

## Review

## Patient-centered care in chronic disease management: A thematic analysis of the literature in family medicine

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## ABSTRACT

**Objective:** The objective was to provide a synthesis of the results of the research and discourse lines on main dimensions of patient-centered care in the context of chronic disease management in family medicine, building on Stewart et al.'s model.

**Methods:** We developed search strategies for the Medline, Embase, and Cochrane databases, from 1980 to April 2009. All articles addressing patient-centered care in the context of chronic disease management in family medicine were included. A thematic analysis was performed using mixed codification, based on Stewart's model of patient-centered care.

**Results:** Thirty-two articles were included. Six major themes emerged: (1) starting from the patient's situation; (2) legitimizing the illness experience; (3) acknowledging the patient's expertise; (4) offering realistic hope; (5) developing an ongoing partnership; (6) providing advocacy for the patient in the health care system.

**Conclusion:** The context of chronic disease management brings forward new dimensions of patient-centered care such as legitimizing the illness experience, acknowledging patient expertise, offering hope and providing advocacy.

**Practice implications:** Chronic disease management calls for the adaptation of the family physician's role to patients' fluctuating needs. Literature also suggests the involvement of the family physician in care transitions as a component of patient-centered care.

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## 1. Introduction

Chronic diseases represent a major health burden worldwide [1]. Experience with chronic diseases implies that the patient, along with having to adopt improved health behaviors, is faced with having to make major adaptations to its repercussions and the daily management of the disease. As many people affected by chronic diseases frequently interact with a family physician [2–4], this professional is in a privileged position to play a significant role in their lives.

Patient-centered care is widely acknowledged as a core value in patient–physician interactions [1,5]. Stewart et al. played a major role in the conceptualization of patient-centered care in family medicine. Their patient-centered care model, initially developed in

the 1980s [6–8] and described later in 1995 in the first edition of their book [9], is now the most cited in family medicine [10–14]. This framework is taught in family medicine residency programs across Canada [15]. Much patient-centered care evidence in family medicine relies on Stewart et al.'s model [10,16,17] that proposes six dimensions: (1) exploring both the disease and the illness experience; (2) understanding the whole person; (3) finding common ground; (4) incorporating prevention and health promotion; (5) enhancing the patient–physician relationship and (6) being realistic.

Several recent studies have focused on patient-centered care in the specific context of patients affected by chronic diseases [18–22]. Some have suggested components of patient-centered care that go beyond Stewart et al.'s model, such as notions of hope [22] or engaging patient expertise [18]. Therefore, the aim of this research was to provide a synthesis of the results of the research and discourse lines on main dimensions of patient-centered care in the context of chronic disease management in family medicine, building on Stewart et al.'s model.

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## 2. Methods

### 2.1. Search methods

We conducted an electronic literature search for English and French articles spanning the 1980 to April 2009 period in Medline (1980–), Embase (1980–), and Cochrane (1991–). An information specialist developed and ran the specific strategies for each database (Appendix A). The following MeSH terms and keywords were used: “patient-centered care” or its linguistic variants and, “family practice,” or “primary health care,” or “primary medical care,” or “primary care”. To broaden the scope of our research, we applied one other search strategy for patient-centered care instruments to the same databases (Appendix A). We also examined articles found in the reference lists of collected articles (hand searching).

### 2.2. Data collection

All search results were transferred to a reference database (Refworks) and duplicates were eliminated. We searched for articles meeting all of the following criteria: (1) pertained to patient-centeredness of care, (2) in the context of chronic disease management in family medicine, and (3) in an adult population.

Titles and abstracts were read by one team member (ML) to exclude articles that were clearly not eligible. We excluded references distinctly not meeting our inclusion criteria and retained all other references for complete evaluation. Two authors (CH and ML) independently appraised the full text of the retained papers to identify potentially eligible articles. Discrepancies between the two reviewers regarding inclusion or exclusion were resolved by submitting the reference to a third evaluator (MEP).

### 2.3. Analysis

The approach taken in this study corresponds to descriptive qualitative research as described by Sandelowski [23,24]. It falls under a postpositivism paradigm [25] which aims to objectively apprehend the reality as closely as possible by rigorous methods. We used thematic analysis to analyze the patient-centered care-related data of the included articles in order to identify patterns from the literature review and to obtain a more detailed analysis [26]. Therefore, themes were created from the semantic content of the data for their explicit meaning.

The thematic analysis was performed on all articles by two evaluators from different professional backgrounds (CH, an experienced general practitioner and ML, an anthropologist), using mixed coding as described by Miles and Huberman [27], with the six dimensions of Stewart's model as a starting point. The relevant features addressed in the papers were organized into a grid according to Stewart's six dimensions and new ones emerging from our analysis. The analysis process was in line with the phases of thematic analysis identified by Braun and Clarke [26]. Initially, familiarization with the data generated ideas to create initial codes. Then, codes that were linked were grouped into potential themes. Each theme was reviewed to ensure that it reflected both its associated coded extracts and the entire data set. Finally, themes were defined and refined by attributing clear definitions and names. Stewart's model was thus iteratively modified to highlight chronic disease realities. Throughout the analysis, disagreements or questions were discussed and interpretations were validated with four (4) co-researchers (MF, JH, CL, MEP). Pair debriefing, triangulation and team validation minimized the influence of researcher subjectivity and preconceptions [28].

## 3. Results

### 3.1. Included studies

Fig. 1 shows the number of references found at each stage of the selection process. The search strategies identified 1745 references, of which 1565 were kept after removing duplicates. The majority of these references were excluded by reading the abstract, as they clearly did not meet our inclusion criteria. One hundred five papers were read completely. References found through hand searching ( $n = 4$ ) were also included, for a total of 109 potentially eligible references. Of these 109 articles, 77 were excluded: 52 did not pertain to the concept of patient-centered care and were related to other concepts (empowerment, quality of care, self-management, continuity of care, involvement, etc.), 19 were not applicable to ambulatory family medicine (hospital setting, medical specialty, nursing, healthcare network, etc.), 5 did not relate to chronic disease, and one concerned patients under 18 years of age. A final sample of 32 articles was retained [5,12,18–22,29–53].

Table 1 presents the characteristics of the included articles.

### 3.2. Themes

Thematic analysis allowed us to group the relevant features addressed in the articles into six major themes: (1) Starting from the patient's situation; (2) Legitimizing the illness experience; (3) Acknowledging the patient's expertise on his/her own life; (4) Developing an ongoing partnership; (5) Offering realistic hope; (6) Providing advocacy for the patient in the health care system. Table 2 presents the number and type of articles falling under each theme and sub-theme.

**Table 1**  
Characteristics of the included articles ( $n = 32$ ).

	Number of articles
Type of publication/study design	
Empirical studies	
Qualitative studies [12,16,17,32,37,39,40,44,46,49]	10
Quantitative studies [38,52,53]	3
Mixed methods [21,35,42]	3
Theory development, opinion papers, commentaries	15
[5,19,20,22,29,31,33,34,36,43,45,47,48,50,51]	
Selected reviews [41]	1
Chronic diseases	
Diabetes [21,32,35,38,49–51,53]	9
Cancer [22,30,31,37,40,44]	6
Chronic diseases (unspecified diseases) [5,33,34,39,41,48]	6
Chronic pain/fibromyalgia/chronic fatigue [42,43,46,52]	4
Asthma/COPD [36,47]	2
Depression [12]	1
Diabetes + asthma + arthritis [29]	1
Erectile dysfunction [20]	1
Long-term disability [45]	1
Migraine [19]	1
Author's location	
United States [5,19,22,31,33,34,36,48,49,51]	10
United Kingdom [21,37,38,41–45,50]	7
Canada [30,39,40,46,47]	5
Australia [29,43]	2
Spain [42,52]	2
Greece [20]	1
Ireland [12]	1
Norway [32]	1
Oman [16]	1
Sweden [35]	1
Thailand [53]	1

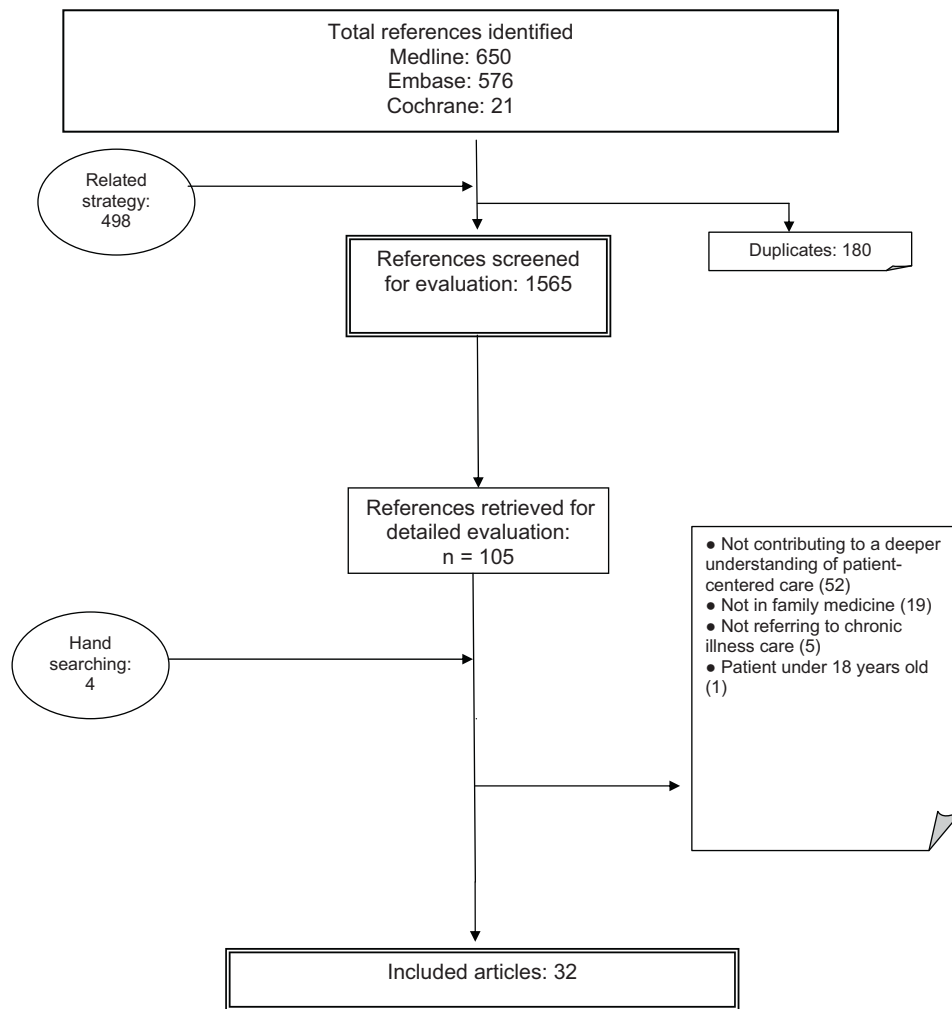


Fig. 1. Number of references identified through the stages of the concept analysis.

3.2.1. Starting from the patient by acquiring a comprehensive understanding of his/her situation: 30 articles

Patients present to the family physician with their own background and unique experience of illness. A rich knowledge of the patient’s situation is a necessary component of chronic disease management. This theme is subdivided into two sub-themes corresponding to Stewart et al.’s dimensions: “Exploring

both the disease and the illness” and “Understanding the whole person”.

3.2.1.1. Exploring both the disease and the illness experience: 25 articles. As suggested by Stewart et al. [17], this theme involves paying as much attention to dimensions of illness (feelings, ideas, and patients’ perceptions of disease seriousness or expectations of

Table 2  
Number and type of articles falling under each theme and sub-theme.

Themes and sub-themes	Number of articles n (%)	Type of publication/study design				
		Empirical studies			Theory development, opinion papers, commentaries n (%)	Reviews n (%)
		Qualitative n (%)	Quantitative n (%)	Mixed methods n (%)		
Starting from the patient by acquiring a comprehensive understanding of his/her situation	30 (94)	10 (31)	2 (6)	5 (17)	12 (40)	1 (3)
• Exploring both the disease and the illness experience	25 (78)	8 (25)	2 (6)	4 (13)	10 (31)	1 (3)
• Understanding the whole person	25 (78)	10 (31)	1 (3)	4 (13)	10 (31)	–
Legitimizing the illness experience	5 (16)	2 (6)	1 (3)	–	2 (6)	–
Acknowledging patient expertise on their own lives	14 (44)	4 (13)	–	2 (6)	7 (22)	1 (3)
Developing an ongoing partnership	27 (84)	7 (22)	2 (6)	5 (17)	13 (41)	–
• Enhancing the patient physician relationship	23 (72)	7 (22)	2 (6)	3 (9)	10 (31)	1 (3)
• Finding common ground	25 (78)	7 (22)	2 (6)	4 (13)	12 (38)	–
Offering realistic hope	2 (6)	–	–	–	2 (6)	–
Providing advocacy for the patient in the health care system	9 (28)	6 (19)	–	–	3 (9)	–

outcomes) as to dimensions of disease (history, physical examination, laboratory tests) [5,12,18,20,21,30,32–34,36–38,41–44,46,47,52,53]. In the context of chronic disease management, understanding the patient's unique experience of illness [17] also entails the exploration of co-morbidity [53], previous experience of care [22,35], health behaviors [53] and confidence about disease management [29,49].

**3.2.1.2. Understanding the whole person: 25 articles.** According to Stewart et al., considering the person as a whole may help increase our understanding of the disease and the illness experience [21,30,34,39,42–44,46,47,50]. This could be accomplished over time by knowing about the patients' life context (family, work, religion, culture, social support, etc.) [18,20,29,31,37,38,48] as well as personal development stages (life history and personal and developmental issues) [12,36,49,53]. In being aware of the multiple aspects of the patient's life [17], health literacy should also be taken into account [22,32,33].

### 3.2.2. Legitimizing the illness experience: 5 articles

This new theme emerged as an integral part of chronic disease management which becomes a persistent presence in the patient's life, including a redefinition of selfhood. Naming the illness [46,52] is a crucial step when possible, or at least addressing the uncertainty of the diagnosis [46]. Patients need to see their concerns, ambivalence, feelings of loss and grief over their prior capabilities acknowledged [30] as well as their uncertainty about the future [22]. They also need to be able to express their individual problems, fears and frustrations with having a chronic disease [29,46].

“Participants experienced a sense of relief now that their struggle was acknowledged and their illness experience legitimized.” [46]

### 3.2.3. Acknowledging patient expertise on their own lives: 14 articles

In chronic disease management, most interventions are undertaken by the patient rather than by the physician. The physician should believe in the patient's capacity [18,33], to enable him/her to self-manage [5,18,29,41,43,50,51,53]. Interventions should be tailored to the person's strengths and challenges in managing his/her care [5,30,32,36,46,53]. Physicians could also help to establish realistic self-management goals [47,50,51].

“Tailoring interventions based on each person's unique set of factors: his or her strengths...” [48]

### 3.2.4. Developing an ongoing partnership: 26 articles

Effective chronic disease management requires sustained and coordinated action by the patient and the physician: an ongoing partnership. That partnership is negotiated over time and in light of patient capacities. The physician has to adjust his/her role to patients' role preference [22]. This theme includes two sub-themes corresponding to Stewart et al.'s enhancement of the physician–patient relationship and finding common ground.

**3.2.4.1. Enhancing the patient–physician relationship: 23 articles.** Each encounter with a patient is an opportunity to develop the patient–physician relationship [34]. The patient often needs compassion [32,42,43,52], trust [31], equality [12,32], respect [35], positive regard [21] and interest [30], recognition [20,53], appreciation and understanding [38] as well as relational continuity [5,18,19,22,29,30,33,36,37,43], enough time [36,43,52] and support [22,44,46,52].

“Continuity of care can foster a relationship which has the potential to empower the patient and enhance the healing

process during the more difficult and stressing phases of the disease process.” [30]

**3.2.4.2. Finding common ground: 25 articles.** The physician uses his/her competency [18] and best medical evidence [36,47] to diagnose, provide results [18] and present information [18,42,44,51] if needed [37,44,52] in an understandable language, in order to find a common ground in regard to management [12,19–21,29,30,33,34,38,42,43]. Patients' participation in their own care should be encouraged [50–52] by stimulating him/her to ask questions [38], providing therapeutic options when available [31,37,44], assessing how much information the patient wants to know [22], and his/her readiness to engage in the discussion [22,32,33]. Patient needs, preferences and beliefs should be respected at all times [18,37,38,42,53]. Family members could be involved if the patient is willing [18,48].

### 3.2.5. Offering realistic hope: 2 articles

This new theme differs from Stewart et al.'s “Being realistic” in its emphasis on hope and support, often in the context of uncertainty or the inevitable decline of chronic conditions. Options for the future should be discussed when appropriate [22].

“Perhaps primary care physicians' greatest skills are the ability to offer hope and wisdom while assisting patients and family as they adjust to an ever-changing social and medical environment.” [31]

### 3.2.6. Providing advocacy for the patient in the health care system: 9 articles

This new theme pertains to the physician's role in guiding the patient through the healthcare system. It assumes increasing importance as the patient's chronic condition and resulting care trajectory become more complex. The physician uses external resources [39] by referring the patient to other members of the primary or healthcare team in the clinic or the health care system [18,22,29,30] as well as support groups and other community-based services [18,22,29]. For example, the physician helps prepare for hospital appointments and tests [37]. In fact, the physician must coordinate care to act as gatekeeper in defending patient interests and safety in the healthcare system [44,46].

“Patients need easy access and prompt assistance to deal with urgent situations.” [31]

### 3.2.7. Over time

Each of the themes previously described includes a longitudinal dimension. Needs and expectations (Section 3.2.1) will change depending on episodes of illness, context of life and illness experience (Section 3.2.2) [22,30,37]. Time is a precious ally to the development of patients' expertise in self-management (Section 3.2.3) [29,33,38]. The physician will have to adapt his/her role taking these new skills into account.

The long-term relationship (Section 3.2.4) and a unique knowledge of the patient contribute to the development of trust that often increases over time and may, in turn, strengthen the relationship [31]. As the disease progresses, values, goals and preferences must be reassessed and discussed [22,29,33,46].

“Offering realistic hope” (Section 3.2.5) calls for a longitudinal perspective as it often refers to upcoming facts or states [30]. Finally, the physician advocacy role (Section 3.2.6) will change according to fluctuations in patient needs [30].

“The patient's expectations of his/her physician will fluctuate during the course of his/her disease.” [30]

## 4. Discussion and conclusion

### 4.1. Discussion

This thematic analysis of the literature is the first attempt to integrate theoretical and empirical literature on patient-centered care in chronic disease management in family medicine, building on Stewart et al.'s model. The four main dimensions of their model emerged from our analysis and were regrouped under broader themes and refined to account for chronic disease realities. For instance, considering the significant prevalence of multimorbidity in primary care practices [54–56], experience of care should extend beyond present experience to capture previous experiences of care [22].

New themes emerged from the literature such as “Legitimizing the illness experience” [22,29,30,46,52]. This theme is in continuity with Stewart’s dimension “Exploring both the disease and the illness experience” that proposes assessing both the disease process and the patient’s unique experience of illness [17]. Three empirical studies [30,46,52] stressed the importance of physicians acknowledging patient feelings of loss and grief over their prior capabilities as well as uncertainty about the future and allowing them to express their individual problems and frustrations with having a chronic disease. It is often a necessary step to help patients regain more control over their health and increase self-management capabilities.

Stewart et al.’s dimension “Being realistic” [17] includes teambuilding and teamwork and recognizes the importance of wise stewardship in accessing resources. “Patient advocacy” [18,22,29,30,33,37,39,44,46] goes further by introducing actions such as helping the patient obtain needed healthcare, ensuring quality of care, defending patient rights, and serving as a liaison between patient and health care system [57,58]. This theme was stressed in six qualitative studies [18,30,37,39,44,46]. Transition in care often constitutes a major issue for patients with chronic diseases. This notion of physician involvement in facilitating transition in care and his/her role in defending the patient stands out from the other themes in this work and from those in Stewart et al.’s model that are more specific to the interaction between patient and physician.

The course of each clinical encounter with the family physician can be considered as being on an ad hoc basis, in the patient-centered care model. The two instruments specifically conceived to measure patient-centered care [59] in fact evaluate the last visit with a physician. Chronic disease management brings a longitudinal component into perspective. In this context, all the dimensions of the concept could be better captured with a measure considering a certain period of time.

Self-determination theory, of which one of the key concepts is autonomy support, addresses several elements related to patient-centered care [60]: eliciting and acknowledging patient perspectives, providing information and treatments options, avoiding physician control over the patient, and supporting patient initiatives for change [61,62]. Recognition and promotion of patient expertise, stressed in six empirical studies [18,30,32,46,50,53] and one review [41], is also a central element of the enablement concept which aims to empower patients to gain more control over their life [63,64]. For people with chronic diseases, professionals’ enabling interventions promote individual empowerment which means a better awareness of one’s life situation, of one’s own strengths and needs, an increase in self-esteem, a decrease in negative feelings and better informed decision-making and learning skills [64]. We consider that individual empowerment is a desired outcome of patient-centered care in chronic disease management as well. The two concepts (patient-centered care and enablement) are in line with Carl Rogers’ concept of client-centered therapy in the 1950s [65–67]. Family medicine promoted the concept of patient-centered care [11,17] whereas enablement or empowerment became a core value of nursing [68–70]. We consider patient-centered care in chronic

disease management and enablement as very similar concepts aiming at similar outcomes of individual empowerment.

Our study has some limitations. A limitation of any review is the potential omission of relevant articles as well as any unpublished material. However, all steps were taken to ensure an exhaustive literature review: our search strategy was adapted for different databases and was developed in collaboration with an information specialist. Moreover, we identified additional articles through hand searching.

Although beyond the scope of this paper, addressing the broader literature (nursing, psychology, sociology, team care, etc.) in further work will broaden the impact of the results. Literature on research conducted among children, which is a specific research area, could also be explored. This literature review is another step toward understanding how family physicians can provide patient-centered care in the context of chronic disease management. Further theoretical and/or empirical work is still necessary to expand the construct and support evidence of the proposed themes, especially for new themes outlined in only a few articles. This is the case for example of the theme “Offering realistic hope” stressed in two non-empirical articles [22,31].

### 4.2. Conclusion

This article presents a thematic analysis of the literature on patient-centered care in the context of chronic disease management in family medicine, building on Stewart et al.’s model. The context of chronic disease management brings forward new dimensions of a patient-centered interaction between the patient and the physician such as legitimizing the illness experience, acknowledging patients’ expertise and offering hope, and proposes the involvement of the family physician in transitions in care (patient advocacy) as a component of patient-centered care. Chronic disease management also calls for the adjustment of the family physician’s role to patients’ fluctuating needs. Further research is needed to validate these results empirically, to better understand which themes are the most meaningful for patients and how they are acted out in practice and team care. Additional studies could also examine or produce evidence linked to those themes.

### 4.3. Practice implications

Chronic disease management requires coordinated action by the patient and the physician to create a real partnership. A rich knowledge of the patient is a necessary step toward this. Patients need their concerns, ambivalence and grief over their prior capabilities to be acknowledged. The physician should provide hope and support and believe in the patient’s capacity. The physician can also play a role in guiding the patient through the system. The patient will have fluctuating needs requiring physicians to adapt their role over time.

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### Conflict of interest

The authors declare that they have no competing interests.

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**Appendix A. Electronic literature search of the Medline, Embase and Cochrane databases**

Database	Set	Searches
Medline	1	"Patient-centered Care" or patient focused care or patient centered care or patient centred care or patient centeredness or patient centredness
	2	Limit 1 to English or French
	3	"Family Practice"
	4	"Primary Health Care" or primary care
	5	"Quality Assurance, Health Care"
	6	"Psychometrics" or psychometric or psychometrics
	7	"Validation Studies" or validation studies or validation study
	8	"Reproducibility of Results"
	9	"Factor Analysis, Statistical" or factor analysis
	10	"Outcome and Process Assessment, Health Care" or "Outcome Assessment, Health Care"
	11	"Questionnaire" or questionnaire or questionnaires
	12	"Process Assessment, Health Care"
		<b>1st strategy</b>
	<b>2nd strategy</b>	2 and (5 or 6 or 7 or 8 or 9 or 10 or 11 or 12)
Embase	1	"Patient-centered Care"* or patient focused care or patient centered care or patient centred care or patient centeredness or patient centredness
	2	Limit 1 to English or French
	3	"Primary Health Care" or primary care
	4	"Primary Medical Care"
	5	"Family Practice"
	6	"Psychometrics" or psychometric or psychometrics
	7	"Validation Studies" or validation studies or validation study
	8	"Reproducibility of Results"
	9	"Factor Analysis, Statistical" or factor analysis
	10	"Outcome and Process Assessment, Health Care" or "Outcome Assessment, Health Care"
	11	"Quality Assurance, Health Care"
	12	"Questionnaire" or questionnaire or questionnaires
	13	"Process Assessment, Health Care"
	<b>1st strategy</b>	2 and (3 or 4 or 5)
	<b>2nd strategy</b>	2 and (6 or 7 or 8 or 9 or 10 or 11 or 12 or 13)
Cochrane	<b>1st and 2nd strategies</b>	Patient focused care or patient centered care or patient centred care or patient centeredness or patient centredness

The words in quotation marks (" ") indicate that they have been used as a MeSH while the words followed by an asterisk (\*) have been sought as a main subject of the articles. All the other words have been used as a keyword.

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