally over time. By its nature, primary care provides continuous, comprehensive and coordinated care across the care continuum.[79] The GP is in a key position to utilise and to promote patient and carer use of relevant information technology in patient empowerment. Tools such as personal health records (PHRs) integrated with electronic health records, interactive tools for health coaching, decision aids and decision support for both health professionals and patients are developing rapidly.[80] However, in order to effectively translate empowerment into clinical practice, will require health-care providers to adopt a truly patient-centred approach.[65]

3. Concluding remarks

Physicians can learn to be experts in management of medical conditions, but only patients can be experts in the conduct of their own lives.[81]

The patient has a role to play in determining his/her own health outcomes.[82] For optimum patient outcomes, there is a need to explore and to clarify for the clinician the various aspects of patient empowerment and the many sources of influence on successful patient self-management. These concepts involve a complex interaction of patient factors, health professional factors, health system factors and multiple other influences that need to be harnessed effectively by all stakeholders.

Author details

Claire Collins* and Andree Rochfort

*Address all correspondence to: claire.collins@icgp.ie

Irish College of General Practitioners, Dublin, Ireland

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