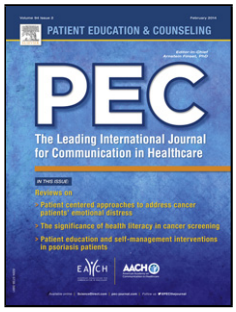
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Title: Self-management interventions for young people with chronic conditions: A Systematic Overview

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Highlights

- We provide a systematic overview of self-management interventions for chronically ill young people aged 7-25 years.
- Interventions' content, formats, underlying theories and outcomes used in evaluation studies were reviewed.
- Most studies aimed at medical management and were unclear about theoretical bases, while formats and used outcomes varied.
- Our overview may assist professionals in determining the breadth and focus of the support they provide.
- We present a content-based evaluation framework that may help researchers to select measures for evaluation studies.

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Self-management interventions for young people with chronic conditions: A Systematic Overview

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Abstract

Objective: To provide a systematic overview of self-management interventions (SMI) for young people with chronic conditions with respect to content, formats, theories, and evaluated outcomes.

Methods: Embase, Medline, PsycINFO, Web-of-Science, CINAHL, and Cochrane were searched. Reviews' reference lists were scrutinized. Selected studies were: Original research articles in English published between 2003-**March 2014**; about the evaluation of SMI for 7 to 25-year-olds with somatic chronic conditions/physical disabilities; with clear outcomes and intervention descriptions. The classification of medical, role and emotion management served to review content. Formats, theories, and evaluated outcomes were summarized.

Results: 86 studies were reviewed. Most aimed at medical management and were unclear about theoretical bases. Although a variety of outcomes was evaluated and the distribution over self-management domains was quite unpredictable, outcomes conceptually related to specific content. A content-based framework for the evaluation of self-management interventions is presented.

Conclusions and practice implications: SMI relate to self-management tasks and skill-building. Yet, conceptualizations of self-management support often remained unclear and content focuses predominantly on the medical domain, neglecting psycho-social challenges for chronically ill young people. Future evaluations should match outcomes/themes to content and characteristics. Our framework and overview of SMI characteristics and outcomes may assist clinicians in providing self-management support.

Key words: self-care; self-management; chronic disease; young adults; adolescents; children; systematic review; evaluation; intervention

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1. Introduction

Worldwide, the number of young people living with a chronic condition or with special health care needs is growing. In the USA, the 2009-2010 National Survey of Children with Special Health Care Needs showed that 15.1% of all under 17-years-olds fell in this category [1]. In the Netherlands, the most recent estimations are 14% of all under 18-year-olds [2] and 11% of all under 25-year-olds [3].

Chronic illness affects young people in many ways during their transition to adulthood and adult care [4, 5]. Supporting them to develop independence and self-management skills is therefore a key task of healthcare professionals. For that matter, self-management support is considered an integral part of healthcare for all people with chronic conditions [6-8]. The WHO definition of health was even redefined as "the ability to adapt and self-manage in the face of social, physical, and emotional challenges" [9].

Living with a chronic condition is an "ongoing process of inner negotiation" between social and medical needs [10] or what is described as shifting between the illness-on-the-foreground and wellness-on-the-foreground perspective [11]. Self-management therefore has been defined as "the individual's ability to manage the symptoms and the consequences of living with a chronic condition, including treatment, physical, social, and lifestyle changes" [12]. Note, however, that self-management is not restricted to one's individual ability, especially not in pediatrics where parents tend to play a key role. Adding the phrase " […] in conjunction with family, community, and healthcare professionals […]" [13] seems to present a more complete picture. This holistic view accounts for the three tasks involved in self-management: medical management (*re.* treatment), role management (*re.* social participation), and emotion or identity management (*re.* emotional consequences of being ill) [14]. Young people with chronic conditions have to learn these tasks, and in supporting them we must take their developmental transition into account [15].

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Various self-management interventions (SMI) for the chronically ill are available, but their effectiveness is not clear [16, 17]. This is even more pertinent to SMI in pediatric care [16, 18, 19]. Newman and colleagues (2009) emphasize that a theory-based approach is needed to evaluate complex SMI, and recommend a more systematic comparison of different types of SMI [20]. Recent studies on SMI for people with chronic conditions in general [17, 21] and for young people with physical disabilities [19] endorse this view, and it is recommended to standardize SMI evaluation by using a core set of outcomes [19, 22].

We reviewed and systematically compared the characteristics and content of offered SMI for young people (7-25 years) with chronic conditions, their theoretical foundations, if any, and the evaluated outcomes. Based on the results we present content-related outcome measures for the evaluation of different types of self-management interventions.

2. Methods

2.1 Study design

A systematic overview, defined by Grant and Booth [23], as a "summary of the literature that attempts to survey the literature and describe it characteristics" was applied. This allows for a systematic comparison of SMI and outcome measures used in evaluation studies. Methodological characteristics according to the 'Search, Appraisal, Synthesis and Analysis' (SALSA) framework [23] are: comprehensive searching, quality assessment, narrative synthesis with tabular features, and thematic analysis. The review process was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [24].

2.2 Search strategy

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The search strategy employed variations and Boolean connections (AND, OR) of the following terms: self-management, children, adolescents, young adults, chronic illness, and intervention. Relevant variations were derived from database thesauruses and relevant review articles (i.e. childhood, youth, chronic disease, physical disability, program etc.). Six health-related databases were searched: Embase, Medline, PsycINFO, Web-of-Science, CINAHL, and Cochrane. An information specialist helped define the final search strategies, employing a combination of free-text and thesaurus terms. The strategy used in Embase is presented in Box 1. Two researchers (JS, MB) supplemented the database searches by scrutinizing relevant reviews' references for additional relevant publications.

2.3 Inclusion criteria

- Study types: only original research articles in English language published from 2003 to **March 2014**. No restrictions were placed on study design.
- Participants: young people (aged 7–25 years) with somatic chronic conditions or physical disability.
- Interventions: studies focusing on the evaluation of an SMI and describing the SMI or referring to previous description(s) of the intervention.
- Outcome measures: No restrictions were placed on the type of outcome measures, as this was our main interest. However, outcome measures needed to be clearly defined.

Studies had to meet all inclusion criteria to be included for further analysis. **Furthermore, the term 'children' is used for young people aged 7-12 years, the term 'adolescents' is used for the age group of 13-18 years, and the term 'young adults' is used for those aged 19-25 years.**

2.4 Selection, quality assessment, and data extraction

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Retrieved records **(n = 5,908)** were imported into Endnote®. Two reviewers (JS, MB) independently selected eligible studies from both title and abstract and categorized them into: include, exclude or not clear. Any discrepancies were resolved, and decisions were made on the 'not clear' category. Full texts of all agreed-upon articles **(n = 444)** were retrieved. The two reviewers decided on final inclusion of articles based on the full text, resulting in **103** publications. The selection process is presented in Figure 1. Three reviewers (JS, MB, PR) assessed methodological quality of randomized controlled trials and cohort studies with methodology checklists of the Scottish Intercollegiate Guidelines Network (SIGN) [25]. For qualitative studies the 'Consolidated criteria for reporting qualitative research' (COREQ) checklist [26] was used. Any discrepancies were resolved by discussion. Seventeen studies were excluded because outcome measures were not clear, leaving **86** studies. Two reviewers (JS, MB) extracted data on study design, study sample, type and content of interventions, settings of interventions, interventionists, theoretical basis, and outcome measures. Data were recorded in an electronic extraction form.

2.5 Analysis

General study characteristics were summarized, i.e. study country, chronic conditions addressed and study designs, as well as SMI characteristics, i.e. the modes, formats, elements and settings of SMI and professionals involved. Lorig and Holman's classification of domains of self-management [14] served as a framework to review the content of SMI. Interventions could be aiming at medical management, role management, emotion management or a combination thereof. Further analysis included comparisons of theories underlying SMI per self-management domain. Finally, evaluated outcome measures were inventoried and linked to the content of SMI. On the premise that certain outcome measures logically relate to specific content of SMI, one reviewer (JS) linked all outcome measures to

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the content descriptions. Another reviewer (MB) checked this to enhance validity of this analysis.

3. Results

*3.1 General study characteristics (n=**86**)*

- Countries: Most studies hailed from the USA (n=**51**), followed by the Netherlands (n=**8**), the UK (n=7), Australia (n=**4**), Canada (n=3), Germany (n=3), Hungary (n=2), Taiwan (n=2), Austria (n=1), China (n=1), Denmark (n=1), **France (n=1)**, Haiti (n=1), and Norway (n=1).
- Chronic conditions: Most studies targeted asthma (n=**18**), followed by diabetes (n=**16**). **Six** studies targeted several chronic conditions (Table 1).
- Study designs: All but **nine** studies had fully quantitative study designs. **Forty-five** of them were randomized controlled trials, **29** were cohort studies and 3 were cross-sectional studies. **Three** studies had fully qualitative study designs, while **five** were mixed-methods studies **and one was a case study**. Twenty-six studies (**30.2**%) were classified as pilot evaluations.
- Interventions: A total of **81** different interventions were reviewed, because **different** studies evaluated the same intervention with different outcome measures **([27] and [28]; [111] and [112]; [93] and [94] and [95]; [75] and [77].**

*3.2 Intervention characteristics (n=**81**)*

Interventions were either applied at individual level (n=**39**; **48.1**%), at group level (n=**34**; **42.0**%) or both (n=**8**; **9.9**%). Most interventions included educational and/or skills training sessions (n=**35**; **43.2**%) or telemedicine systems (n=**14**; **17.3**%). **Intervention formats and elements are summarized in Table 2**. **In 20 interventions (24.7%), parents were included**

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as participants. These interventions often considered educational and/or skills training and most included both separate and joint sessions. Three interventions (3.7%) offered joint sessions only, while seven interventions (8.6%) offered separate but parallel sessions for parents and their children. Intervention settings were camping sites (n=**10**; **12.4**%), inpatient or outpatient clinics (n=**35**; **43.2**%), home or public environments (n=**13**; **16.0**%), school (n=**9**; **11.1**%), or online (n=**10**; **12.4**%). Settings were not exclusive for the formats of interventions. **Four** studies (**4.9**%) did not detail the settings.

Interventionists included pediatricians, nurses, physiotherapists, occupational therapists, psychologists, social workers, pedagogues, dietitians, job coaches, and speech pathologists. In some cases, interns or research assistants were additionally available. Occasionally, the whole healthcare team was involved. **Twenty-two** studies (**27.2**%) lacked this information. See Appendix A for an overview of general study characteristics and intervention characteristics per study.

3.3 Medical, role and emotion management: content of self-management interventions

The content of interventions includes the actual themes, topics, issues or specific skills discussed, reviewed or practiced during the interventions. Content is categorized by the domains of self-management [12] in Table **3**. Many interventions (**46.2**%) were solely aimed at medical management; some considered role management (**6.4**%) or emotion management (**2.6**%) alone. Others addressed multiple domains, see Figure 2.

Medical management was either disease-specific or of a more general nature. The former refers to tasks or topics associated with or related to a specific diagnosis, e.g., self-monitoring of blood glucose values in diabetes. This type of content is not exchangeable between interventions, e.g., education on treatment of cystic fibrosis is not useful for renal transplant patients. General medical management refers to health and healthcare related tasks

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irrespective of diagnosis. For instance, accessing healthcare, but also child-parent sharing or teamwork related to medical management tasks.

Role management referred to tasks or topics on domains related to social participation, such as communicating, decision-making, assertiveness, and keeping up with peers. Domains are school, work, community, living, housing, recreation, sports and leisure, relationships and sexuality. A major focus is on peer relationships and disclosure of the condition in social environments.

Emotion (or identity) management referred to the young person's feelings and intrinsic characteristics. Topics covered are building self-confidence, developing a positive body image, self-appreciation, maintaining positive thinking, stress management, but also acceptance of the condition.

The content of interventions was not specifically linked to certain modes, formats, elements or settings of SMI. In general, interventionists were not exclusive for content of interventions, although occasionally specific interventionists were included, e.g., a sexologist. See Appendix A for the classifications of self-management domains per study.

3.4 Self-management interventions for different age groups

Most interventions targeted 12 to 18–year-olds (n=**36**; **44.4**%) or 7 to 11–year-olds (n=**23**; **28.4**%). Only five SMI (**6.2**%) targeted over 18–year-olds. For the rest, age groups overlapped. Formats and classification of self-management domains did not seem to be related to specific age groups, but content or themes obviously were not applicable to the whole age range. For example, an intervention classified as targeting both role and emotion management for children (mean age 10 years) targeted communication and social problem solving in general [50], while for young people (mean age 20 years) such an intervention targeted the social subtheme of intimate relationships [64]. Another theme specific for older

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age groups is vocational participation. Two interventions aimed at the whole age range (7 to 25 years) addressed medical management and self-monitoring through daily diaries, respectively.

3.5 Conceptualization of self-management: theoretical bases of self-management interventions

Fifty-five studies (**67.9**%) either failed to state whether the interventions were based on a theory (n=**48**) or, if they did so, did not specify the theoretical base (n=7). Of the other studies, most referred to learning theories like Bandura's (cognitive) social learning theory or cognitive behavioral theory (Table **4**). A theoretical base was mostly mentioned in relation to interventions targeting medical management alone, while **only one** of the studies evaluating role management interventions mentioned a theoretical base. In general, neither the content of interventions nor intervention characteristics were specific for a certain theoretical base.

3.6 Evaluating self-management interventions: measured outcomes

Interventions were evaluated on a wide variety of outcomes, primarily health outcomes (**61.5**%), health-related quality of life (HRQoL) (**35.9**%), and knowledge about the disease and/or treatment (**29.5**%) (Table **5**).

Interventions solely aimed at medical management (n=36) were evaluated on all outcome measures except psychosocial functioning, and support by others. Of the **five** interventions solely aimed at role management, two were evaluated only on health outcomes, two on psychosocial functioning and one on social participation. One of the two emotion management intervention studies evaluated knowledge of disease and/or treatment, and the other social participation (Table **5**). None of the outcomes or groups of outcomes could be related to one particular type of intervention and the distribution over self-management

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domains or combinations of self-management domains was quite unpredictable. Appendix A presents an overview of outcome measures per study (Table A.1) and the groups of outcomes (Table A.2).

3.7 Linking content and outcomes: a content-based evaluation framework

Regarding the content of interventions (Table 2), certain content logically relates to groups of outcomes or themes. If, for example, 'understanding of the disease' and 'adherence' is addressed, it would seem logical to evaluate intervention effectiveness from improved knowledge, clinical outcomes and self-reported adherence rather than from psychological outcomes such as depressive symptoms or anxiety. Grounded on this premise, a conceptual content-based measurement framework for the selection of outcome measures in the evaluation of SMI is presented in Figure 3. The outcome measures correspond to the numbered content descriptions in Table 3. The only outcome related to all three domains was HRQoL.

4. Discussion and Conclusion

4.1 Discussion

4.1.1 The focus of today's self-management support

This review revealed that most interventions for young people represented in the literature solely aim at medical management, like interventions for adults [17, 113, 114]. This is not surprising, because medical tasks form the very core of healthcare. Moreover, these tasks represent common ground for healthcare professionals and people with chronic conditions, since medical consultations without fail will address symptoms and treatments. This may also explain why very few interventions address role management or emotion management alone. Still, the fact that 44% of interventions aim at multiple domains indicates a shift in focus of

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today's self-management support for young people with chronic conditions. Healthcare professionals nevertheless are challenged to pay more attention to role management and emotion management.

Six self-management skills match the tasks of medical, role and emotion management: "problem solving, decision making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring" [14]. Several SMI indeed were directed at developing such skills, e.g., drawing up an action plan. SMI content also seems to match self-management needs of people with chronic conditions, addressing the following processes: 'focusing on illness needs', 'activating resources', and 'living with a chronic illness' [21]. The first is addressed in, for example, SMI aiming to deal with symptoms, the second in SMI helping young people realize when and how to ask support.

However, the above-mentioned processes basically reflect experiences of adult patients. Additional developmental processes or factors will relate to young people's self-management processes as well [115], such as 'determining health needs' and 'communication with the medical team', processes that have been incorporated in the Pediatric Self-management Model [15]. Several SMI indeed target such processes, albeit the Pediatric Self-management Model seems to more narrowly focus on medical management. Young people have to learn to balance or "articulate" [116] self-management tasks, which their parents use to be responsible for. Parental involvement can either hinder or facilitate adolescents' development of self-management [117], and professionals and researchers should be aware of this [15, 117]. Some SMI involved parents in the intervention or assessed family interaction or conflict. However, the notion that social context deserves attention when researching self-management, has only recently gained more attention [14, 17, 19, 117-120].

4.1.2 The conceptualization of self-management support

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For most of the interventions a theoretical base was not provided, which was also found in other reviews of SMI for both adults and young people [16-18]. The studies that did mention a theoretical base often referred to social learning and cognitive behavioral theories which were also found to underlie SMI for adults [16, 17]. Social learning theory argues that people learn from others and in general aims at enhancing self-efficacy [121], while employing an "experiential" approach to self-management [17]. In this view, self-management refers to learning about and believing in yourself, and self-management support facilitates environments that allow to 'learn from others' and gain 'mastery experiences'. On the other hand, cognitive behavioral theory aims to change thoughts and attitudes and ultimately behavior [122], and from this point of view self-management support might be targeted at behavior thought to be beneficial from a medical perspective. In this light, it could represent a more "authoritative" approach to self-management [17]. The different theoretical bases thus represent different views on self-management. For young people, the experiential approach seems more appealing, as telling them what to do is less effective. Young people tend to weigh medical advantages against social disadvantages [4]. Moreover, self-assurance would form a firm basis for healthy behavior [115].

4.1.3 Evaluating self-management interventions: losing focus on what we wish to achieve

Outcome measures or themes varied greatly between studies and even within SMI aiming at a specific diagnostic group, as also reported by others [19]. Health outcomes predominated, which is not surprising given the focus on medical management. Remarkably, however, some studies that focused on a (partially) medical management intervention did not measure health outcomes. Likewise, some medical management interventions were evaluated with psychological outcomes, and an emotion management intervention was evaluated on knowledge of the disease. It seems that current evaluation studies tend to lose focus on what

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interventions are aimed at, which also hampers conclusions about their effectiveness. Others have recognized this, too, and recommend use of a core set of measurement outcomes to evaluate SMI [19, 22, 123].

4.1.4 A content-based framework for the selection of outcome measures or groups of outcome measures

The framework presented in Figure 3 proposes a start for a more standardized evaluation approach for SMI for young people with chronic conditions. The outcomes matched those in comparable reviews [18, 19], which strengthens the validity of the framework. It may be used to select outcome measures on the basis of the specific content of interventions (as described and numbered per domain in Table 3). However, the classification is broad and measures must be selected based on the goal of the intervention and the measurement properties of the measure. Further sharpening requires more studies into outcomes and measurement instruments.

A fact worth mentioning is the lack of qualitative evaluation studies for SMI. Since qualitative research delves into the contexts of interventions, we recommend future studies to employ a mixed-methods design including a qualitative component. This would help identify 'effective ingredients' of SMI and answer the question of what works for whom [124]. The outcome measures in our framework may serve as themes for qualitative research, but themes related to the characteristics of interventions need to be included as well.

4.1.5 Strengths, limitations and other considerations

This study included a systematic and comprehensive search, and was the first to review content of pediatric SMI and classify interventions using a broad self-management framework. Other recent reviews in this field that focus particularly on children and/or

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adolescents (0-18 years), aimed at researching the effectiveness of SMI and included only RCT's or studies with repeated measures designs [18, 19]. In contrast, our study shed light on the broad content and range of today's self-management support for young people with chronic conditions. As such, we dealt with the more fundamental question of what exactly is meant by self-management and self-management support. Furthermore, by matching content of SMI and outcome measures used, a selection tool for future evaluation studies was presented. This also corresponds to the fundamental question of what might be expected from self-management support, and provides a first step towards a much-needed general evaluation framework for different types of interventions.

Lorig & Holman's model is often referred to in the self-management literature and seems valid to classify SMI in children, adolescents and young adults, because our results showed that SMI aimed at certain domains of self-management are not exclusive for age groups. This does not imply that certain content is applicable to all ages; for example, vocational participation is more relevant for older adolescents than for younger children. Differences between age groups should therefore be taken into account when evaluating SMI.

This study looked at many types of SMI across a range of chronic conditions. **This may be a limitation, because our search terms did not include specific chronic conditions and we might have missed studies that did not include specific key words from our search. However, we feel this is always an issue when performing a systematic literature review which probably is more related to the way databases are organized than to the sensitivity of our search strategy**. **Furthermore, our non-categorical approach** may also be a strength, because it enables a more general view on self-management irrespective of diagnosis. This is relevant because these young people face comparable challenges and similar adaptive tasks irrespective of type of condition [4, 115]. Yet, they may need different support in view of individual socio-demographic and

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psychological factors [117]. In this respect young people within a specific diagnostic group may differ as much as those in different diagnostic groups [125]. Interestingly, only 7% of the SMI found in the present study were developed for chronic conditions in general. Since specific pediatric diagnostic groups are often small, achieving effectiveness and cost-effectiveness of disease-specific SMI would be problematic [20]. A more generic approach with a disease-specific component for different diagnostic groups may be more convenient [4], and should not be problematic since the core elements of self-management support are the same across different approaches [126]. An example is the 'Skills for Growing Up' tool developed in pediatric rehabilitation and adjusted on disease-specific content for use in pediatric nephrology [127].

Gaining insight into effectiveness of different types of interventions was hindered by the heterogeneity in outcome measures. Most studies in this review were from Western countries, and interventions for young people with diabetes or asthma predominated. These conditions generally include a burdensome medical regimen, which may have added to the focus on medical management. Yet, a sub-analysis (not presented in this paper) showed that even after removing diabetes and asthma studies, the focus still remained on medical management alone than on other self-management domains.

4.2 Conclusions

The content of different SMI relate to self-management tasks of people with chronic conditions, and self-management skills they should develop. Yet, healthcare professionals should be aware of the importance of role and emotion management in self-management. Also, in view of these young people's developmental challenges, an experiential approach focusing on learning (from others) and 'mastery experiences' might be more appropriate in pediatric care.

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Future evaluations should provide details about theoretical bases of interventions, and should match evaluation outcomes and themes to intervention content and characteristics. The content-based evaluation framework presented in this study may assist in this, while further research might help identify valid outcome measurement instruments. Mixed-methods research is recommended to gain more insights in the contexts, including social context, and working mechanisms of SMI.

4.3 Practice implications

Self-management support is important for people with chronic conditions to help them deal with their condition in daily life. This is even more pertinent to young people growing up with chronic conditions, who have to face the normal tasks of development (e.g., acquiring autonomy) and have to engage in lifelong medical management of their condition. Therefore, it remains important to research the effects of SMI. Future evaluation studies should make sure that their evaluation outcomes match with the content and characteristics of the SMI, and may benefit from the use of more generic outcome measures in SMI evaluation. Our content-based evaluation framework and overview of SMI content, characteristics and outcomes may assist researchers in doing so. Furthermore, our overview may give clinicians and other healthcare professionals insight into the broad range of self-management **and self-management** support, and as such may assist them in determining the breadth and focus of the support they provide.

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Figure titles and footnotes

Box 1. Search strategy in Embase

Figure 1. Selection process

Figure 2. Distribution of interventions (n=78) over (combinations of) self-management domains*
*MM - medical management, RM - role management, EM - emotion management

Figure 3. A content-based framework for the selection of (groups of) outcome measures*
*The numbers presented next to the outcomes correspond to specific content in Table 3.

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Box 1. Search strategy in Embase

(('self care'/de OR 'self medication'/de OR 'self help'/de OR 'drug self administration '/de OR (((self OR shared) NEAR/3 (manag* OR care* OR medicat* OR efficac* OR help*))):ab,ti) OR ((('coping behavior'/exp OR 'health education'/de OR 'patient education'/de OR emotion/de OR emotionality/de) AND ('intervention study'/de OR psychotherapy/exp OR 'program development'/de)) OR (psychotherap* OR ((coping OR cope OR cognitiv* OR behavio* OR emotion* OR education* OR psychologic*) NEAR/6 (therap* OR interven* OR program*))):ab,ti)) AND ('chronic disease'/de OR 'genetic and familial disorders'/exp OR 'congenital disorder'/exp OR 'disabled person'/de OR 'handicapped child'/de OR disability/exp OR (((chronic* OR longterm OR 'long term' OR 'end stage' OR endstage* OR degenerat* OR persisten* OR genetic* OR familial* OR congenit*) NEAR/3 (ill* OR disease* OR condition* OR disorder*)) OR (physic* NEAR/3 (handicap* OR disab* OR challeng*))):de,ab,ti) AND (child/exp OR adolescent/exp OR adolescence/exp OR 'child health care'/de OR 'child care'/de OR 'child hospitalization'/de OR 'handicapped child'/de OR (young OR youth OR child* OR adolescen* OR teenage* OR teen OR teens OR juvenile*):ab,ti) AND ('comparative effectiveness'/de OR 'clinical effectiveness'/de OR evaluation/de OR 'self evaluation'/de OR (effectiv* OR evaluat*):ab,ti)

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Table 1. Studies by chronic condition (n=86)

Chronic condition	References	No. (%)
Asthma	[26-43]	18 (20.9)
Diabetes	[44-59]	16 (18.6)
Cancer	[60-64]	5 (5.8)
Chronic fatigue syndrome	[65]	1 (1.2)
Chronic condition (various)	[66-71]	6 (7.0)
Chronic pain	[72-76]	5 (5.8)
Chronic respiratory condition	[77]	1 (1.2)
Cystic Fibrosis	[78-81]	4 (4.7)
Eczema (atopic dermatitis)	[82]	1 (1.2)
End-stage renal disease	[83-85]	3 (3.5)
Epilepsy	[86]	1 (1.2)
Heart disease	[87]	1 (1.2)
Hiv	[88,89]	2 (2.3)
Inflammatory bowel disease	[90]	1 (1.2)
Ichthyosis	[91]	1 (1.2)
Juvenile Fibromyalgia	[92-94]	3 (3.5)
Juvenile Idiopathic Arthritis	[95-98]	4 (4.7)
Migraine	[99]	1 (1.2)
Phenylketonuria	[100]	1 (1.2)
Physical disability	[101-103]	3 (3.5)
Sickle cell disease	[104-108]	5 (5.8)
Spina bifida	[109-111]	3 (3.5)

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Table 2. Formats and elements of self-management interventions according to mode

Modes	Formats	Elements
Individual	Educational sessions (with or without parents) or written materials	- Informational (comic) books and videos - Daily diaries or notebooks (with or without rewards) - Homework assignments (written or skills practice) or workbook - Check-in or booster telephone calls by interventionist - Role reversal (between educator and the one(s) being educated)
	Motivational interviewing sessions	- Awareness building - Problem solving - Goal setting
	(Skills) training sessions	- Symptom treatment (e.g. relaxation techniques or pain provocation technique)
	Cognitive behavioral therapy sessions (some of them with parents)	- Educational and skills training - Instructions for home practice
	Family sessions	- Written materials - Responsibility-sharing plan - Family discussions (with conflict resolution) - Problem solving training - Communication training - Homework assignments (behavior)
	Telemedicine system (e.g. through personal devices, text-messaging, websites, or web-based systems)	- Monitoring through daily diaries - Overview of (trends in) disease-specific outcomes - Individualized feedback - Reminders or cueing - Social media communication or online discussion board - 'Gamification' (with feedback or rewards), role-playing or knowledge quizzes

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Table 2. Formats and elements of self-management interventions according to mode (continued)

Modes	Formats	Elements
Individual	Telemedicine system (e.g. through personal devices, text-messaging, websites, or web-based systems)	- Goal-setting or action plans - Information messages, animated lessons or tips - Skills training - Modules with homework - Possibility to contact healthcare provider
	CD-ROM	- Educational modules - Active coping plan - 'Gamification' with feedback
	Peer-support (e.g. befriending program)	- Mentorship
	Individual (transition) plan	- Age and developmentally appropriate information resources - Goal-setting
Group	Cognitive behavioral therapy sessions	- Fun activities and games or role-playing - Homework (skills practice) - Involvement of parents as coaches - Goal-setting
	Art therapy sessions	- Discussion of weekly topics - Art making - Discussing art and related feelings
	Camping programs	- Traditional camping activities (e.g. horse riding, boating, arts etc.) - Disease specific activities (e.g. educational sessions, support groups, discussions, problem solving, role-playing, knowledge-testing games)
	Skills training or workshop	- Goal assessment and goal-setting - Drafting action or transition plans

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Table 2. Formats and elements of self-management interventions according to mode (continued)

Modes	Formats	Elements
Group	Skills training or workshop	- Practicing strategies for goal achievement (e.g. through role-playing, coaching, use of audio-visual aids, accessing the Internet etc.)
	Educational and/or support sessions	- Informational videos, (coloring) books, written information, educational stories - Didactic presentations - Question and answer sessions - Discussions and problem solving - Homework assignments, exercise books and skills practice - Self-monitoring with contingency management - Self-management plans - Devices for self-monitoring (e.g. peak flow meter) - Peer education - Sharing experiences
	Family sessions (parallel but separate groups for children and parents; in some cases one mixed session)	- Play therapy, narrative therapy or role play - Relaxation training - Group work - Social support - Training in coping strategies - Homework (practice skills)
	School program (with continued phone contact)	- Didactic presentation about the disease - Peer education

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Table 3. Content of interventions categorized by the domains of self-management[a]

Domains[b]	Content of interventions	References
Medical management	Disease-specific: 1. Understanding the disease 2. Understanding (the necessity of) medication and treatment regimen; understanding side effects; adherence 3. About the use of specific treatment devices or techniques (e.g. peak flow meter for asthma) 4. Dealing with symptoms 5. Drafting an individualized care plan 6. Self-monitoring of clinical outcomes	[27, 30, 31-50, 52-57, 59, 60, 63, 64, 66, 73-76, 79, 82-85, 87, 90-93, 96, 100, 101, 105-109]
	General: 7. Accessing healthcare 8. Communication with healthcare professionals 9. Managing doctor visits 10. Coping with hospitalizations 11. Goals and dreams for the future related to health and healthcare (transition) 12. Child-parent sharing / teamwork related to disease-specific medical management 13. Knowing where to find specific information about the disease 14. Knowing when to ask for (medical) help 15. Risk behavior (e.g. unsafe sex or drug and alcohol abuse)	[33, 39, 44, 47, 50, 54, 65, 76, 82, 84, 85, 89, 92, 96, 98, 103, 105, 110]
Role management	1. Social initiation and friendship making; social networks; family and romantic relationships 2. Managing teasing and bullying; conflict resolution 3. Participating in normal social activities; keeping up with peers; Internet and social media 4. Goals and dreams for the future related to school, work, community, living, housing, recreation and leisure (looking ahead); school issues 5. Romantic relationships and sexuality 6. Explaining the condition to others (disclosure); educating peers 7. Setting (life) goals and becoming assertive; growing up 8. Communication and social problem solving (sometimes within families); organizational skills 9. Independent living; traveling/staying abroad 10. Social rights and benefits	[27, 29, 33, 39, 47, 51, 57, 59, 61-63, 65-67, 69, 71, 72, 76, 81, 82, 86, 87, 89, 92, 96-99, 102-104, 107, 110, 111]

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Table 3. Content of interventions categorized by the domains of self-management[a] (continued)

Domains[b]	Content of interventions	References
Emotion management	1. Self-confidence or self-esteem building; developing a positive body image; body esteem 2. Self-appreciation; enhancing hope; enhancing self-efficacy 3. Empathy; fear-related thinking; 4. Feelings related to condition; sharing of feelings and experiences 5. Accepting condition; self-reflection 6. Healthy expressions of anger and transforming or managing anger 7. Helpful / positive thoughts; stress management 8. Decreasing negative thoughts 9. Decreasing stress and boredom; decreasing social isolation 10. Spirituality 11. Emotions	[29, 40, 42, 47, 49, 51, 59, 61, 62, 65-67, 70, 71, 74, 76, 80, 83, 86, 87, 96, 99, 100, 103, 104, 111]

[a]Number of studies is 78, three studies were unclear about the content of the intervention: [58, 68, 88]
[b]According to the model of Lorig & Holman (2003) [14]

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Table 4. Theoretical bases of self-management interventions, no. (%)

Theoretical base	Number of interventions (n=26)	References
(Cognitive) social learning theory	10 (38.5)	[29, 31, 48, 51, 59, 65, 75, 76, 79, 89]
Cognitive behavioral theory	9 (34.6)	[64, 66, 70, 74, 75, 91, 93, 106, 109]
Health Belief Model	2 (7.7)	[35, 85]
Prochaska's transtheoretical model	1 (3.8)	[35]
Self-regulation model of health and illness	1 (3.8)	[65]
Transactional model of stress	1 (3.8)	[40]
Orem's self-care deficit theory of nursing	2 (7.7)	[39, 44]
Game-playing and health theory	1 (3.8)	[108]
Flirt Model	1 (3.8)	[67]
Self-confrontation	1 (3.8)	[99]
Model of Human Occupation	1 (3.8)	[104]

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Table 5. Outcomes used in the evaluation studies distributed over (combinations of) self-management domains

(Combined) domains of self-management[a] No. (% of total studies[b]) Groups of outcome constructs or themes[c]	MM n=36 (46.2)	RM n=5 (6.4)	EM n=2 (2.6)	MM+RM n=8 (10.3)	MM+EM n=6 (7.7)	RM+EM n=9 (11.5)	MM+RM+EM n=12 (15.4)	Total[b] n=78
Health outcomes	27 (75.0)	2 (40.0)		4 (50.0)	5 (83.3)	3 (33.3)	7 (58.3)	48 (61.5)
Health-related quality of life	13 (36.1)			5 (62.5)	1 (16.7)	4 (44.4)	5 (41.7)	28 (35.9)
Knowledge of disease / treatment	12 (33.3)		1 (50.0)	6 (75.0)		2 (22.2)	2 (16.7)	23 (29.5)
Psychological outcomes	7 (19.4)			1 (12.5)	1 (16.7)	5 (55.6)	2 (16.7)	16 (20.5)
Self-efficacy	8 (22.2)			3 (37.5)		2 (22.2)	2 (16.7)	15 (19.2)
Vocational participation	5 (13.8)			2 (25.0)	1 (16.7)	2 (22.2)	2 (16.7)	12 (15.4)
Social participation	2 (5.6)	1 (20.0)	1 (50.0)	1 (12.5)		5 (55.6)	2 (16.7)	12 (15.4)
Coping	1 (2.8)			1 (12.5)	2 (33.3)	3 (33.3)	1 (8.3)	8 (10.3)
Self-care	2 (5.6)			3 (37.5)			2 (16.7)	7 (9.0)
Psychosocial functioning		2 (40.0)			1 (16.7)	1 (11.1)	2 (16.7)	6 (7.7)
Family involvement or conflict (related to disease-related management tasks)	4 (11.1)			1 (12.5)		2 (22.2)		7 (9.0)
Sense of control	1 (2.8)			2 (25.0)				3 (3.8)
Attitudes towards illness	2 (5.6)			1 (12.5)		1 (11.1)		3 (3.8)

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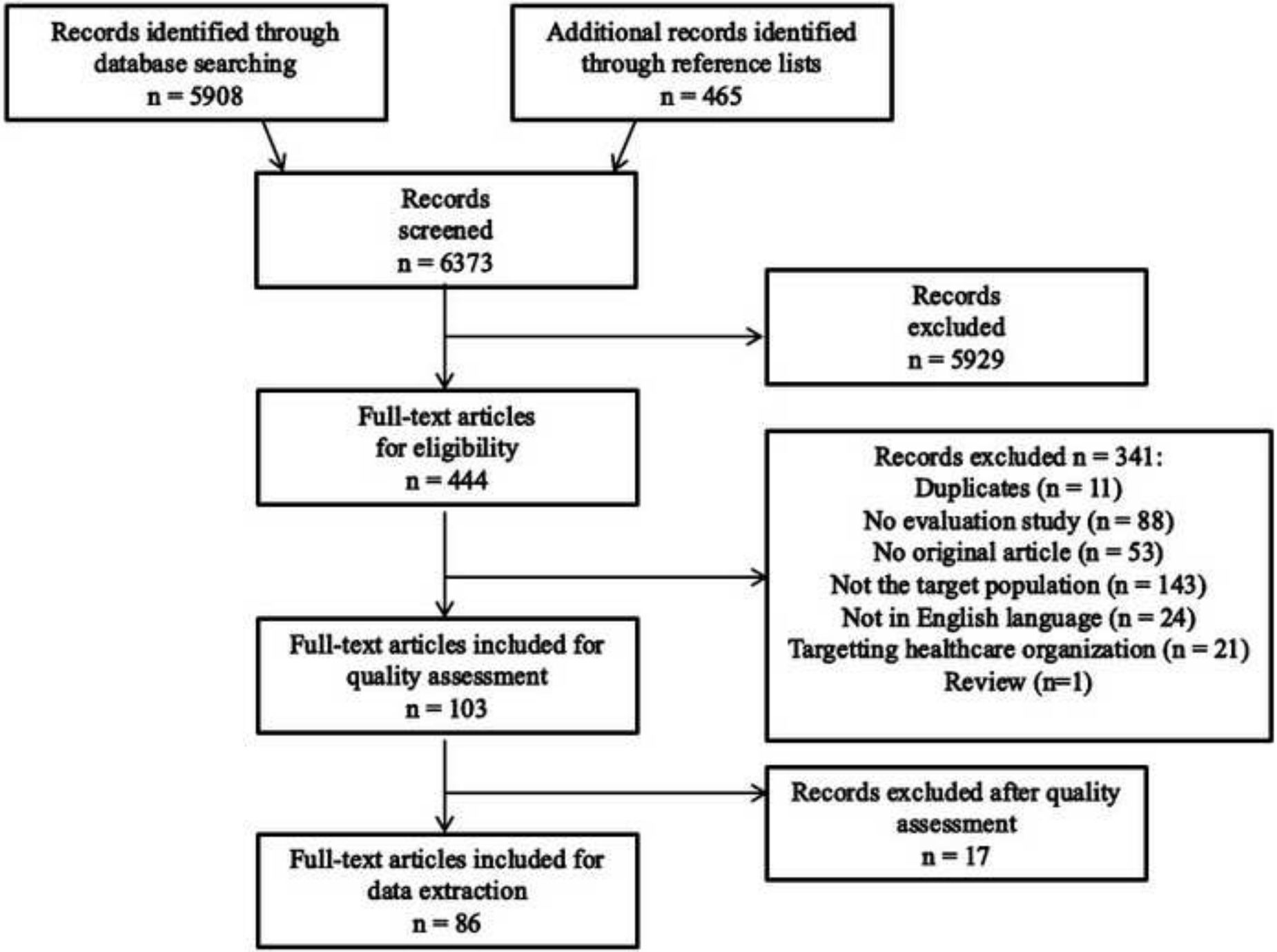
Table 5. Outcomes used in the evaluation studies distributed over (combinations of) self-management domains (continued)

(Combined) domains of self-management[a] **No. (% of total studies[b])** **Groups of outcome constructs or themes[c]**	**MM** n=32 (47.1%)	**RM** n=4 (5.9%)	**EM** n=2 (2.9%)	**MM+RM** n=7 (10.3%)	**MM+EM** n=6 (8.8%)	**RM+EM** n=6 (8.8%)	**MM+RM+EM** n=11 (16.2%)	**Total[b]** n=68
Self-perception of competencies	1 (3.1)			1 (14.3)				2 (2.6)
Problem solving	2 (6.3)							2 (2.6)
Support by others			1 (50.0)				1 (9.1)	2 (2.6)

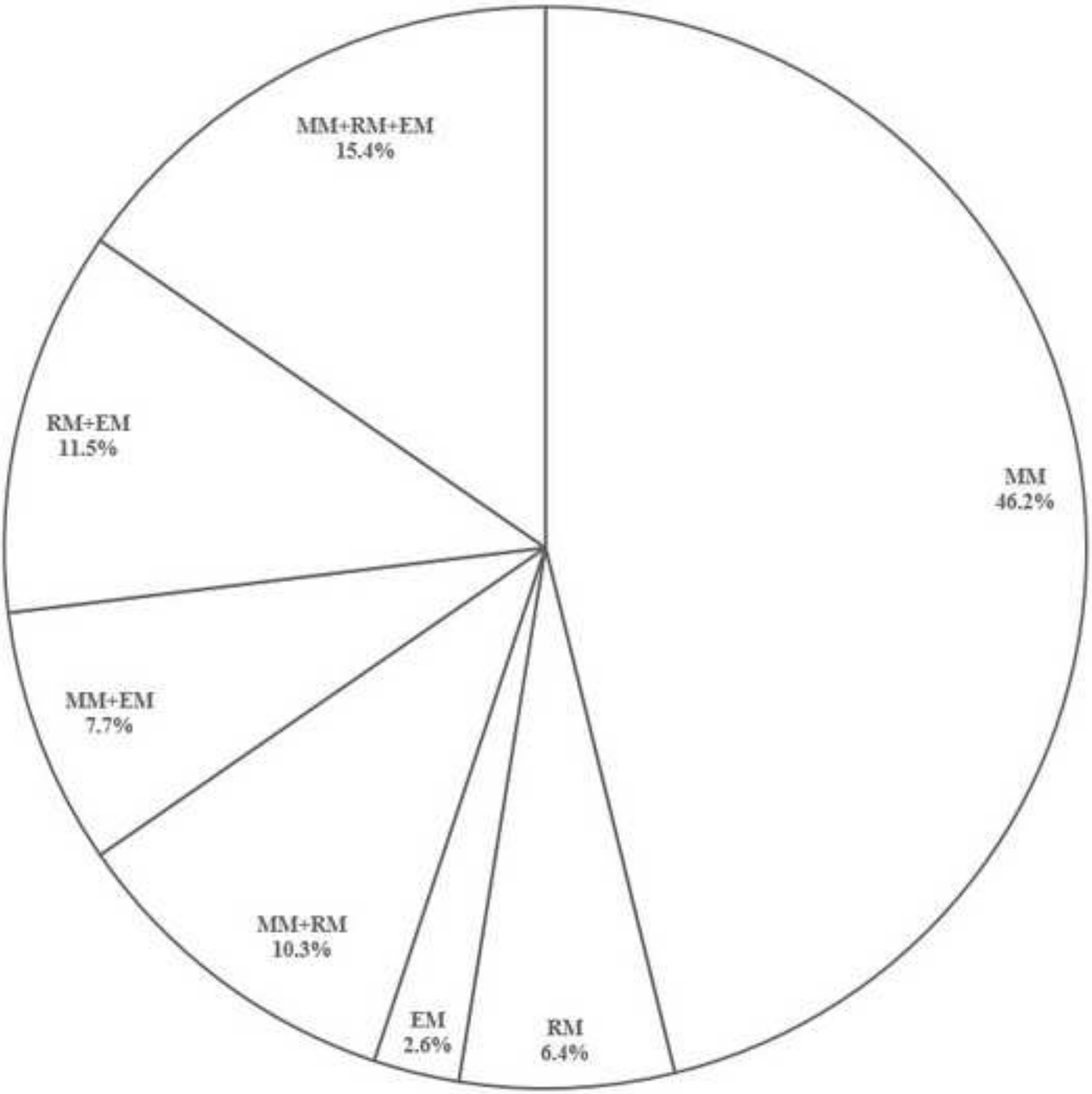
[a]According to the model of Lorig & Holman (2003) [14]: MM = medical management, RM = role management, EM = emotion management
[b]Number of studies is 78, three studies were unclear about the content of the intervention: [58, 68, 88]
[c]Only measured in young people (e.g., no parent proxy measures)

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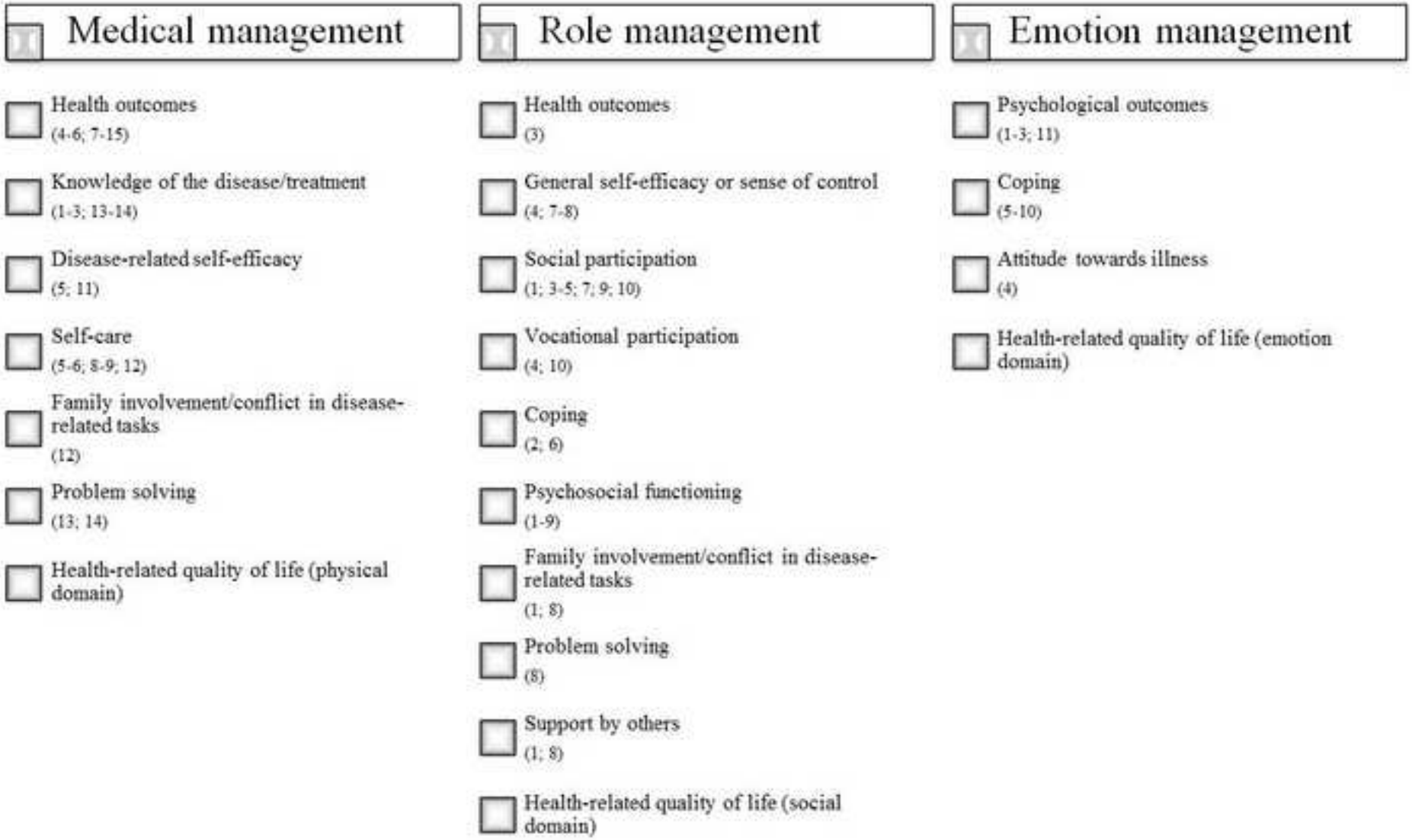
Figure


Records identified through database searching n = 5908
Additional records identified through reference lists n = 465
Records screened n = 6373
Records excluded n = 5929
Full-text articles for eligibility n = 444
Records excluded n = 341:
Duplicates (n = 11)
No evaluation study (n = 88)
No original article (n = 53)
Not the target population (n = 143)
Not in English language (n = 24)
Targetting healthcare organization (n = 21)
Review (n=1)
Full-text articles included for quality assessment n = 103
Records excluded after quality assessment n = 17
Full-text articles included for data extraction n = 86

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Figure


Medical management
Health outcomes
(4-6; 7-15)
Knowledge of the disease/treatment
(1-3; 13-14)
Disease-related self-efficacy
(5; 11)
Self-care
(5-6; 8-9; 12)
Family involvement/conflict in disease-related tasks
(12)
Problem solving
(13; 14)
Health-related quality of life (physical domain)
Role management
Health outcomes
(3)
General self-efficacy or sense of control
(4; 7-8)
Social participation
(1; 3-5; 7; 9; 10)
Vocational participation
(4; 10)
Coping
(2; 6)
Psychosocial functioning
(1-9)
Family involvement/conflict in disease-related tasks
(1; 8)
Problem solving
(8)
Support by others
(1; 8)
Health-related quality of life (social domain)
Emotion management
Psychological outcomes
(1-3; 11)
Coping
(5-10)
Attitude towards illness
(4)
Health-related quality of life (emotion domain)