

Postprint Version	1.0
Journal website	<a href="http://onlinelibrary.wiley.com/doi/10.1111/hex.12346/abstract">http://onlinelibrary.wiley.com/doi/10.1111/hex.12346/abstract</a>
Pubmed link	<a href="http://www.ncbi.nlm.nih.gov/pubmed/?term=25619975">http://www.ncbi.nlm.nih.gov/pubmed/?term=25619975</a>
DOI	10.1111/hex.12346

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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 1 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.

## Acknowledgements

The authors thank Jane Sattoe (Rotterdam University, Center of Expertise Innovations in Care) for useful comments on earlier drafts of this article, and information specialist Wichor Bramer (Erasmus MC, Rotterdam, the Netherlands) for assistance with the literature searches. We are grateful to Ko Hagoort for editorial support.

## FUNDING

This work was supported by the Netherlands Organisation for Health Research and Development (ZonMw).

## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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FIGURES

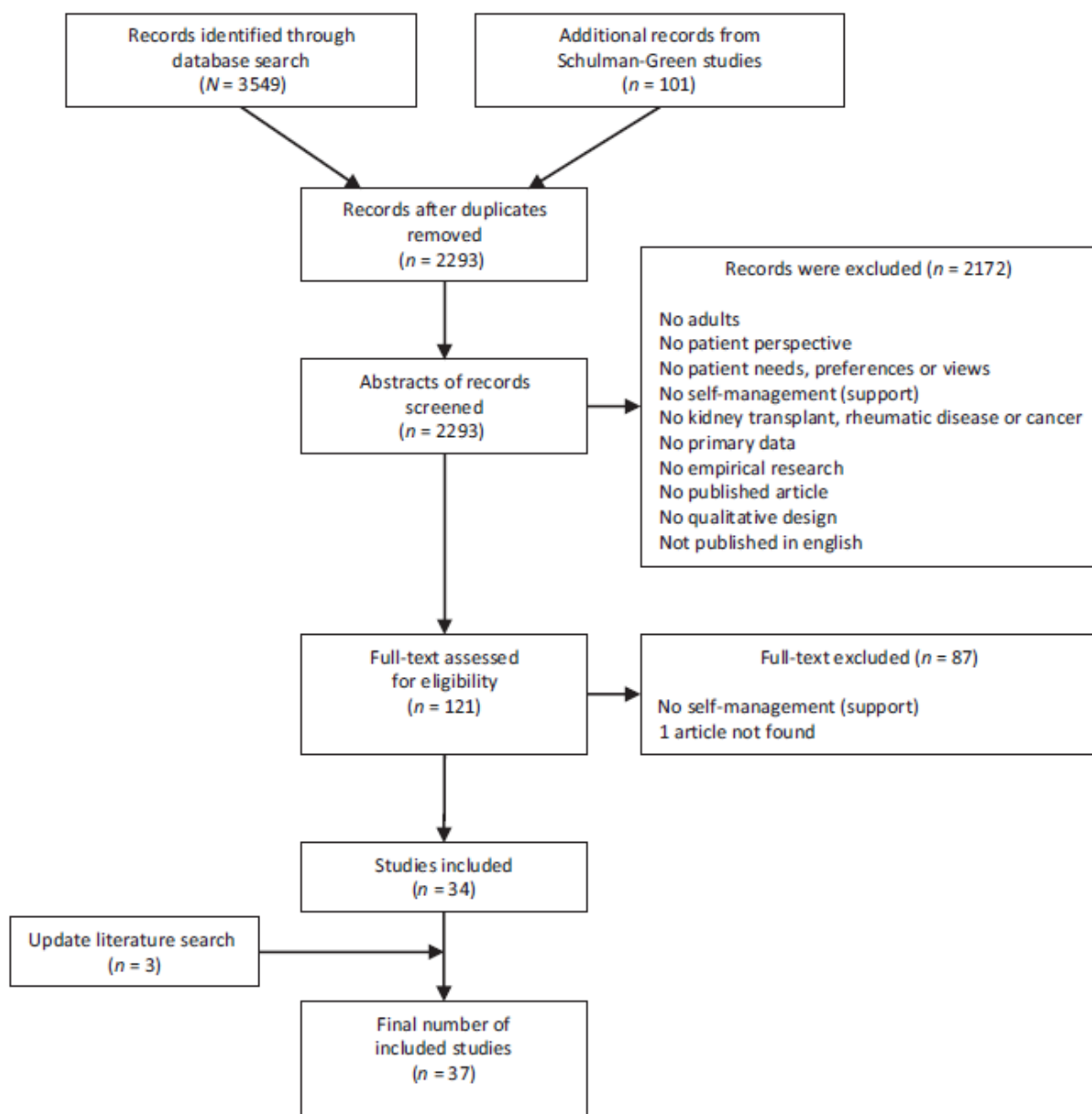
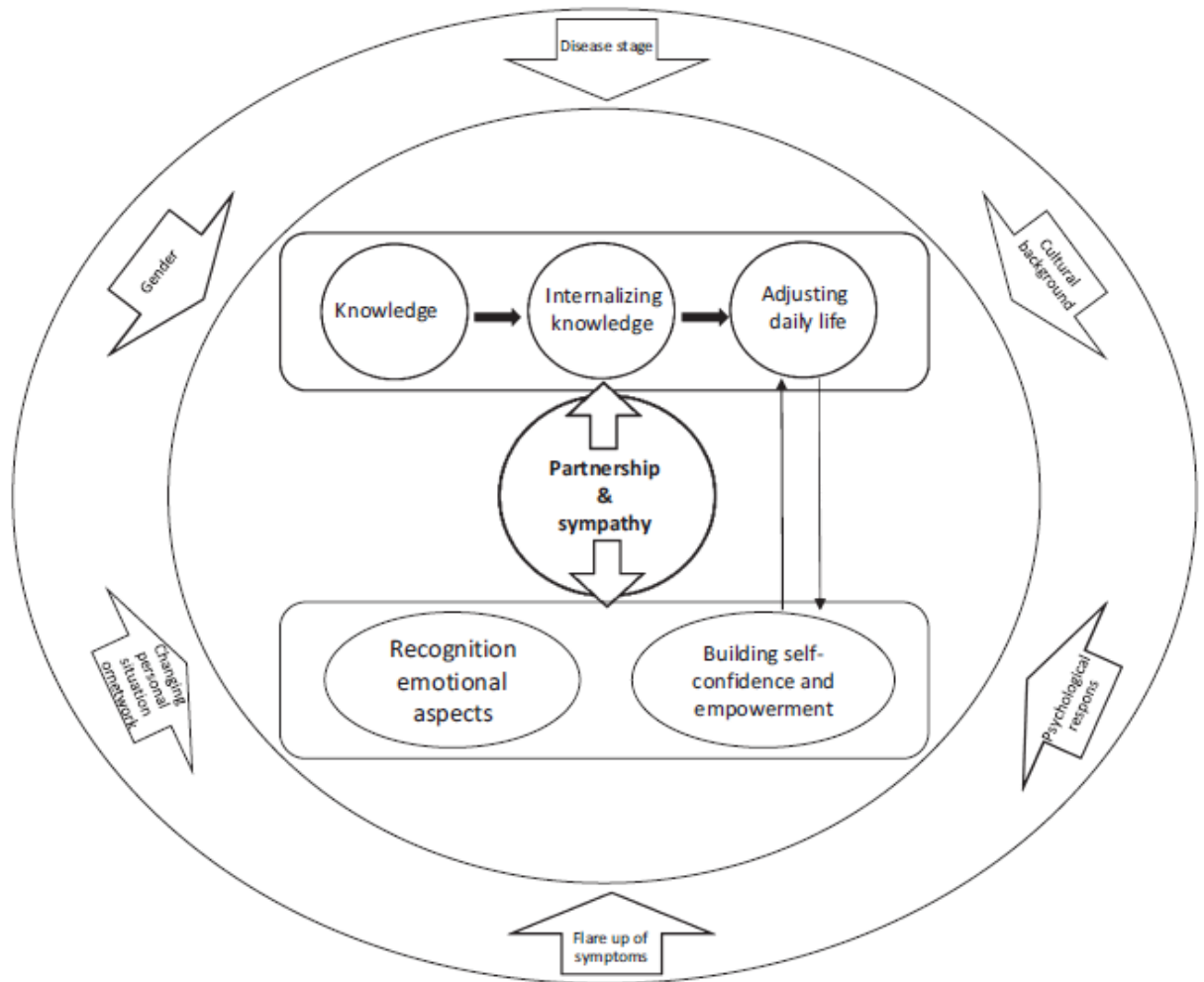


Figure 1 Flowchart of studies: from identification to inclusion.



**Figure 2** Interrelations between the identified patient needs.