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Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies

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ABSTRACT

Background

Receiving adequate support seems to be crucial to the success of self-management. Although different empirical studies separately examined patients' preferences for self-management support (SMS), an overview is lacking.

Objective

The aim of this qualitative review was to identify patients' needs with respect to SMS and to explore by whom this support is preferably provided.

Search strategy

Qualitative studies were identified from Embase, MEDLINE OvidSP, Web of science, PubMed publisher, Cochrane central, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycINFO.

Inclusion criteria

Articles needed to meet all of the following criteria: (i) focuses on self-management, (ii) concerns adult patients with rheumatic diseases (rheumatoid arthritis and fibromyalgia), a variant of cancer or chronic kidney disease, (iii) explores support needs from the patients' perspective, (iv) uses qualitative methods and (v) published in English.

Data extraction and synthesis

A thematic synthesis, developed by Thomas and Harden, was conducted of the 37 included studies.

Main results

Chronic patients need instrumental support, psychosocial support and relational support from health-care professionals, family/friends and fellow patients to manage the chronic condition. Relational support is at the centre of the support needs and fuels all other types of support.

Discussion and conclusions

Patients do not self-manage on their own. Patients expect health-care professionals to fulfil a comprehensive role. Support needs can be knitted together only when patients and professionals work together on the basis of collaborative partnership. Dynamics in support needs make it important to regularly assess patient needs.

INTRODUCTION

Today, people with a chronic condition are expected to take a more active role in their own health care.[1, 2] The increasing emphasis on self-management fits within a new paradigm of patient identity.[3, 4] Nevertheless, the meaning and definition of the concept of self-management are not self-evident. It is a socially constructed concept that varies across different contexts.[5] Professionals tend to define self-management as following a doctor's instructions.[6] This conceptualization resonates with a policy trend of 'responsibilization' that strongly focuses on the individual moral responsibility for good health.[7-9] However, this definition has been criticized as having an exclusive individual focus, while it is known that social networks influence the individuals' capabilities to manage a chronic condition.[7, 9, 10] Moreover, 'strategic non-compliance', too, is recognized as an expression of self-management.[11]

In this study, we adopt a holistic definition of self-management, namely the 'individual's ability to manage the symptoms, treatments, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition'.[12] A qualitative metasynthesis has found that patients need skills to manage three processes: focusing on illness needs; activating resources and living with chronic illness.[13] Obtaining and managing social support was found to be important in this regard. However, the review did not consider what support patients need to develop the identified skills.

The concept of self-management seems to imply dealing with a chronic condition all by yourself.[10, 14] Nonetheless, receiving adequate support seems crucial [5, 15] and is an important task of health-care professionals.[16-19] On the other hand, self-management support (SMS) is not the exclusive domain of professionals. Self-management goes on around the clock within the social context of the patient's own life and significant others such as relatives, partners and friends will have to step in.[15] Self-management interventions can help patients cope,[20, 21] provided that these incorporate the patients' view.[22]

Recent reviews about SMS were aimed to identify effectiveness or working mechanisms of self-management interventions,[23] but do not focus on the patients' view on SMS. Some reviews proved SMS to be ineffective.[24, 25] Incorporating the patients' view is morally desirable, but may also improve effectiveness of interventions.[25, 26] Although different empirical studies have examined patients' preferences for SMS, an overview with a focus on holistic views on SMS is lacking.[25, 26] A deep understanding of the patients' view can be gained from

qualitative research.[27, 28] A qualitative synthesis methodology allows for generalization, as it covers larger and more diverse samples and more dimensions of the topic of interest.[29, 30] The aim of this study was twofold: (i) to identify patients' needs with respect to SMS and (ii) to explore by whom this support is preferably provided.

METHODS

Identifying relevant studies

The study was conducted within the framework of a research programme focusing on: (i) rheumatic diseases, (ii) cancer and (iii) chronic kidney disease. We therefore limited our search strategy to these conditions. This selection covers a variety of conditions that are either life-threatening or long-term and have a variable impact on daily life. A list of relevant search terms was covering the broad field of self-management and specifying the chronic conditions to be included. An extensive search for qualitative peer-reviewed journal articles was conducted in Embase, MEDLINE OvidSP, Web of science, PubMed publisher, Cochrane central, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycINFO in February 2013 (see Box 1 for search terms). Articles needed to meet all of the following criteria: (i) focuses on self-management, (ii) concerns adults with one of the three selected chronic conditions, (iii) explores support needs from the patients' perspective, (iv) uses qualitative methods and (v) published in English. The self-management processes described by Schulman-Green et al. [13] served to define self-management. There was no publication year limit.

BOX 1. SEARCH TERMS IN EMBASE

('self care'/exp OR 'self monitoring'/de OR 'self control'/de OR 'drug self administration'/de OR 'self examination'/exp OR 'self injection'/de OR (((self OR shared) NEAR/3 (manag* OR care* OR medicat* OR efficac* OR help OR control* OR monitor* OR regulat* OR decision* OR examinat* OR inject* OR administrat*)):ab,ti) AND ((rheumatology/de OR 'rheumatic disease'/exp OR 'chronic arthritis'/de OR (((deformans OR chronic) NEAR/3 (arthr* OR polyarthr*)) OR rheumat* OR 'beauvais disease'):ab,ti) OR ('kidney transplantation'/exp OR ((kidney OR renal) NEAR/3 (transplant* OR graft* OR allograft*)):ab,ti) OR (oncology/de OR neoplasm/exp OR 'cancer patient'/de OR 'cancer survivor'/de OR 'cancer therapy'/exp OR (oncolog* OR cancer* OR neoplas* OR tumo*):ab,ti)) AND ('qualitative analysis'/de OR 'qualitative research'/de OR 'unstructured interview'/de OR 'semi structured interview'/de OR 'grounded theory'/de OR ethnography/de OR phenomenology/de OR 'life history'/de OR 'participant observation'/de OR 'thematic analysis'/de OR 'content analysis'/de OR 'constant comparative method'/de OR 'field study'/de OR 'audio recording'/de OR (qualitative OR multimethodolog* OR (mixed NEXT/1 method*) OR (compatibility NEXT/1 thes?s) OR (pragmat* NEXT/1 paradigm*) OR ((unstructur* OR open OR 'semi structured') NEAR/3 interview*) OR (focus NEXT/1 group*) OR (grounded NEXT/1 theor*) OR ethnograph* OR etnograf* OR ethnograf* OR phenomenolog* OR hermeneutic* OR (life NEAR/3 (histor* OR stor*)) OR (participant* NEAR/3 observation*) OR ((thematic OR content) NEXT/1 analys?s) OR (observation*

NEAR/3 method*) OR ('constant comparative' NEXT/1 method*) OR (field NEXT/1 (note* OR stud*)):ab,ti).

Study selection and appraisal

Three authors (JD, EB, HB) individually screened all titles and abstracts to exclude articles that did not meet the inclusion criteria. Studies on a single type of cancer were excluded, because their inclusion would result in disproportional representation of breast and prostate cancer studies. Mixed methods studies were included only when qualitative data were reported separately.[31] Differences in opinion on inclusion were discussed until consensus was reached. Two authors (JD, EB) screened the remaining articles' full texts for descriptions of SMS needs. In case of doubt, the article was discussed by the three authors until consensus was reached. Quality appraisal was performed on the guidance of the qualitative research review guideline RATS.[32] No studies were excluded due to quality flaws. The studies included in the qualitative metasynthesis of Schulman-Green et al. [13] were screened for information on support needs. The final literature search was conducted in November 2013.

Data extraction and analysis

Key information from the included studies was extracted using a review form (Supplementary Table 1). A thematic synthesis [33] was conducted in three stages with the aim to identify common themes. This method combines thematic analysis techniques with adaptations from grounded theory and meta-ethnography.[34] The first stage entailed free line-by-line coding of findings related to patients' support needs. Next, these codes were inductively organized into key descriptive themes, distinguished by the sources of support identified. The final step was generating analytical themes.[33] Disagreements or uncertainties were discussed and interpretations were validated with three researchers (JD, EB, and HB).

RESULTS

Included studies

Figure 1 shows the number of studies found at each stage of the selection process. Eventually, 37 studies were included as follows: five concerning chronic kidney disease, 13 concerning cancer and 19 concerning rheumatic diseases. The studies included 992 patients from Australia, Canada, Europe and the United States. Eleven studies used focus groups, 28 studies used unstructured or semi-structured interviews, and four studies used observations.

[FIGURE 1]

Support needs – main themes

Key descriptive themes were grouped under two broad analytical themes. The first describes 'types of support patients need' to manage the chronic condition. We distinguished three types of support: instrumental, psychosocial and relational support. Instrumental support is related to the disease and focuses on its medical management. Psychosocial support relates to strengthening of emotional and psychological resources needed to manage the illness. Relational support refers to helpful interactions with others.

The synthesis shows that support from three different sources is needed: professionals, family and friends, and fellow patients (Supplementary Table 2). It appeared that nature of the chronic condition is not decisive for the support needs. Supplementary Table 3 provides an overview of the types of support expected from the different sources of support.

The second analytical theme, 'dynamics in self-management support' describes that patients' support needs are unique and changeable over time. Two clusters of factors were found to contribute to this uniqueness: (i) disease-related factors and (ii) individual factors.

Figure 2 synthesizes the two analytical themes and shows interrelations between themes and subthemes.

[FIGURE 2]

Instrumental support

Knowledge – information and instruction (26/37 studies)

Professionals were valued for their expert knowledge. Patients needed information from an expert about diagnosis, symptoms, treatment options, side-effects and possible interaction effects and instruction on alleviating symptoms themselves.[35-48] Support should be available shortly after symptoms arise or when there are problems with medication.[37, 42-44, 49] In some studies, patients appreciated information about spiritual matters and complementary therapy.[35, 40, 50] Professionals also helped evaluate internet information,[51] a role attributed to relatives in another study.[52] Information about health-care facilities was needed from professionals.[35, 37, 40, 44] Some studies pointed out that providing information to relatives is important as well.[40, 44, 52, 53] Relatives usually lack knowledge on the disease, which may result in social restrictions for patients.[44, 49, 53] Patients did not always trust information provided by relatives themselves.[54] Patients differed with respect to the amount of information they would like to receive from professionals. Some wanted an expert to 'explain the disease to the fullest'[45] while others wished to receive information step by step, because 'full disclosure is devastating'. [37, 45, 50, 52] Several studies pointed out that professionals should be sensitive to these differences.[38, 40, 44, 45] Many studies showed that fellow patients were capable of sharing practical information (in lay terms) and personal experiences about treatment procedures, side-effects and outcomes,[40, 43, 53-58] strategies for symptom self-management [35, 53, 57, 59] and interaction with health-care professionals.[55] From the perspective of professionals, this information might have been of minor importance, whereas it was of great importance to patients.[45, 52, 54, 60] On the other hand, one study found that patients distrusted online information provided by other patients, because it is hard to verify.[52]

Internalizing knowledge (11/37)

Receiving information and instruction is a crucial starting point, but this is not enough. Several studies reported that patients had to internalize the information they received from professionals in order to become familiar with it.[36, 44, 45, 48, 56, 61] Information must be integrated 'in the thoughts, feelings or reasoned actions of

daily life'. [61] It is difficult to follow 'generic' treatment recommendations. [45, 46] Patients preferred making treatment-related decisions that coincide with their lifestyles, which would require more extensive discussion with professionals and dissemination of disease-related information. [45] A number of studies indicated that an extensive discussion with a professional about disease-related information in the context of their own lives helped patients to internalize the information. [44, 45, 56] Paying attention to cultural background may also help internalization of information. [35]

Patients also wanted to learn how to 'navigate the jungle of therapies'. [41] For example, kidney patients needed more guidance on food choice and preparation. [48] Patients also benefited from guidance on new self-management strategies. [36, 43, 48] This could be accomplished through group discussions with fellow patients in which professionals provided suggestions for effective strategies rather than direct advice. Patients needed 'a guided discovery process' to 'work it out [them]selves'. [56] Interaction with other patients helped to reduce fear of the symptoms of the chronic condition. [61] Some studies indicated that professionals can be instrumental by facilitating an open and caring atmosphere for group interactions. [53, 56]

Adjusting daily life (19/37)

A number of studies pointed out that patients wanted to learn from professionals how to manage increased disease activity, pain, fatigue and other symptoms. [37, 39, 40, 42, 46, 49, 56] One study added that patients wanted to learn from professionals how to communicate with others about limitations in daily activities. [37] Some patients are reluctant, however, to receive support from professionals about fatigue and other symptoms, because they were already dependent on them for many other issues. Others feared to be seen as 'complainers'. [46, 62]

In various studies, support from relatives was thought essential for self-management, [46, 49, 53, 62-64] for example by doing household duties, taking care of the children or providing financial assistance [47-49, 58, 62, 64] or even nursing tasks. [63] On the other hand, patients did not always want support from relatives. Too much input from relatives felt like a form of social control. [47] Some studies stressed the importance of independence. [62, 63, 65] Overstraining familial relationships can make patients reluctant to accept support. [62]

In some studies, contact with fellow patients helped patients to self-manage the disease. Realizing that others are faced with similar symptoms made them feel less anxious. [52, 57, 66] One study indicated that identifying with a fellow patient helped to normalize living with the disease. [54]

Psychosocial support

Recognition of emotional aspects of the chronic condition (19/37)

Several studies indicated that patients wished to explore feelings and share emotions with professionals. [37, 44, 47, 48, 50, 63] In other studies, patients did not need emotional support. Patients recently diagnosed with cancer (<18 months) did not feel that distress needed immediate attention, although this could change in the future. [67] Reluctance to address psychosocial consequences of the disease could be due to not believing this was feasible in the short term. [41]

In a number of studies, relatives provided emotional support.[52, 62-64] However, this may have drawbacks, for example when relatives have difficulty handling cancer-related repercussions and force patients to assume a positive attitude to avoid upsetting others.[51, 53] Moreover, relatives can grow tired of providing support.[51] In one study, patients preferred sharing problems with someone outside of their social environment.[37, 57]

A number of studies pointed out that fellow patients were valuable in dealing with emotional challenges. Knowing that others may experience the same hardship provided comfort.[57] Online and offline contacts with fellow patients were felt as close bonds with a strong sense of togetherness and emotional connection.[44, 51-53, 55-57, 60, 61] Several studies described that humour in the emotional connection between patients served as a mechanism to cope with treatments and difficult experiences.[51-53, 61] Within these bonds, there was no barrier to 'whining' and complaining.[52, 53, 61] Nonetheless, whining and complaining could also bring people down.[52, 53, 55, 68] Gender differences might play a role in this respect. Bell and colleagues (2010) remarked that women attend peer support groups to share emotions, while men 'are really there for the medical'.[55]

Building self-confidence and empowerment (13/37)

Several studies indicated that patients need a professional to help them build self-confidence.[36, 61] Professionals should 'help to see that the patient is not as helpless as he thinks'.[47] Professionals can support patients by instructing them and encouraging them to adjust daily life. This may lead to a sense of control and stimulate active coping strategies. When approved by professionals, patient felt less guilty about making changes in daily life.[36, 37, 47, 69] Figure 2 illustrates that building self-confidence makes it easier to adjust daily life and vice versa. Building self-confidence could also be accomplished by interaction with fellow patients.[42, 52, 53, 60, 70] Identification with someone in the same situation can be a powerful experience.[54] Moreover, comparing your own situation with that of someone who is worse off will help to relativize the severity of your own situation[52] and thus reinforce individual identity and strength.[51] Not only verbal interaction between patients built confidence; being confronted with a catheter, fistula or operation scar in real life was empowering.[54] However, identification with fellow patients could also be confronting.[53-55, 60]

Relational support

Relational support is at the centre of the support needs of patients and fuels all other types of support. Partnerships with health-care professionals contribute to instrumental support, because they facilitate addressing individual needs and concerns. Within a relationship based on partnership and sympathy, it is also easier to recognize emotional problems.

Partnership (19/37)

Studies addressing patients' relationship with professionals make clear that patients wish to be treated as a person and not as a vessel for a disease.[37, 42-44, 49, 51, 68, 69] Being treated as a person helped them to focus on their own needs.[41] Several studies pointed out that patients wished to establish partnerships with health-care providers with the aim to get support in managing the illness. Meeting the same professional at all stages of the illness contributes to partnership, because this makes

patients feel confident to talk about problems.[37, 42, 43, 69] Professionals should be easy to talk to in consultations [37] and patients should be allowed to ask ‘stupid’ questions, repeatedly if necessary.[61]

Still, patients differed in their preference for the type of role to play. Some wanted to be actively involved in decision-making about their treatment.[43, 45, 47, 48, 51, 68] For example, decisions about treatment (goals) required self-analysis that could be supported by professionals.[56] Other patients preferred that professionals helped them assess how they were doing disease-wise and whether they were getting the right medication,[42] and others still wanted direction in relation to treatment decisions.[43, 45]

Interaction with fellow patients also contributed to professional-patient partnership.[52-54] If fellow patients helped them prepare for a consultation, patients feel more confident to ask questions.[52, 53] One patient claimed to be more confident about rejecting a treatment that he felt was imposed on him by a professional.[52, 54] Several studies showed that fellow patients formed mutual partnerships. Contact with other patients made patients realize they are not the only ones in this situation, and realizing this already made them feel better.[42, 48, 51, 52, 57, 60]

Sympathy (18/37)

A number of studies mentioned that sympathy from professionals is valued.[37, 42, 47, 50, 69] Sympathy was proven by listening,[37, 47, 69] by showing genuine interest,[42, 43] by friendliness [50] and by clear and supportive communication.[36, 37] In a supportive and calm atmosphere, patients are more likely to be not afraid to be themselves and to ask questions.[69]

Several studies indicated that it was difficult to receive empathy from relatives who do not know what patients go through and lack understanding of the problems facing patients.[53, 64, 70] After a while, a lack of mutuality made relatives poor listeners.[51]

Fellow patients were valued for their empathetic capacity, because they ‘know exactly how you're feeling’.[53] Empathy enabled to share experiences [69] and to make patients feel they were being listened to.[54, 70] Mutual understanding was mentioned in many studies as a major benefit of peer support, and it was often contrasted with support by relatives or lack thereof.[51-53, 57, 59, 60, 66, 70] Peer support strengthens relationships with family and friends.[53, 59, 61] It helps a patient cope with the chronic condition and increases the likelihood of being seen as a ‘normal person’ by relatives.[53]

Dynamics in self-management support

The above-mentioned support needs were not relevant to all patients. Some patients were of the opinion that tailored support is important to ‘meet individual challenges’.[41] The results of the synthesis showed that patients had different SMS needs. Two clusters of factors were found to contribute to this uniqueness of support needs: (i) disease-related factors and (ii) individual factors. The outer circle in Fig. 2 shows the individual and disease-related factors that influence SMS needs.

Disease-related factors

The most important disease-related factor is the disease process.[65] Several studies show that self-management behaviour and learning is related to the disease stage, for

example the disease onset. Need of support and information will thus vary from stage to stage.[44, 49, 52] During the early stage of diagnosis, patients focus on information about the disease and available treatments, while later on, they wish to know how to manage symptoms and the side-effects of treatment.[52] After completion of treatment or in the chronic phase, other types of support such as psychosocial support tend to become more important.[55, 67] Patients who feel capable of self-managing the disease may need support when health deteriorates or when symptoms flare up.[37] Patients who are diagnosed but are symptom-free and do not experience adverse consequences have no need for support aimed at dealing with these consequences.[59, 63] In one study, some patients did not attend scheduled consultations because they felt that they had developed ‘an intuition’ that allowed them to know when to seek medical attention.[65]

Individual-related factors

Although both younger and older patients need support,[44] it is clear that information provision should be age-appropriate.[45] There is some evidence that cultural background influences the need for support and the preferred type of support. For some ethnic groups, talking about disease is considered ‘dirty laundry’,[55] preventing them from joining self-help groups or feeling confident to ask for advice.[40] For others, the heredity of the condition may be a taboo subject.[60] Certain types of support might be ethnically suitable, like ‘American Indian cancer survivor testimonies and storytelling, which are a culturally important method for transmitting information in American Indian communities’.[35] No clear evidence was found for a gender difference in needs and preferences for SMS, although men may seem to prefer an educational component, whereas women mainly seek emotional sharing.[55] Gibbs described that especially men consider being employed a barrier to join support groups, for both structural reasons (lacking time and energy) and social-cultural reasons (the belief that the interventions are designed for people who are not employed).[71]

Patients who feel capable of self-management may need support when their personal situation changes and affects their sense of coping.[37] Not only long-term changes, but also daily hassles and crises can affect personal resources and the need for support.[37, 49]

Lastly, the psychological response to a disease influences the need for SMS. Initially, patients may prefer day-to-day information. They leave it to others (professionals or relatives) to see the bigger picture.[52] Later on, they process information differently and need to take other kinds of decisions.[52] Patients may be reluctant to focus on the disease [42] or to receive certain information.[52] Others may be too proud to ask for advice [40] or be ambivalent about wanting to manage on their own and needing support.[49]

DISCUSSION

Three types of SMS needs emerged from this analysis, that is instrumental, relational and psychosocial support, which are all needed to self-manage a chronic condition. Moreover, patients need support from different sources, each with its unique contribution. Health-care professionals, relatives and fellow patients all fulfil their own distinctive role. People with a chronic condition are not capable of self-management on their own. Significant others are needed to live a good life with a

chronic condition.[14, 72] Richard & Shea adequately add the phrase ‘in conjunction with family, community and health-care professionals’ to their definition of self-management.[73] This conjunction with others is not self-evident. Several studies make clear that the involvement of informal network members does not always have a positive influence.[74] Considering the increased focus of policy makers on patients' informal networks, this aspect should not be overlooked. The high burden of informal caregivers has already been acknowledged.[75] However, this synthesis shows that informal care could burden patients as well. They may be wary of being dependent on their relatives or feel obligated to have a positive attitude towards the chronic condition.

This review shows that fellow patients are an important source of support. Not only by sharing their own lived experiences, but also by fulfilling psychosocial needs. Fellow patients are able to show sympathy and provide emotional support. Identification with a fellow patient can empower other patients. These findings resonate with earlier suggestions that it would be advisable to not only focus on SMS provided by professionals but to also invest in peer support.[12, 16] Rogers and colleagues have shown that these weaker-tie relationships avoid feelings of dependence and make it ‘possible to construct more of a sense of reciprocal exchange’.[76]

With respect to instrumental support, receiving only information from professionals is not enough to adjust life to the medical condition. Patients wish to discuss things at length with professionals. They want to be guided while trying out new self-management strategies. Research shows that professionals often perceive SMS as merely handing out written information and telling patients what to do.[77, 78] Even when a ‘whole system approach’ intervention is implemented, professionals are still inclined to focus on patient education.[24]

There is evidence that relational support is paramount to patient-centred SMS. Changing the traditional professional-patient relationship into a collaborative partnership is a key to SMS. Patients vary in the extent to which they want to be involved in medical decision-making, but the review made clear that there is a need of partnership. Still, professionals seem to have difficulty in developing partnerships and are inclined to take control.[24, 79-81]

Patients would like to get sympathetic attention from professionals with regard to the emotional dimension of living with a chronic illness. Parkin and colleagues have shown that greater professional empathy results in greater acceptance of decisions made.[82] Previous research shows that current SMS is still much focused on medical and behavioural skills, with less attention to emotions.[16, 83, 84]

The analysis also shows that SMS is a dynamic process. Support needs change during the course of illness, especially when symptoms arise. This finding is in line with the conclusion of a quantitative investigation to the effect that patients who perceive their illness as episodic have greater SMS needs than patients who perceive their illness as stable.[85]

Almost all studies emphasize that support needs are individually determined. Patients stress the importance of tailoring SMS to their own needs and want to be seen as an individual by professionals. This implies the desirability of patient-professional partnerships and a ‘one size does not fit all’ approach. From the organizational point of view, this means that professionals should be accessible when the patient needs their support. Individual factors influencing support needs are: age, ethnicity, sex,

experience with the disease and psychological characteristics, which include feelings about the disease. This list gives some indication about the direction of tailoring, but the evidence is limited. Tailoring SMS is still in its infancy.[72]

Study strengths and limitations

This study brings together opinions on SMS from 992 patients in Western countries. This is crucial information for professionals and developers of self-management interventions. The findings for the three selected chronic conditions might be less clear for other chronic conditions. The assumption that the process of integrating chronic illness self-management strategies is the same for different chronic conditions [86, 87] would seem to suggest that adding other chronic conditions would not change the findings of this review. Rijken and colleagues pointed out that a generic disability approach might appeal to patients with complex needs.[72] Although we found some evidence that patients recognize the importance of cultural appropriateness, the focus on Western countries and English-language publications precludes a fine grained understanding of these issues.

This study did not differentiate between physicians, nurses and other health-care professionals as this distinction was not made in the reviewed studies. Still, considering that SMS is a multidisciplinary assignment, it is less important to have insight into the various roles of the various health-care professionals.

Unfortunately the original studies did not provide detailed information about the characteristics of the participants. The information was mostly limited to type of chronic condition, sex and mean age. It has been shown that a patient's educational level might influence SMS needs. It remains unclear, however, whether the synthesis incorporated all educational levels.

Practice implications

The findings of this review can be factored in when developing and implementing self-management interventions. Box 2 provides an overview of the practice implications that can be derived from this study. Some innovative self-management interventions already take these into account by focusing on patients' social networks and everyday life priorities[88] or establishing meaningful and effective relationships.[89] Underlying the recommendations there is a fundamental need of a paradigm shift.[90, 91] Patients expect health-care professionals to fulfil a comprehensive role in SMS. These support needs can be knitted together only when patients and professionals work together on the basis of collaborative partnership. Relational support is at the centre of the support needs of patients and fuels all other types of support. Fulfilling individual patient's needs requires understanding of the patient's viewpoint.[81] However, many studies show that professionals experience difficulties in achieving this. Implementing self-management interventions without changing the values underlying the relationship between patients and professionals seem to be in danger of ineffectiveness.[24] Further research should be focused on the prerequisites of this paradigm shift and how to implement this in daily practice.

Box 2.

Practice implications: What do we learn from patients?

Patients do not self-manage on their own.

Patients need support on a broad range of self-management tasks: they need instrumental, psychosocial and relational support.

Relational support – partnership and empathy – should be at the center of self-management support interventions.

Patients need instrumental support in order to be able to integrate information and to adjust daily life.

Fellow patients can play a stimulating role in self-management.

Support from family and friends is crucial, but not self-evident.

Gender, disease stage, cultural background, psychological response, flare up of symptoms, and changes in personal situation or network all influence self-management support needs.

The dynamic and individual character of self-management requires a frequent assessment of patient support needs.

CONCLUSION

The aim of this qualitative review was to identify patients' needs with respect to SMS and to explore which support-givers are preferred. Although the importance of meeting individual needs stood out, it is still possible to provide a general overview of support needs. Patients need instrumental, psychosocial support and relational support from different sources. Fellow patients can share practical information and help each other to integrate the information into daily life. Sharing experiences also provides emotional support and builds confidence in living with the chronic condition. Relatives can provide support, too, but there are concerns about possible drawbacks of this support.

Professionals are valued for their expert knowledge but are expected to do more. Patients' also need help to integrate the information into their daily lives.

Furthermore, professionals are expected to pay attention to the emotional aspects of living with the chronic condition and help patients build self-confidence. Patients appreciate sympathetic listening by professionals and a relationship based on partnership. Changing the traditional professional-patient relationship into a collaborative partnership is essential to SMS.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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FIGURES

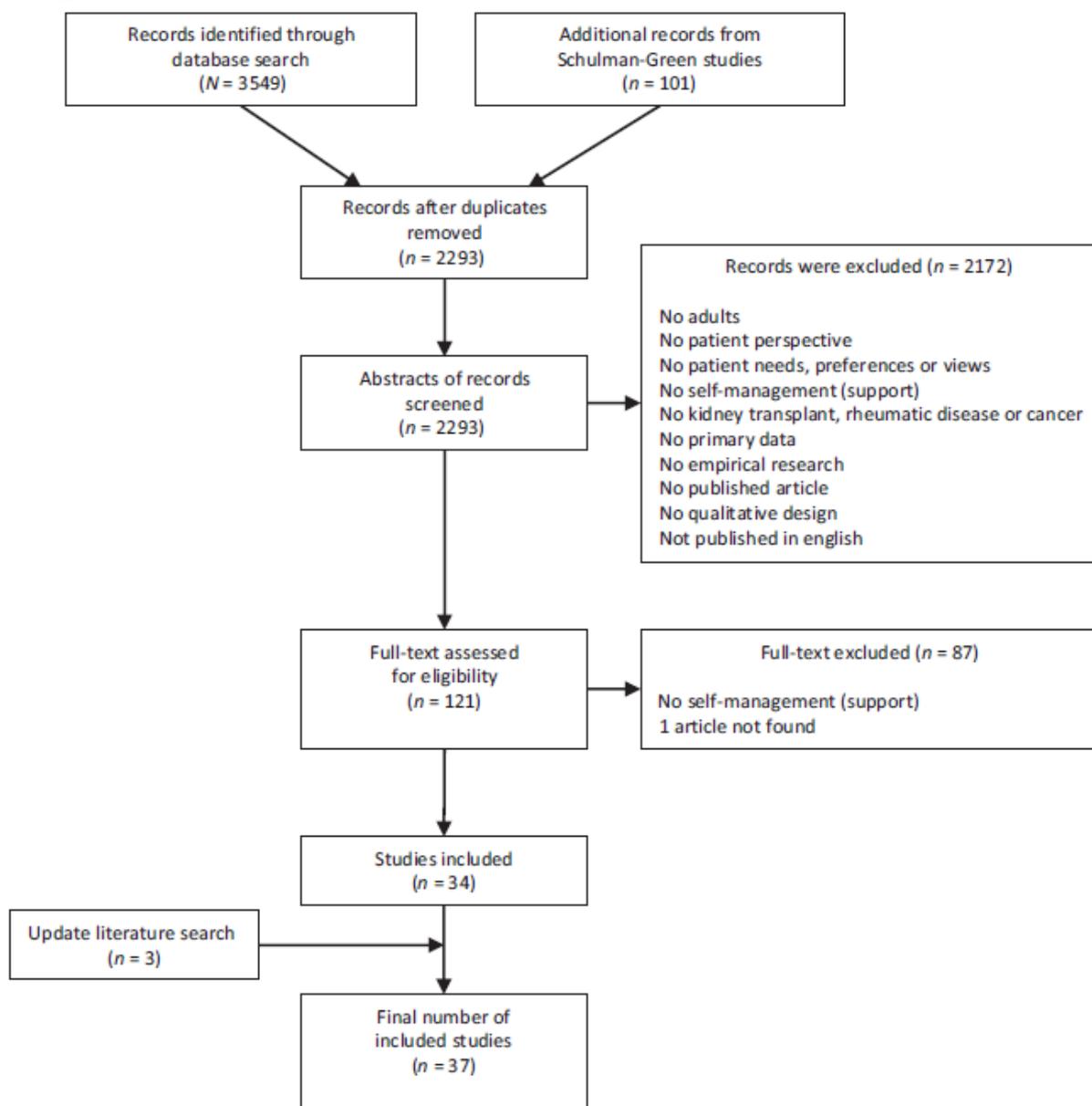


Figure 1 Flowchart of studies: from identification to inclusion.

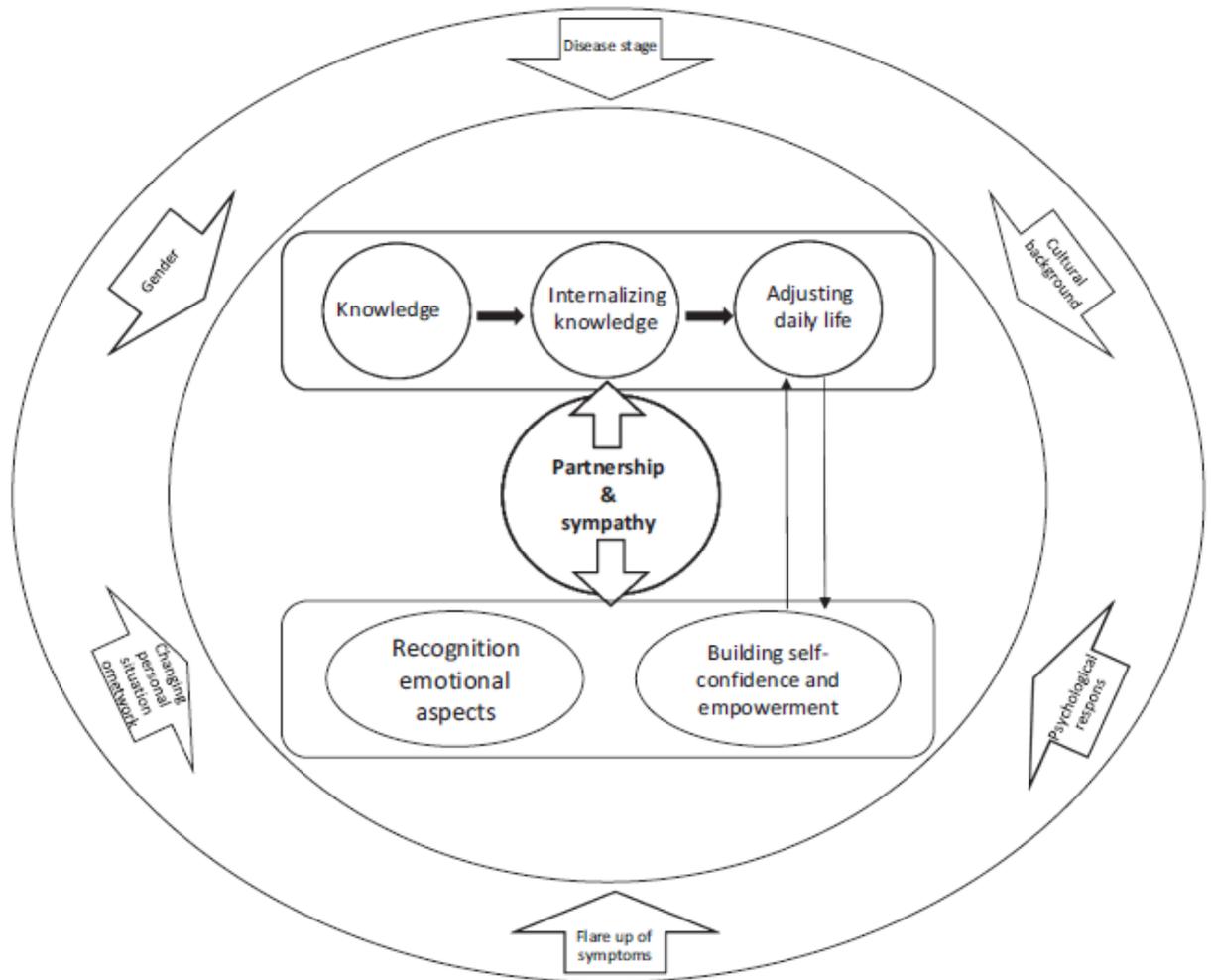


Figure 2 Interrelations between the identified patient needs.

Instrumental support	Health care professional	Family / friends	Fellow patients
Knowledge	<ul style="list-style-type: none"> - Providing expert information and instruction related to the chronic disease - Providing information about health care facilities - Providing Information about spirituality and complementary therapy - Helping with evaluating internet information - Providing information to family members 	<ul style="list-style-type: none"> - Helping with evaluating internet information 	<ul style="list-style-type: none"> - Sharing practical information in lay terms - Sharing personal experiences about (1) treatment procedures, side effects and outcomes, (2) strategies for symptom management and (3) interaction with health care providers
Internalizing knowledge	<ul style="list-style-type: none"> - Discussing disease-related information in the context of the patients' life extensively - Guiding patients in trying out and experiencing the effect of new self-management strategies - Supporting group discussion between patients - Providing information that takes into account patients' lifestyle and cultural background 	No findings	<ul style="list-style-type: none"> - Discussing disease related information together
Adjusting daily life	<ul style="list-style-type: none"> - Teaching patients how to manage increased disease activity, pain, fatigue and other problems in daily life - Helping individuals realize that it is permissible to make one's own choices in order to be comfortable in one's own life situation - Teaching patients how to communicate with others about their limitations 	<ul style="list-style-type: none"> - Performing household duties, cooking meals, financial assistance and taking care of children 	<ul style="list-style-type: none"> - Validating symptoms in order to reduce fear and feel less guilty about symptoms
Psychosocial support			
Recognition of emotional aspects of the chronic condition	<ul style="list-style-type: none"> - Considering the emotional dimension of diagnosis and treatment 	<ul style="list-style-type: none"> - Providing emotional support 	<ul style="list-style-type: none"> - Sharing experiences - Bonding: experiencing strong sense of togetherness - Relating to each other in a humorous and optimistic way
Building self-confidence and empowerment	<ul style="list-style-type: none"> - Helping to build confidence in living with a chronic condition 	No findings	<ul style="list-style-type: none"> - Identifying with others helps build confidence - Relativising own situation
Relational support			
Partnership	<ul style="list-style-type: none"> - Treating patients as a whole person and not as an illness - Working closely together with patients - Involving patients in decision making and helping them to make choices 	No findings	<ul style="list-style-type: none"> - Helping to prepare for consultation with professionals - Knowing that you are not the only one who has to face such challenges
Sympathy	<ul style="list-style-type: none"> - Listening to patients - Showing interest - Communicating in a clear and supportive way 	<ul style="list-style-type: none"> - Problems concerning receiving empathy from family and friends 	<ul style="list-style-type: none"> - Mutual understanding

Table III Support needs specified by the three sources of self-management support

Authors	Disease	Instrumental support needs			Psychosocial support needs		Relational support needs	
		Knowledge	Internalizing knowledge	Adjusting daily life	Emotional aspects	Building confidence	Partnership	Sympathy
Avis et al.	Cancer	X			X	X	X	X
Baker et al.	Cancer				X			
Bauman et al.	Cancer			X				X
Bell et al.	Cancer	X			X	X		
Dickerson et al.	Cancer	X		X	X	X	X	X
Foster & Roffe	Cancer	X		X	X		X	X
Grahn & Danielson	Cancer		X		X	X	X	X
Hodge et al.	Cancer	X	X					
Rotegard et al.	Cancer	X			X	X	X	X
Schumacher et al.	Cancer			X	X			
Spichiger et al.	Cancer			X	X			
Taylor et al.	Cancer	X			X			X
Ussher et al.	Cancer	X	X	X	X	X	X	X
Constantini et al.	Chronic kidney disease	X	X				X	
Goldade et al.	Chronic kidney disease			X				
Hughes et al.	Chronic kidney disease	X		X		X	X	X
Nygaardh et al.	Chronic Kidney Disease	X	X				X	X
Tong et al.	Chronic kidney disease	X	X	X	X		X	
Arvidsson et al.	Rheumatic diseases					X	X	X
Bergsten et al.	Rheumatic diseases	X		X			X	
Bode et al.	Rheumatic diseases	X						X
Coty & Wishnia	Rheumatic diseases			X	X			X
Cunningham & Jillings	Rheumatic diseases				X		X	
Dager et al.	Rheumatic diseases	X	X			X		X
Dures et al.	Rheumatic diseases	X	X	X	X		X	
Van Eijk-Hustings et al.	Rheumatic diseases	X		X	X	X	X	X
Gibbs	Rheumatic diseases							
Harrold et al.	Rheumatic diseases	X						
Hewlett et al.	Rheumatic diseases	X		X				
Kett et al.	Rheumatic diseases	X		X				
Moe et al.	Rheumatic diseases	X	X		X		X	
Primdahl et al.	Rheumatic diseases	X		X		X	X	X
Radford et al.	Rheumatic diseases	X	X		X		X	
Repping-Wuts et al.	Rheumatic diseases	X	X	X				
Ryan et al.	Rheumatic diseases	X		X	X	X	X	X
Sinclair et al.	Rheumatic diseases					X		X
Tak	Rheumatic diseases	X		X				
TOTAL		26	11	19	19	13	19	18

Table II: Support needs addressed by reviewed studies

Author title Journal (year)	Country	Aim of the study	Data collection	Data analysis	Participants	Mean age (range)	Sample origin and sampling method	RATS
Arvidsson et al. A nurse-led rheumatology clinic's impact on empowering patients with rheumatoid arthritis: A qualitative study <i>Nursing and Health Sciences</i> (2006)	Sweden	To describe a nurse-led rheumatology clinic's impact on empowering patients with rheumatoid arthritis.	Interviews	Carried out in several steps in line with recommendations of phenomenography	16 patients (4 M) with rheumatoid arthritis	51 (31–89)	Nurse-led rheumatology clinic in hospital for rheumatic diseases in southern Sweden. Patients sampled with multivariation.	27/40
Avis et al. Ethnicity and participation in cancer self-help groups <i>Psycho-oncology</i> (2006)	Sweden	To explore possible reasons for people from some ethnic groups to not have participated in self-help to the same extent as the rest of the community; and to identify ways in which participation of people from ethnic groups can be increased.	Semi-structured and unstructured interviews	Thematic qualitative analysis	49 members of self-help groups (34 cancer, 10 other problems, 5 not specified). 30 black/ethnic minority; 17 not black and 2 not disclosed	Not reported	Members of self-help groups across the country. Sampled with snowball method.	28/40
Baker et al. 'You're putting thoughts into my head': a qualitative study of the readiness of patients with breast, lung or prostate cancer to address emotional needs through the first 18 months after diagnosis <i>Psycho-oncology</i> (2013)	United Kingdom	To investigate the readiness of patients to address emotional needs up to 18 months following a diagnosis of breast, lung or prostate cancer.	Semi-structured interviews	Constant comparative approach	42 patients (23 M) with lung, prostate and breast cancer. 39 white British; 3 black/ethnic minority	63 (36–86)	Two hospitals serving a largely urban population. Sampling method not reported.	37/40
Bauman et al. Factors associated with cancer patients' participation in support groups <i>Journal of Psychosocial Oncology</i> (1992)	USA	To examine correlates of participation in two supportgroups for outpatients with cancer, and to establish patterns of and barriers to use.	Survey 30-minute interviews	Not reported	26 patients with lymphoma or leukemia	Not reported	Outpatient clinic Memorial Hospital New York. Patients purposively sampled.	21/40

Bell et al. Is There an "Ideal Cancer Support Group? Key Findings from a Qualitative Study of Three Groups <i>Journal of Psychosocial Oncology</i> (2010)	Canada	To study differently composed cancer support groups to generate insights into what groups are attractive to the widest range of participants, and how they might be best structured and composed.	(participant) observations and in-depth interviews	Ethnographic coding and content analysis	25 F metastatic cancer patients; 30 (14 M) colorectal cancer. 96 (61 M) Chinese cancer patients. In total 49 white; 100 Chinese; 1 South Asian and 1 Hispanic patient(s)	50 (20-80)	Three cancer support groups from cancer treatment centre in West Canada. Sampling method not reported.	25/40
Bergsten et al. "Striving for a Good Life" – The Management of Rheumatoid Arthritis as Experienced by Patients <i>The Open Nursing Journal</i> (2011)	Sweden	To generate a theoretical model how patients experience their management of rheumatoid arthritis in everyday life.	Interviews	Open, axial and selective coding	16 patients (6 M) with rheumatoid arthritis	61.5 (28-82)	Sample origin not reported. Patients purposively sampled.	33/40
Bode et al. Limited results of group self-management education for rheumatoid arthritis patients and their partners: explanations from the patient perspective <i>Clinical Rheumatology</i> (2008)	Netherlands	To identify the reasons for limited results of group self-management for RA patients and their partners.	Semi-structured interviews	Framework approach	20 patients (10 M) with rheumatoid arthritis	57 (28-69)	Outpatient clinics of two hospitals in the Netherlands. Patients purposively sampled.	27/40
Constantini et al. The Self-Management Experience Of People with Mild to Moderate Chronic Kidney Disease <i>Nephrology Nursing Journal</i> (2008)	Canada	To elicit participant's perceptions of health, kidney disease, and supports needed for self-management.	Semi-structured interviews	Qualitative content analysis approach	14 patient (8 M) with mild to moderate Chronic Kidney Disease	57 (19-69)	Nephrology clinics in Toronto, Ontario, Canada. Patients purposively sampled.	30/40
Coty & Wishnia Adjusting to recent onset of rheumatoid arthritis: a qualitative study <i>Journal of Research in Nursing</i> (2013)	USA	To examine the experiences of men and women living with rheumatoid arthritis (RA).	Semi-structured telephone interviews	Thematic analysis	16 patients (7 men) who were recently diagnosed with RA	50 (35–60)	Participants of a larger quantitative study. Sampling method not provided.	27/40

Cunningham & Jillings Individuals' Descriptions of Living With Fibromyalgia <i>Clinical Nursing Research</i> (2006)	Canada	To explore individuals' descriptions of life with FM, and to gain insight into aspects of the illness and its treatment that would provide direction for future nursing practice and research.	In-depth, semi-structured interviews	Constant comparative analytical proces	8 patients (1 M) with fibromyalgia	(30-79)	Patients were recruited through key informants and through individuals who had heard of the study from a faculty newsletter and sampled purposively.	24/40
Dager et al. "It is about taking grips and not let myself be ravaged by my body": A qualitative study of outcomes from in-patient multidisciplinary rehabilitation for patients with chronic rheumatic diseases <i>Disability and Rehabilitation</i> (2012)	Norway	To explore how patients experience the personal impact and process of deriving outcomes from a rheumatological rehabilitation program.	Semi-structured interviews	Thematic analysis	23 patients (2 M) with divers inflammatory rheumatic diseases	47 (no range reported)	Patients with inflammatory rheumatic diseases attending the rehabilitation program were invited to participate in the study at the end of their stay at the hospital based rehabilitation unit. Purposively sampled.	31/40
Dickerson et al. Seeking and Managing Hope: Patients' Experiences Using the Internet for Cancer Care <i>Oncology Nursing Forum</i> (2006)	USA	To describe experiences of patients with cancer using the Internet for information and support in order to manage the self-care aspects of illness and treatment, including symptom management.	Informal interviews	Seven-stage hermeneutical proces	20 F patients with a variety of cancer diagnoses (breast, gynaecologic, gastrointestinal, lymphomas, hematologic cancers) and variety of stages (diagnosis, treatment, and survivorship)	52.3 (34-65)	Researchers attended local and national Oncology Nursing Society meetings, explained the study, and asked for volunteers to recruit patients who used the Internet for cancer care. Purposively sampled.	32/40
Dures et al. "They Didn't Tell Us, They Made Us Work It Out Ourselves": Patient Perspectives of a Cognitive-Behavioral Program for Rheumatoid Arthritis Fatigue <i>Arthritis Care & Research</i> (2012)	UK	To explore the patient perspective of a cognitive-behavioral therapy. (CBT) program for RA fatigue and the impact of behavior changes.	Focus groups	Inductive and deductive thematic analysis	38 patients (8 M) with RA with a score 6 on a fatigue scale and unchanged medication for 16 weeks (or 6 weeks for steroids) that attended a CBT program	60.9 (35-77)	Patients that attended a CBT program in 2 teaching hospitals in Bristol, UK. Purposively sampled.	35/40

Foster & Roffe An exploration of the internet as a self-management resource <i>Journal of Research in Nursing</i> (2009)	UK	To explore contributions to the online discussion forum to identify examples of how people used the internet to seek and share information and support in the context of cancer in order to support their self-management of problems.	Observations of online interactions	Thematic analysis	24 people with cancer	Not reported	UK online discussion forum used by people affected by cancer. The topic selected for this analysis was chosen as an example of a popular topic (based on number of posts, high number of viewings and length of time over which the topic was active).	32/40
Gibbs Identifying Work as a Barrier to Men's Access to Chronic Illness (Arthritis) Self-Management Programs <i>International Journal of Men's Health</i> (2007)	Australia	To improve understanding of why men are underrepresented as users of arthritis sm-programs.	Semi-structured interviews	Constant comparative approach	17 patients (M) with arthritis. 11 Anglo/Celtic; 1 Aboriginal; 1 UK; 1 Greek; 1 Italian and 1 Filipino/ Asian and 4 partners (F)	18 to >75	Sample origin not reported. Maximum variation sampling.	26/40
Goldade et al. Kidney Transplant Patients' Perceptions, Beliefs, and Barriers Related to Regular Nephrology Outpatient Visits <i>American Journal of Kidney Diseases</i> (2011)	USA	To understand kidney transplant recipients' perspectives and beliefs regarding barriers to follow-up outpatient nephrology visits.	Interviews Focus groups	Thematic analysis	39 (26 m) Kidney Transplant Recipients. 20 African American, 4 Hispanic, 4 White, 11 other.	Not provided	Hennepin County Medical Center. Patients purposively sampled.	33/40
Grahn & Danielson Coping with the cancer experience. Evaluating an education and support programme for cancer patients and their significant others <i>Patient Education</i> (1996)	Sweden	To capture the participants' experiences of their coping pattern, as related to the education-and-support intervention.	Interviews Focus groups	Grounded Theory approach	73 patients recently diagnosed with different kinds of cancer receiving chemotherapy and/or radiotherapy. Swedish speaking.	> 18	Cancer patients and their significant others who attended most of the sessions of the structured Learning to live with cancer Programme at the Department of Oncology, University Hospital, Lund.	32/40

Harrold et al. Patients and providers view gout differently: a qualitative study <i>Chronic Illness</i> (2010)	USA	To gain a better understanding of why deficits in gout care occur and in developing hypotheses for further investigation.	In-depth telephone interviews	Thematic analysis	26 patients (20 M) with gout. All Caucasian.	73 (30-59)	Members of the group-model component of the Fallon Community Health Plan (FCHP), who received care from the Fallon Clinic, a multispecialty group practice.	34/40
Hewlett et al. Patients' Perceptions of Fatigue in Rheumatoid Arthritis: Overwhelming, Uncontrollable, Ignored <i>Arthritis & Rheumatism</i> (2005)	UK	To explore the concept of fatigue, as experienced by patients with rheumatoid arthritis.	Semi-structured interviews	Thematic analysis	15 patients (3 M) with rheumatoid arthritis and with a score > 6 on a fatigue scale.	55.6 (28-80)	Sample origin not reported. Patients purposively sampled.	32/40
Hodge et al. "Weaving Balance into Life": development and cultural adaptation of a cancer symptom management toolkit for Southwest American Indians <i>Journal of Cancer Survivorship</i> (2012)	USA	To develop and implement a self-management toolkit.	Focus groups	Constructivist Grounded Theory techniques	132 American Indian cancer survivors, family members, and others (37 M).	>18	Sample origin not reported. Respondents purposively sampled.	25/40
Hughes et al. Exploring kidney patients experiences of receiving individual peer support <i>Health Expectations</i> (2009)	UK	To explore kidney patients' experiences of receiving individual peer support.	Telephone interviews	Framework method	18 patients (7 M)S with chronic kidney failure and two informal caregivers.	(26-80)	Patients who had previously received between 1 and 9 months of peer support from renal units from two teaching hospital in South London.	33/40
Kett et al. Self-Management Strategies used during Flares of Rheumatoid Arthritis in an Ethnically Diverse Population <i>Musculoskeletal Care</i> (2010)	UK	To explore patients' experiences of the characteristics of flares of RA, their beliefs about the causes of such flares and their self-management strategies.	Semi-structured interviews	Grounded Theory approach	21 patients (7 M) with RA who suffered from flares in the past. 10 South Asian; 9 white and 2 Afro-Caribbean.	56 (23-72)	Rheumatology department of Sandwell and West Birmingham Hospitals NHS Trust, Birmingham, UK. Patients purposively sampled.	35/40

Moe et al. Development of a brief multidisciplinary education programme for patients with osteoarthritis. <i>BMC Musculoskeletal Disorders</i> (2011)	Norway	To develop a brief, patient oriented disease specific multidisciplinary education programme (MEP) to enhance self-management of patients with osteoarthritis.	Focus groups	The analytical strategy followed the six analytical propositions using categorisation, saturation and creating subcategories to explore the opinions and attitudes of the groups.	16 patients (3 M) diagnosed with hand, hip or knee OA.	59 (range not reported)	Osteoarthritis outpatient clinic in Norway. Critical case sampling.	28/40
Nygaardh et al. The experience of empowerment in the patient–staff encounter: the patient’s perspective <i>Journal of Clinical Nursing</i> (2011)	Sweden	To explore empowerment within the patient–staff encounter as experienced by out-patients with chronic kidney disease.	Interviews	Content analysis	20 patients (14 M) with chronic kidney disease	69 (38–86)	The national register of patients with CKD (Swedish Renal Registry 2011) in a middle-sized municipality with approximately 125,000 inhabitants in the south of Sweden. Patients strategically selected.	36/40
Primdahl et al. Being an outpatient with rheumatoid arthritis – a focus group study on patients’ self-efficacy and experiences from participation in a short course and one of three different outpatient settings <i>Scandinavian Journal of Caring Sciences</i> (2011)	Denmark	To explore the patients’ experiences of participation in a course and one of the three different outpatient settings; and to explore whether some of these experiences can explain possible changes in self-efficacy beliefs.	Focus groups	Meaning analysis	33 patients (10 M) with rheumatoid arthritis	Not reported (39-78)	Patients of two Danish hospitals that already participated in a larger study.	33/40
Radford et al. ‘It’s quite hard to grasp the enormity of it’: Perceived needs of people upon diagnosis of rheumatoid arthritis <i>Musculoskeletal Care</i> (2008)	UK	To explore what professional support patients feel that they receive upon diagnosis, and what support they think would be most helpful	Focus groups	Thematic analysis	12 patient (2 M) with rheumatic arthritis.	54.7 (34-80)	Patients who attended a pilot ‘new patient support’ clinic with a rheumatology nurse specialist (RNS) and experienced patients. Patients purposively sampled.	31/40

Repping-Wuts et al. Fatigue as experienced by patients with rheumatoid arthritis (RA): A qualitative study <i>International Journal of Nursing Studies</i> (2008)	Netherlands	To explore the experience of fatigue in Dutch RA patients, including the concept, causes and consequences of fatigue, patients' selfmanagement strategies and bottlenecks in professional care.	Semi-structured interviews	Thematic analysis	39 patients (12 M) with rheumatic arthritis.	59 (36-80)	A rheumatology outpatient clinic. Patients selected by some prefixed criteria.	31/40
Rotegard et al. Cancer Patients' Experiences of Their Personal Strengths Through Illness and Recovery <i>Cancer Nursing</i> (2012)	Norway	To explore and describe cancer patients' experiences and perception of the strengths needed or used by themselves or supported by their care providers.	Focus groups	Thematic analysis	26 patients (11 M) with cancer (breast, prostate or lymphoma)	63.9 (50-79)	The Norwegian Cancer Society's patient support groups. Patients purposively sampled.	36/40
Ryan et al. Control perceptions in patients with rheumatoid arthritis: the impact of the medical consultation <i>Rheumatology</i> (2003)	UK	To identify factors that patients perceive as prerequisites in obtaining a sense of control over the consequences of their arthritis.	Interviews	Colaizzi's procedural steps	30 patients (14 M) with rheumatic arthritis	56.3 (23-72)	Outpatient department of the Staffordshire Rheumatology Centre. Convenience sampling	29/40
Schumacher Reconceptualizing Family Caregiving: Family-Based Illness Care During Chemotherapy <i>Research in Nursing & Health</i> (1996)	USA	To further the development of a theory on the process of caregiver role acquisition during a family health crisis, by investigating the process of taking on the caregiving role at the outset of chemotherapy for cancer.	Semi-structured interviews and observations	Grounded Theory approach	20 patients (10 M)with cancer (gastrointestinal, lung, genito-urinary, breast, gynecological, and lymphoma) receiving chemotherapy. 14 Euro American, 3 African American, 1 Asian American, 1 Hispanic American	62.4 (range not reported)	Cancer centers, oncology group practices, clinics, and private practices in the San Francisco Bay Area. Patients purposively sampled.	38/40
Sinclair & Blackburn Adaptive coping with rheumatoid arthritis: the transforming nature of response shift <i>Chronic Illness</i> (2003)	USA	To examine adaptive coping patterns reported by a sample of women with rheumatoid arthritis (RA).	Semi-structured telephone interviews	Thematic analysis	19 Caucasian women with rheumatoid arthritis	47 (24-68)	44 of 90 women with RA who completed a cognitive-behavioural intervention programme. Sampling not reported.	34/40

Spichiger et al. Fatigue in patients undergoing chemotherapy, their self-care and the role of health professionals: A qualitative study <i>European Journal of Oncology Nursing</i> (2012)	Switzerland	To explore cancer chemotherapy recipients' current perspectives regarding fatigue, with particular attention to related communication with health professionals, self-care activities, and perceived effectiveness of these measures.	Interviews	Grounded Theory approach	19 patients (8 M) with cancer (lymphomas, breast, lung or colorectal)	57 (23-77)	A Swiss tertiary care hospital's oncology outpatient clinic. Maximum variation sampling.	32/40
Tak An Insider Perspective of Daily Stress and Coping in Elders With Arthritis <i>Orthopaedic Nursing</i> (2006)	USA	To explore stressors in daily life, coping strategies, and social support resources from the perspective of older adults with arthritis.	Semi-structured interviews	Content analysis within an ethnographic framework	13 patients (4 M) with arthritis	72.8 (60-84)	Participants in programs of local chapters of the Arthritis Foundation, members of senior centers, and visitors to grocery stores in southeastern states. Convenience sampling.	29/40
Taylor et al. Multicomponent psychosocial support for newly diagnosed cancer patients: participants' views <i>International Journal of Palliative Nursing</i> (2004)	UK	To qualitatively investigate and report on patients who had completed a 10 session programme consisting of education, social interaction, psychological support, exercise and complementary therapy for newly diagnosed cancer patients.	Focus groups	Thematic analysis	23 white European women with cancer (breast, ovarian)	55 (34-70)	Early-diagnosed day service of the Rosendale Hospice. Patients purposively sampled	30/40
Tong et al. Patients' Experiences and Perspectives of Living With CKD <i>American Journal of Kidney Diseases</i> (2009)	Australie	To describe the range and depth of experiences and perspectives from patients with CKD about the meaning of CKD and its treatment, its impact on lifestyle and relationships, and the coping strategies adopted by patients.	Focus groups	Thematic analysis	63 (31 M) patients with chronic kidney disease. 14 National backgrounds	52.3 (20-78)	4 institutions involved in the study (Princess Alexandra Hospital, Queensland; Royal Prince Alfred Hospital, Sydney; Westmead Hospital, Westmead; and Royal Melbourne Hospital, Melbourne, Australia). Patients purposively sampled.	35/40

Ussher et al. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer <i>Social Science and Medicine</i> (2006)	Australia	To examine questions of what cancer support groups provide that other supportive relationships do not, and what the self perceived consequences are of support group attendance.	Interviews and observations	Thematic decomposition	93 patienten (18 M) with cancer	62 (38-85)	Nine cancer groups based in New South Wales (NSW), Australia. Sampling method not provided.	36/40
Van Eijk-Hustings et al. Patients' needs and expectations with regard to rheumatology nursing care: results of multicentre focus group interviews <i>Clinical and epidemiological research</i> (2013)	Netherlands	To explore chronic inflammatory arthritis' patients' needs and expectations with regard to rheumatology nursing care.	Focus groups	Krueger's 'long table approach': content analysis followed by consensus meetings	20 patients (5 M) with chronic inflammatory arthritis (rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis. Dutch speaking	56.6 (32-76)	Outpatient clinic of three large rheumatology clinics in different areas in the Netherlands. Patients purposively sampled.	31/40

Table I Study characteristics