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Self-management interventions for young people with chronic conditions: A systematic overview

JANE N.T. SATTOE [A,B,*], MARJOLIJN I. BAL [A,C], PEPIJN D.D.M. ROELOFS [A], ROLAND BAL [B], HARALD S. MIEDEMA [A], ANNELOES VAN STAA [A,B]

[a] Rotterdam University of Applied Sciences, Research Centre Innovations in Care, Rotterdam, The Netherlands
[b] Erasmus University Rotterdam, Institute of Health Policy & Management, Rotterdam, The Netherlands
[c] Erasmus Medical University, Department of Rehabilitation Medicine, Rotterdam, The Netherlands

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.

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 and 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.

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].

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 [16] 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

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.

[BOX 1]

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

Retrieved records (n = 5908) 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 Fig. 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.

[FIGURE 1]

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 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].

[TABLE 1]

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 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.

[TABLE 2]

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 Fig. 2.

[TABLE 3][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 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 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.

[TABLE 4]

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).

[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 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 Fig. 3. The outcome measures correspond to the numbered content descriptions in Table 3. The only outcome related to all three domains was HRQoL.

[FIGURE 3]

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 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

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 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 Fig. 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 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 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.

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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APPENDIX A. SUPPLEMENTARY DATA

The following are the supplementary data to this article:

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BOX, TABLE, FIGUUR

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)

Fig. 1. Selection process.

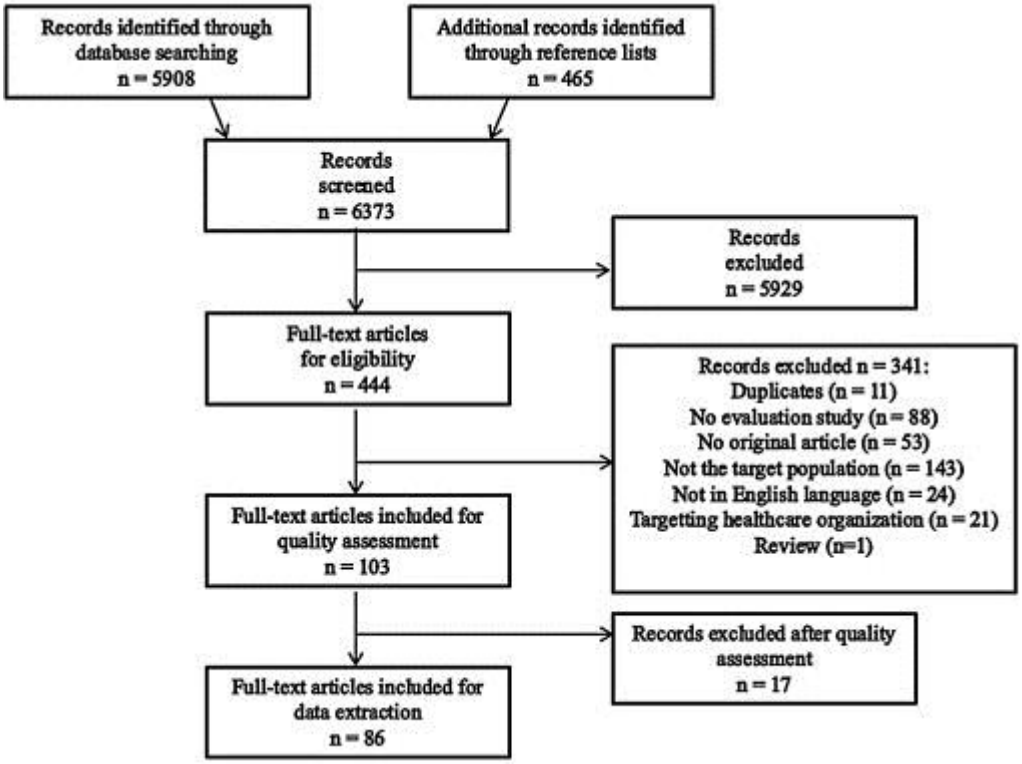


Table 1. Studies by chronic condition (n = 86).

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)

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,	- Monitoring through daily diaries - Overview of (trends in) disease-specific outcomes

Modes	Formats	Elements
	websites, or web-based systems)	- Individualized feedback - Reminders or cueing - Social media communication or online discussion board - 'Gamification' (with feedback or rewards), role-playing or knowledge quizzes
	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
	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

Table 3. Content of interventions categorized by the domains of self-managementa.

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 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]	[27,30–50,52–57,59,60,63,64,66,73–76,79,82–85,87,90–93,96,100,101,105–109]
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]
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].

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

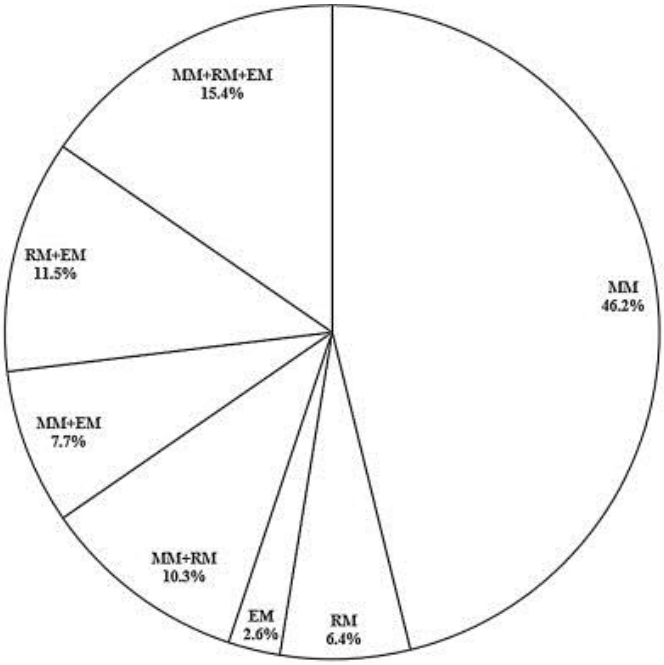


Table 4. Theoretical bases of self-management interventions, no. (%).

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]

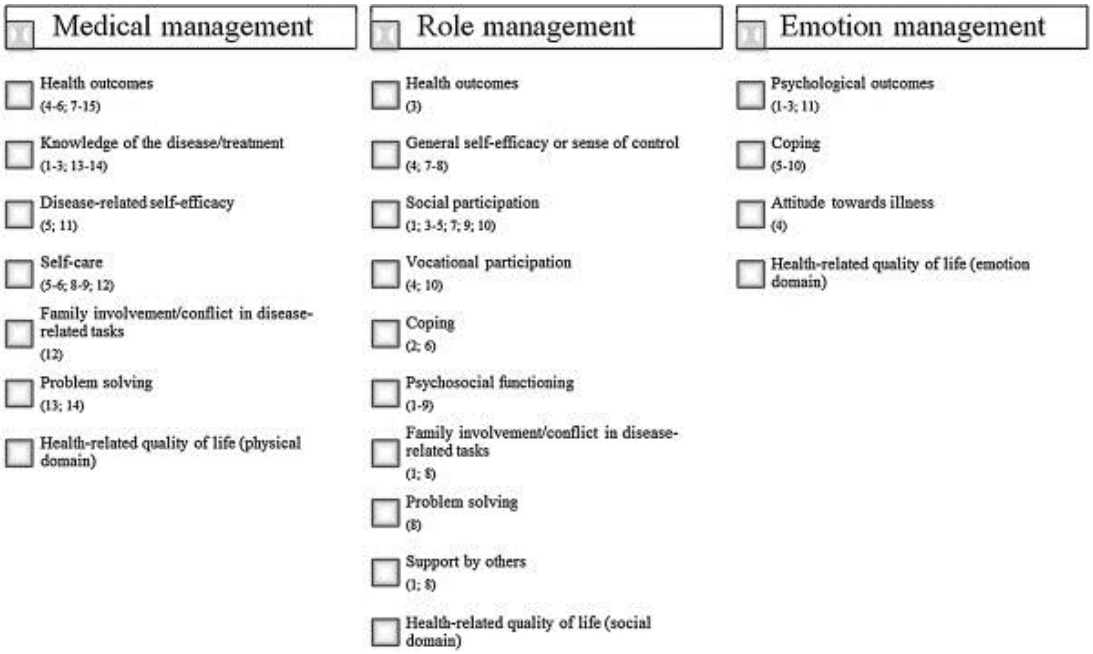


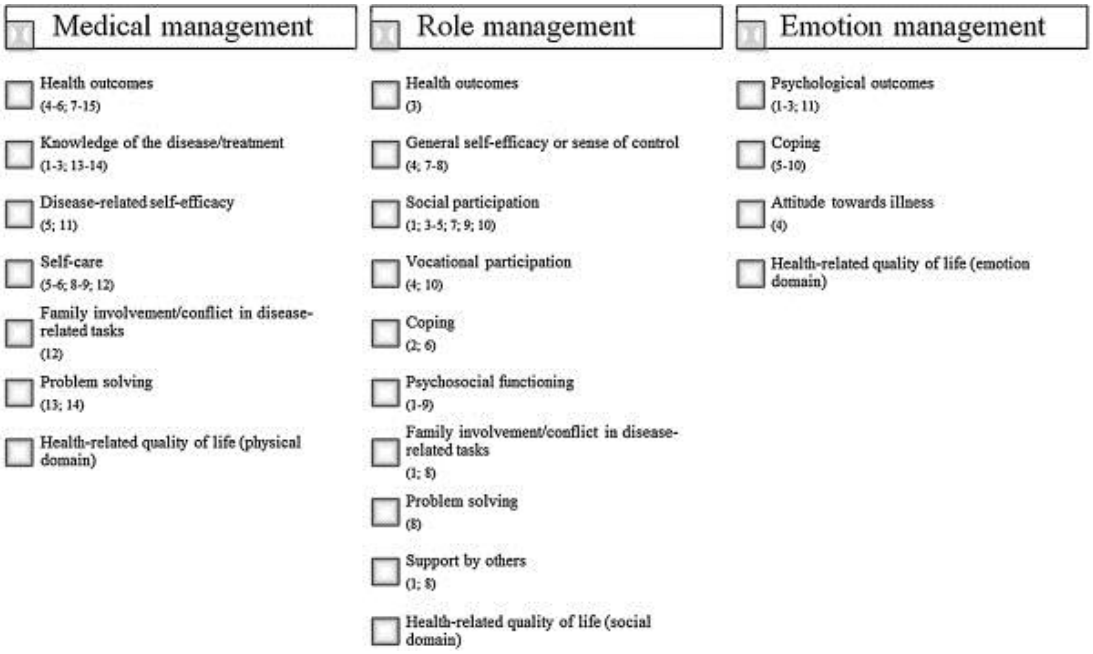
Table 5. Outcomes used in the evaluation studies distributed over (combinations of) self-management domains.

(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	4 (11.1)			1 (12.5)		2 (22.2)		7 (9.0)

(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**
tasks)								
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)
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).

Fig. 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.



Appendix A:

Table A.1 Overview of study and intervention characteristics

Table A.2 Overview of outcome measures used in the evaluation studies

Table A.1 Overview of study and intervention characteristics (n=86)*

Study characteristics			Participants		Intervention characteristics							
Identifier	**Country**	**Design**	**Condition**	**Mean age or age range (in years)**	**Mode**	**Delivery location**	**Interventionists**	**Format(s)**	**Element(s)**	**Timing**	**Domain(s) of SM**	**Theoretical base**
Barakat et al. 2010	United States of America	RCT	Sickle cell disease	14.1	Individual	Home environment	Doctoral students in clinical psychology or psychologists	Educational sessions	Daily paper-and-pencil pain diaries, homework, review of homework, and biweekly check-in telephone calls	Sessions take 90 minutes. Intervention: 4 sessions (3 sessions, 2 weeks apart with a booster session 1 month later)	MM	NA**
Barrera & Schulte 2009	Canada	Cohort	Cancer	12.7	Group	Clinic (Pediatric center)	Psychologist, and clinical assistants	Skills training sessions	Fun activities and games guided by cognitive behavior strategies and expressive therapies such as music, art, and drama.	A 2-hr group session once a week for 8 weeks.	RM and EM	NA
Beebe et al. 2010	United States of America	RCT	Astma	7-14	Group	School	NA	Art therapy sessions	Art making, and sharing feelings related to the art created.	A 1- hour session for 7 weeks.	MM and EM	NA
Bekesi et al. 2011	Hungary	Cohort	Oncology, diabetes, juvenile immune arthritis	13.3	Group	Camp, and clinic (medical centre)	Volunteers (selected and trained, profession not mentioned)	Camping program	Adventure-based program with activities and fun.	NA	RM	NA
Berrien et al. 2004	United States of America	RCT	HIV	10 .0	Individual home visit	Home	Experienced registered nurse	Educational sessions	A comic book, a video, filling out notebooks with rewards (prizes) if they did, and eventually role reversal.	NA	MM	NA

Betz et al. 2011	United States of America	RCT	Spina Bifida	16.0	Group	Clinic	Trainer (not mentioned if this was a healthcare professional)	Skills training sessions	Making a transition plan, and practicing strategies to obtain goals, i.e. role playing, one-to-one consultation, coaching, reinforced learning, use of audio visual aids, accessing the Internet, and mentored learning.	2-day workshop	MM and RM	NA
Bultas et al. 2013	United States of America	Cohort	Heart disease	8-15	Group	Camp	Pediatric nurses and cardiologists	NA	NA	5 days and 4 nights	NA	NA
Burkhart et al. 2007	United States of America	RCT	Asthma	7-12	Group sessions	Clinic (university center for nursing reserach)	Research associate	Educational sessions	Educational videos, and homework assignments	NA	MM	(Cognitive) social learning theory
Butz et al. 2005	United States of America	RCT	Asthma	8.0	Group sessions	School	Asthma educator (not mentioned if this was a healthcare professional)	Skills training sessions	Practiced and demonstrated specific skills (peak flow meter and inhaler technique). Discussions with the educator, and a coloring book, a peak flow meter, and a spacer device were given to children.	4 hours of instruction during two seperate sessions	MM	NA

Cafazzo et al. 2012	Canada	Cohort	Diabetes	14.9	Individual	Online	Clinicians	Telemanagement system	Reminders, cueing, social media communication, and the gamification of routine management tasks.	NA	MM	NA
Canada et al. 2007	United States of America	Cohort	Cancer	21.3	Individual	Clinic	Doctoral level clinical psychologist	Educational (and support) sessions	Workbook, homework, and follow-up phone calls	NA	RM and EM	NA
Channon et al. 2007	United Kingdom	RCT	Diabetes	15.3	Individual	Home	Nurses, and a health psychologist	Motivational interviewing sessions	Awareness building, problem solving, and goal-setting.	The frequency and location of appointments was determined by the participants to fit with the patient- driven principles of motivational interviewing. Interviews lasts between 20 and 60 min.	NA	NA
Chiang et al. 2009	Taiwan	RCT	Astma	6–14	Individual	Home, and clinic	Nursing graduate student	Skills training sessions	Relaxation training	During the 12-week intervention, participants practiced relaxation for 30 min at least three times per week.	MM	NA
Christian & D'Auria 2006	United States of America	RCT	Cystic Fibrosis	8-12	Individual home visit, and group session	Home, and clinic	NA	Educational sessions and support sessions	A computer software program, a notebook with worksheets, and a journal (individual). Discussion and peer contact (group).	NA	RM	NA

Clark et al. 2004	United States of America	RCT	Astma	7-10	Goup	School	NA	Educational sessions	Handouts and homework assignments, group discussions, asthma action plan.	NA	MM	NA
Clark et al. 2010	United States of America	RCT	Asthma	11.9	Group lessons	School	Graduate students, and community leaders trained in the program (profession not mentioned)	School program	Interactive problem-solving activities. Peer education component (not necessarily Asthma patient) in which peers educated asthma awareness to participants through skits, creative dramas or music.	NA	MM, RM and EM	NA
Connelly et al. 2006	United States of America	RCT	Migraine	7-12	Individual	Home	NA	CD-ROM	Educational modules, active coping plan, and gamification (with feedback).	NA	MM and EM	NA
Creedy et al. 2004	Australia	Cohort	Various chronic conditions	10-14	Group sessions	NA	Graduates of a leadership training course co-facilitated the intervention with healthcare professionals	Family sessions (parallel but seperate sessions for parents and children).	Peer support	8 weeks	RM and EM	NA

Curle et al. 2005	United States of America	Qualitative	Various chronic conditions	7-12	Group sessions	Clinic (specialized unit)	A clinical psychologist, occupational therapist, mental health nurses, and specialist pedatric nurses or social workers.	Family sessions (parallel but seperate sessions for parents and children).	Play therapy, narrative therapy, relaxation training and group work.	6-8 sessions	EM	Cognitive behavioral theory, and Systemic theory
Cushner-Weinstein et al. 2007	United States of America	Cohort	Epilepsy	7-17	Group sessions	Camp	Medical professionals, and counseling staff	Camping program	Traditional camp activities (rope course, swimming, arts, crafts etc.) combined with activities with condition-specific goals and relevance, and support groups (peer contacts).	7 days	MM, RM and EM	NA
Davis et al. 2004	United States of America	RCT	Cystic Fibrosis	7-17	Individual	Home	NA	CD-ROM	Educational modules	NA	MM, RM and EM	NA
Dobson 2014	United States of America	Cohort	Sickle cell disease	6-8	Individual	Clinic and home	Child life specialist	Diary and guided imagery, including one training session	Participants kept a diary, recording their daily activities and all pain episodes, including location and intensity, as well as strategies for management. The diaries included blank daily pages with the instruction, “Use one page a	The training sessions lasted from 15-45 minutes	MM	Cognitive behavioral therapy

									day to describe your activities and your pain, and one page to draw a picture".			
Downs et al. 2006	Australia	RCT	Cystic Fibrosis	8.4	Individual	Clinic	Caregivers	Cognitive behavioral therapy sessions	NA	10-week period, with each of the 10 chapters taking approximately 20 minutes to complete	MM	(Cognitive) social learning theory
Dufresne et al. 2013	France	Cohort	Ichthyosis	6 and older	Group	Reception centre	Physician and paramedic team member	Two sessions called 123 Tem'peau sessions And a game with a set of multiple-choice questions was used.	Children and siblings: "What is ichthyosis? Why do I need the cream? Why am I sick? Is it normal to have pain? What about school and me? What about the hospital and me?" Parents, children and siblings >12 years: "What is ichthyosis? What are the treatments? What is genetics? What is functional management? What are my social rights?" The game addressed various topics: therapy, genetics, care, pain, rehabilitation and social rights.	Two sessions of two hours each	MM+RM	NA
Eccleston et al. 2003	United Kingdom	Cohort	Chronic pain	14.3	Individual and family-centered	Clinic	A paediatric rheumatologist, clinical psychologist, physiother	Educational sessions, and cognitive behavioral therapy sessions.	Many sessions required evening or weekend written and skills practice homework. Patients received written information about all aspects of	Overall contact time was 110 hours (60 hours of physical and occupational activity; 35 hours of cognitive therapy, and 15 hours education). Each session lasted	MM and EM	(Cognitive) social learning theory, and Cognitive

							apist, occupational therapist, and a nurse		the programme which built into a patient manual.	50 minutes. The day was structured as a school day from 9 00 am to 3 45 pm.		behavioral theory
Franklin et al. 2006	United Kingdom	RCT	Diabetes	11-16	Individualized	Clinic, and by phone	Diabetes healthcare team	Telemedicine system (text-messages on phone)	Individual goal-setting at clinic. Automated delivery of a series of messaging, including a weekly reminder of the goal set, and a daily message providing tips, information or reminders to reinforce this goal (by phone).	NA	MM	(Cognitive) social learning theory
Fuchs et al. 2013	Netherlands	Cohort	Juvenile idiopathic Arthritis	14-19	Individual	NA	Child psychologist and counselor/ philosopher	Narrative self-reflections	Phase 1: self-investigation, about important life experiences; Phase 2: process-promoting, about daily situations and coping, Phase 3: second self-investigation, consistencies and changes in person narratives;	Phase 1 included one SMC session. Phase 2 consists of 6 weekly individual sessions of about 1 h each. Phase 3 consists of 3 weekly individual sessions of about 1 h each.	RM+EM	Self-confrontation method

Gerber et al. 2007	United States of America	Cohort	Diabetes	22.3 yrs	Individualized, but also online discussion with peers possible	Online	Psychologist, patient advocacy expert and social worker	Telemedicine system (web-based)	Educational module, and goal-setting exercises with individualized feedback, role-playing, group discussion, empowerment activities, and communication skills training to improve interactions with health professionals. There was a discussion board available, and there were three 'ask the experts segments'.	NA	MM	NA
Grey et al. 2009	United States of America	RCT	Diabetes	9.9 yrs	Group sessions	Clinic	Mental health professional	Educational sessions	Role play, coaching, and practice at home.	6 weekly sessions	RM and EM	(Cognitive) social learning theory
Hackett et al. 2005	United Kingdom	Cross-sectional	Juvenile Idiopathic Arthritis	Median: 14 yrs	Group	Camp	Occupational therapist, Physiotherapist, Nurse / therapist, assistant	Camping program	Climbing, canoeing, abseiling and a trip to a theme park.	4 day annual event	RM	NA
Hampel et al. 2003	Germany	Cohort	Astma	11.6 yrs	Group	Clinic (inpatient)	Psychological, educational, and medical staff	Family sessions (seperate for parents and children)	Educational group work	4 weeks stay, 10 1 h-long training sessions.	MM and EM	Stress theory

Hanauer et al. 2009	United States of America	RCT	Diabetes	17.9 yrs	Individualized	Online	NA	Telemedicine system (web-based)	BG diaries (blood glucose check) and two daily factoids of which one was related to diabetes and one related to unusual fun facts or trivia. System sends reminders to check BG, and gives (positive) feedback.	NA	MM	NA
Hayutin et al. 2009	United States of America	Cohort	Inflammatory Bowel Disease	13-17 yrs	Group sessions	NA	NA	Family sessions (separate for parents and children, except for relaxation session and conflict resolution communication session)	Review of written homework, didactic presentations, discussion, problem solving and practice of the new skill, plans for application during the week, and assignment of homework related to the skills.	10 sessions	MM	Cognitive behavioral theory
Hechler et al. 2010	Germany	Cohort	Chronic pain	14.0 yrs	Individualized	Clinic (inpatient)	Therapists	Skills training sessions	Interoceptive exposure; bilateral stimulation in the form of tapping; and cognitive coping strategies to reduce pain intensity.	NA	MM	NA
Herbert et al. 2013	United States of America	Qualitative	Diabetes (type 1)	11-14	Group	Clinic	Study team counselors, but not mentioned who these were	TeamWork. Adolescent-parent type 1 diabetes (T1D) program developed to prevent deterioration in diabetes care among adolescents	Coping skills session topics included communication and diabetes management, problem solving to improve blood glucose management, healthy food	NA	MM	NA

								with T1D. Coping skills or education group with a study team counselor at four consecutive regularly scheduled diabetes clinic visits.	choices and avoiding arguments, and how attitudes affect behaviors and how these relate to physical activity. Each session started with an overview of the skill and was followed by a discussion about what was typical for the family and how they could use the skill in daily life.			
Hilberink et al. 2013	Netherlands	Mixed methods	Cerebral palsy, spina bifida, Neuromuscular disease	19.9 yrs	Group	School, and rehabilitation clinics	Pedagogues, psychologists, social workers, a sexologist, and a teacher	Educational/support sessions	Homework assignments	7 sessions (90 min each, scheduled over a 12-week period).	RM and EM	Flirt model
Hojberg et al. 2010	Denmark	Cohort	Congenital physical disability	18-25 yrs	Group sessions	Rehabilitation clinic (and a trip to Lithuania)	Occupational therapist, and a socio-educational assistant (if necessary another assistant was hired)	Developmental instructional training course (skills training sessions)	NA	The group met 20 hours per week, 4 days a week. Approximately every sixth week out of house activities of 2-3 days duration. In addition: a 10-day study trip to Lithuania.	RM	NA
Huss et al. 2003	United States of America	RCT	Asthma	9.6 yrs	Individual	Home	NA	CD-ROM	Interactive game including levels and quizzes and feedback from an on-screen nurse.	NA	MM	NA

Jan et al. 2007	Taiwan	RCT	Asthma	10.5 yrs	Individual	Clinic (outpatient)	NA	Telemedicine system (Internet-based)	Educational modules, electronic diary, action plan, and monitoring system	NA	MM	NA
Jones et al. 2010	United States of America	RCT	Cancer	12-18 yrs	Individual	Home	Trained healthcare professionals	CD-ROM	Information videos, text, stories, and a game.	NA	MM and RM	NA
Joseph et al. 2007	United States of America	RCT	Asthma	15.3 yrs	Individual	School	NA	Telemedicine system (web-based)	Theory-based health messages and information on Asthma control. Normative (compared with other students) and ipsative (compared with your last session) feedback.	NA	MM	Transtheoretical, and Health belief model
Kashikar-Zuck et al. 2012; 2013	United States of America	RCT	Juvenile Fibromyalgia	15.0 yrs	Individual	Clinic	Therapists with postdoctoral training in pediatric psychology	Cognitive-behavioral therapy sessions (in 3 of the 8 parents were also present)	Education and skills training. Instructions for home practice were also reviewed with participants.	8 weekly individual sessions, and 2 booster sessions.	MM	Cognitive behavioral theory
Kato et al. 2008	United States of America	RCT	Cancer	13-29 yrs	Individual	NA	NA	CD-ROM (PC-game)	Game	NA	MM	Self-regulation theory, and (Cognitive) social learning theory
Koontz et al. 2004	United States of America	RCT	Sickle cell disease (anemia)	8-12 yrs	Group session	School	Teachers	School program	Peer education	1 hour	MM and RM	NA
Kouba et al. 2013	United States of America	Cohort	Asthma	15.9	Group and individ	School	Registered nurses, dietitian	The ICAN program is thus composed of	Quest for the Code, an interactive, three-	The ICAN educational session covered an 8-week	MM	Orem's Self-Care

					ual		and dietetic interns	four elements: (1) asthma education, (2) nutrition education synthesized with CST, targeting obesity prevention and management, (3) reinforcement visits with a registered nurse (RN) and dietetic intern, and (4) a family information meeting. Sessions included group problem-solving and role-pay activities, which allowed opportunities to increase perceived competence and foster peer support for improved health choices. In addition electronic modules were developed and offered.	dimensional video that combines asthma education with rich graphics and top celebrities, was viewed by the students in groups during lunch periods. The second session included a review, discussion about the group's asthma symptoms, medications, management, and additional content from the ''Fight Asthma Now'' program developed by the Respiratory Health Association. Each nutrition session included a focused nutrition lesson followed by introduction of a coping skill. Then interactive exercises were completed with students allowing them the opportunity to practice the coping skill with a nutrition scenario. The CST strategies were used to reinforce nutrition information. CST is a cognitive behavioral strategy	period including the makeup session. This was followed by two reinforcement visits. The total program length spanned 14 weeks.		Deficit theory of Nursing

									that teaches students personal and social coping skills to assist in making health-related decisions. Electronic modules: These interactive modules encouraged students to seek resources and make decisions related to the target behaviors using existing Internet resources.			
Krishna et al. 2003	United States of America	RCT	Asthma	7-17 yrs old	Individual (clinical staff leaves when the patient is working on IMPACT)	Clinic	Multidisciplinary team involved in determining content of the program.	Telemedicine system (interactive multimedia program)	Animated lessons, each averaging a minute in length. Each template was designed to illustrate concepts, test comprehension and reinforce learning, develop decision-making skills or improve a child's ability to communicate their asthma.	During office visits	MM	NA
Kumar et al. 2004	United States of America	RCT	Diabetes	13.6 yrs	Individual	Online	NA	Telemedicine system (personal device)	Game with rewards	NA	MM	NA

Laffel et al. 2003	United States of America	RCT	Diabetes	12.1 yrs	Individualized, child with parent (during office visits)	Clinic	Research assistant	Family sessions (for child and parent together)	Written materials, discussion, making a responsibility-sharing plan	During office visits	MM	NA
Løding et al. 2008	Norway	Cohort	Diabetes	13-17 yrs	Group sessions	Clinic (outpatient)	A team of nurses, medical doctors, and a trained social worker	Separate support/educational/skills sessions for adolescents and parents	Warm-up activity such as painting, movement/exercises, or a round of questions about topics that were not related to diabetes, followed by group discussion.	NA	MM, RM and EM	NA
MacDonald & Greggans 2010	United Kingdom	Qualitative	Cystic Fibrosis	8-18 yrs	Individual	Home/public environment	Volunteers (after following a training programme)	Peer-support	Mentorship	NA	EM	NA
Martin et al. 2009	United Kingdom	Cohort	Diabetes	9-11 yrs	Group sessions	Clinic	Pediatric diabetes nurse specialist, assistant psychologist under supervision of a consultant (pediatric clinical psychologist).	Educational sessions	Educational stories about diabetes, group discussions, coloring/drawing pictures, one-to-one computer session.	NA	MM and EM	(Cognitive) social learning theory

Maurice-Stam et al. 2009	Netherlands	Cohort	Cancer	8-12 years	Group sessions	Clinic (outpatient)	Dermatologists or pediatricians, psychologists, and dietitians	Educational/skills/support sessions	Modelling, contingency management, exposure exercises and cognitive techniques.	NA	MM, RM and EM	Cognitive behavioral theory
McClellan et al. 2009	United States of America	Cross-sectional	Sickle Cell Disease	8-20 yrs	Group session and individual device	Clinic, and by phone	NA	Skills training session, and telemedicine system (personal device)	Daily pain diary and coping skills practice (through audio files).	NA	MM	Cognitive behavioral theory
McDonagh et al. 2007	United Kingdom	Cohort	Juvenile Idiopathic Arthritis	14.2 yrs	Individual	Clinic	Project coordinator from clinic assisted by local consultant rheumatologist	Individual (transition) plan	Age and developmentally appropriate information resources, and goal-setting	NA	MM and RM	NA
Meade et al. 2003	United States of America	Cross-sectional	End-stage renal disease	13.7 yrs	Group sessions	Clinic	A nurse from the transplant team, and a nephrologist.	Educational/skills/support sessions	Problem solving, stress management/relaxation, talking with other teens and/or parents, communication role-plays, questions and answers with the nephrologist, medication presentation by the nurse.	2 4-hour sessions	MM	NA
Merlijn et al. 2005	Netherlands	Cohort	Pain	14-18 yrs	Group sessions, and individual	Clinic	NA	Educational and skills training sessions (two sessions were for parents	Training and exercise book, peers, written material, exercises and homework assignments.	NA	MM, RM and EM	(Cognitive) social learning theory

					telephone contacts			only: one at the beginning and one at the end). The others were for adolescents only.				
Nansel et al. 2007	United States of America	Cohort	Diabetes	11-16 yrs	Individualized	Home or public environment	Trained non-professionals (bachelor degree and/or graduate students in health related fields)	Skills training sessions with motivational interviewing incorporated, supplemented with telephone calls.	Reviewing self-monitoring records, goal-setting, going through the steps of behavior change, brainstorming about possible solutions of difficulties encountered (problem-solving). The personal trainers provided suggestions, encouragement, and positive feedback.	6 sessions	MM	NA
Newcombe et al. 2012	Australia	RCT	Chronic respiratory condition	13.4 yrs	Individualized, but also online conversation with peers	Online	NA	Telemedicine system (educational website)	Information on web-site, daily diary, assignments/homework and peer contact.	NA	MM	NA
Newton & Ashley 2013	United States of America	RCT	Diabetes (type 1)	13-18	Individual, but online contact with peers	Online	Moderators, but not mentioned who these were	Telemedicine system: interactive web-based intervention with problem solving through discussion in forums, chat	Three types of asynchronous discussions were held in the forums: 1) General discussion on the weekly topic. 2) Diabetes-related scenarios	7-week, weekly topics	MM+RM+EM	Bandura's Self-Efficacy Theory

								rooms and blogs	discussing psychosocial diabetes-related issues. 3) Open discussion where participants could post their own problems to the group. Weekly topics were: Frustrations with diabetes, Benefits of good control, Family, Friends, Body image, exercise and diet, Community, School and sports, Worries about diabetes.			
Ng et al. 2008	China	RCT	Asthma	9.2 yrs	Group sessions	Clinic	NA	Educational/support sessions	Joint activity (to talk about take-home tasks from previous meeting), parallel groups (children and parents work separately on a common theme), joint activity (discussion).	5 educational sessions, and 6 support sessions.	MM, RM and EM	NA
O'Mahar et al. 2010 Holbein et al. 2013	United States of America	Cohort	Spina bifida	16.6 yrs	Group and individual	Camp	Counselors, but not mentioned who these are.	Camping program with support sessions	NA	11 2-hour group sessions	RM and EM	NA
Palermo et al. 2009 Fales et al. 2014	United States of America	RCT	Chronic pain	14.8 yrs	Individualized	Online	Online therapist: a psychology postdoctoral fellow who had	Telemedicine system (web-based program).	Treatment modules with video files and audio files, and daily diary. Also queries (assignments).	NA	MM	(Cognitive) social learning theory, and Cognitive

							one year of specific experience in delivery of face-to-face CBT					behavioral theory
Payne et al. 2013	United States of America	Case study	End-stage renal disease	14-16	Individualized	Clinic	NA	Six modules: four individual and two joint (with parents). A quiz was given after each sesion to assess knowledge of skills before progressing to the next module.	Sessions were designed to identify and address knowledge, behavioral, and cognitive barriers to medication adherence. Session 1: knowledge and education about regimen, 2) sharing regimen responsibilities (joint session), 3) review of problem-solving skills and solutions (joint session), 4) role of cognitions as adherence barriers, 5) emotional regulation and coping skills to overcome barriers to adherence, 6) review of skills learned throughout intervention.	The intervention was completed in a minimum of 6 weeks. Including data collection, sessions lasted 60 to 90 minutes.	MM	Health Belief model

Pulgaron et al. 2010	United States of America	RCT	Asthma	10.4 yrs	Group sessions	Camp	Interventionists were clinical psychology graduate students, trained and supervised by two pediatric psychologists and an advanced graduate student; interventionists were not camp counselors.	Camping program with skills training sessions	Group discussion, modeling of how to apply the PAC-T, and role plays. Participants received personal manuals with blank fill-in sheets to list potential solutions to each problem.	NA	MM	NA
Raghavendra et al. 2013	Australia	Mixed methods	CP, physical disability or acquired brain injury	10-18	Individualized	Home	Speech pathologist and research assistants	Educational and skills training sessions	Focused on: identifying and evaluating the family's current computer and Internet access; teaching the youth and family about cyber safety including the use of filtering and privacy settings, the development of house rules for expected online behaviour, and explanations/ discussion of age-appropriate social media; providing appropriate software and	NA	RM	NA

									equipment based on the goals; providing training materials including visual supports or instructions as well as hands on training and practice to use the software, equipment or Internet; providing interface solutions, such as speech recognition software for text entry, word-prediction software or screen reading software. Training was framed to ensure youth accessed the identified web sites to engage in social networking with their peers, friends and families.			
Rami et al. 2006	Austria	RCT	Diabetes	10-19 yrs	Individualized	Online/Phone	NA	Telemedicine system (on phone)	Monitoring through daily diaries.	NA	MM	NA
Rhee et al. 2011	United States of America	RCT	Asthma	14.6 yrs	Group sessions	Camp	Peer leaders selected by school teachers/nurses or clinicians	Camping program	Peer leaders led group activities that involved discussion, strategic thinking, knowledge-testing games, and role playing.	Each session lasted approximately 45-60 minutes.	MM and RM	NA

Rhee et al. 2012	United States of America	RCT	Asthma	17.6 yrs	Training sessions	Camp	Peer leaders selected by school teachers/nurses or clinicians	Camping program	Disease-specific activities (sessions)	NA	NA	NA
Sattoe et al. 2013	Netherlands	Mixed methods	End-stage renal disease	16-25	Group	Camp	Pediatric nephrology health care professionals	Camping program: with different elements: workshop present yourself, movie making workshop, dancing workshop, sports, cooking teams, free time, theater performance by professional artists, art workshop, drumming workshop, acting workshop. Also: buddy-attendant concept (peer-to-peer support).	Aimed at independent living with ESRD and developing self-management skills, but no focus on disease-specific issues; about transition to adulthood in general, i.e. aimed at general competencies like self-confidence, self-efficacy etc.	Five days	RM+EM	NA
Shames et al. 2004	United States of America	RCT	Asthma	8.0 yrs	Individualized	Clinic, and home environment	Case manager, allergist / immunologist, and pediatric nurses	Educational and skills training sessions	Informational books, phone calls by interventionists, video game, asthma management plan	NA	MM	NA

Smith Fawzi et al. 2012	Haiti	Mixed methods	HIV	10-17 yrs	Group sessions	Clinic	Social workers	Family sessions (child-parent pairs)	Sharing experiences	The sessions were implemented over a one year period (held bi-monthly).	MM, RM and EM	(Cognitive) social learning theory
Staab et al. 2006	Germany	RCT	Atopic dermatitis (Eczemia)	8-18 yrs	Group sessions	Clinic	Dermatologists, pediatricians, psychologists, and dieticians	Educational sessions and skills training	Sharing experiences, practicing skills	NA	MM and EM	NA
Stinson et al. 2010	Canada	RCT	Juvenile Idiopathic Arthritis	15.6 yrs	Individualized, but contact with peers possible	Online	Trained coach: non healthcare professional with an undergraduate degree in psychology	Telemedicine system (web-based)	Goal-setting (diary), homework, knowledge quizzes, discussion board, feedback from coach	NA	MM, RM and EM	NA
Stulemeijer et al. 2005	Netherlands	RCT	Chronic Fatigue Syndrome	15.5 yrs	Individualized	Clinic	Child therapists who were trained and supervised by an experienced cognitive behavioral therapist	Cognitive-behavioral therapy sessions	NA	10 sessions	MM, RM and EM	Cognitive behavioral theory
Ten Hoedt et al. 2011	Netherlands	RCT	Phenylketonuria	15 yrs	Individualized	Online	Dietician	Telemedicine system (secured website)	Monitoring through daily diaries	NA	MM	NA

Torok et al. 2006[65]	Hungary	Cohort	Diabetes, oncologie	Oncologie 15.58 yrs; Diabetes 14.90 yrs	Group	Camp	NA	Camping program	Disease-specific activities and reinforcement of positive thinking.	2 separate 8-day sessions	NA	NA
Velsor-Friedrich et al. 2005	United States of America	RCT	Asthma	10.1 yrs	Group sessions, and invididualized nurse visit	School	Nurse practitioner	Educational sessions	Interactive teaching approach utilizing group discussion, stories, games, and role-play.	Six weekly sessions	MM and RM	Self-care theory
Verhoef et al. 2014	Netherlands	Cohort	Physical disability	16-25	Group and individual	Clinic (outpatient)	Occupational therapist, psychologist, jobcoach, social worker	Educational and skills training sessions	Group sessions provided information and discussion about work-related topics and aimed to increase insight into personal (dis)abilities, addressing work objectives, coping strategies (dis)abilities, addressing work objectives, coping strategies, occupational balance, finding a (suitable) job, how to present oneself at a job interview, and employment regulations and social security. In addition, group sessions offered opportunities to develop communication and	Group support programme consisting of six 2-hour sessions over 8 weeks.	RM and EM	Model of human occupation (MOHO)

									interaction skills, to share experiences, and to increase group members' self-efficacy. Homework assignments, for example preparing a self-presentation or preparation for a job interview, contributed to active participation and planning. Individual sessions: developing vocational skills and work routines, enhancing self-management skills, providing work placement opportunities and work experience, and advising on workplace modifications.			
Wang et al. 2008	United States of America	Cohort	Diabetes	14.0 yrs	Group sessions	Camp	Physician, medical students, and a dietitian	Camping program	Educational sessions	NA	MM	NA
Wysocki et al. 2007	United States of America	RCT	Diabetes	14.0 yrs	Family-centered	Clinic	Psychologists	Educational and skills training sessions	Problem solving training, communication training, and cognitive restructuring and functional-structural family therapy. Therapists participated actively, frequently	12 sessions over 6 months attended	MM and RM	NA

									providing instructions, feedback, modeling, and rehearsal. Also homework was given each session.			
Xenakis et al. 2010	United States of America	Cohort	Physical disabilities, 93% congenital	14-21 yrs	Individualized and group sessions	Clinic / Hospital based center	A program coordinator, instructors and tutors, a care assistant, and volunteers. The instructors, experts in their chosen fields, have prior experience working with adolescents and/or persons with physical disabilities	Educational sessions	Discussions, expressive arts, goal-setting, field trips (community recreation and learning institutions).	12 consecutive 2½-hour weekly sessions	MM, RM and EM	NA
Yoon et al. 2007	United States of America	Cohort	Sickle Cell Disease	10.7 yrs	Individualized	Clinic	NA	CD-ROM	Game with feedback	NA	MM	Gaming theory

*Abbreviations: NA=Not available (meaning this information couldn't be derived from the original research article); RCT=Randomized Controlled Trial; SM=Self-management; MM=Medical management; RM=Role management; EM=Emotion management

Table A.2 Overview of outcome measures used in the evaluation studies*

Groups of outcomes	Specific outcomes	References
Health outcomes	Clinical outcomes (e.g. blood glucose levels, peak expiratory flow rate or pulmonary functioning, BMI, fatigue)	[27, 30, 38, 39, 41, 44-47, 51-53, 55-57, 64, 66, 99, 101]
	Number of (outpatient) clinic visits or disease-related emergency department visits	[35, 39, 44, 64, 105]
	Hospitalizations (due to chronic condition)	[35]
	Frequency or intensity of disease-specific symptoms, i.e. morbidity (e.g. asthma episodes or pain)	[28-33, 35, 36, 38, 39, 41-45, 66, 73-77, 83, 91, 93, 96, 100, 105, 109]
	Activity limitations or functional or disease-related disability / perceived difficulty in performing daily activities	[73, 75, 77, 91, 93-95]
	Medication or treatment adherence or usage	[31, 34, 35, 38, 41, 44, 46, 55-57, 64, 79, 85, 90, 96, 101]
	Self-perceived health status	[41]
	Somatic awareness	[74]
	Disease-specific coping (e.g. coping with pain during SCD-related pain episodes)	[95, 105]
	Functional health status / Physiologic health status / Physical functioning or activity	[64, 66, 74, 81,94, 99]
	Condition-related disability	[100]
	Goal status in individual health and wellness planning	[103]
	General satisfaction with health	[40]
	Condition-specific goals	[11]
	Risk behavior (e.g. smoking)	[35]
Self-care	Self-care behavior or practice	[39, 44, 46, 110]
	Disease-related skills	[65]
	Independent health behavior (e.g. self-medication or independent consultations)	[98]
	Motivation, knowledge, skills and abilities for self-care	[39]
	Disease-related self-regulation	[33]
Self-efficacy	Disease-related self-efficacy	[28, 32, 39, 44, 46, 51, 55, 59, 63, 64, 86, 96, 109]
	Self-efficacy related to managing interactions with healthcare providers	[105, 86
	General self-efficacy	[67, 86]
	Outcome expectations of disease-related self-management	[59]
Self-perception	Confidence regarding disease-specific management	[108]
	Self-rated competence in the areas of (a) scholastic work, (b) social acceptance, (c) athletic ability, (d) physical appearance, (e) behavioral conduct, and (f) global self-worth	[107]
Sense of control	Sense or locus of control	[63, 64]
	Role mastery	[110]

Groups of outcomes	Specific outcomes	References
Psychological outcomes	Depressive symptoms / depression	[51, 56, 61, 71, 74, 75, 78, 93-95]
	Anxiety or (dis)stress	[41, 62, 64, 71, 73, 74, 96]
	Catastrophic thinking about the condition	[74]
	Psychological symptoms	[89]
	Self-esteem	[39, 67, 71]
	Body image	[62]
Psychosocial functioning	Psychosocial adjustment	[29, 81]
	Developmental goals	[102]
	Psychosocial functioning	[49, 89, 99]
Coping	Coping or coping styles	[51, 63, 71]
	Adaptive and maladaptive behaviors and emotions	[42]
	Coping abilities/competencies and resourcefulness or coping styles	[40, 42, 44, 82]
	Internalizing and externalizing behavior	[61]
Health-related quality of life or subjective wellbeing	(Health-related) Quality of Life (generic)	[37, 54, 64, 69, 86, 93, 104]
	Disease-specific health-related quality of life	[27, 28, 30, 32, 33-36, 42-44, 46, 47, 51, 55, 56, 59, 61, 63, 76, 93, 96, 98]
	Subjective wellbeing	[110]
Vocational participation	School functioning (absence/attendance or grades)	[35, 43, 66, 73, 74, 105, 107, 109]
	Academic performance	[43]
	Occupational performance / work participation	[104]
	Pre-vocational experience	[98]
	Social and academic activities competencies	[61]
	Occupational problems	[102, 104]
Social participation	Challenges / problematic situations encountered in different life areas	[70, 82]
	Days of changed plans	[35]
	Physical, emotional and behavioral concerns related to certain life areas	[62]
	(Autonomy in) participation in several life areas (e.g., living and romantic relationships)	[67, 72, 109]
	(Influence on) daily life with the condition	[47, 86]
	Social skills	[61, 92, 112]
	Social goals / goal attainment	[111, 112]
	Social acceptance by peers	[112]
	Dating	[62]
	Independence	[112]
	Parent involvement in diabetes care	[54]
	Family functioning	[51]

Groups of outcomes	Specific outcomes	References
Family involvement or conflict (related to disease-related management tasks)	Division/sharing of responsibility, conflict or interaction within families related to disease specific tasks (e.g. blood glucose monitoring or insulin injections)	[46, 54, 57, 60, 85, 111, 112]
Support by others	Perceived support	[80]
	Social support by family and friends	[89]
Others (not included in groups)	Knowledge of the disease and/or treatment	[28, 32, 34, 36-39, 44, 49, 53, 62-64, 79, 82, 90, 92, 96, 98, 105, 107, 108, 111]
	Attitudes towards illness	[27, 78, 79, 86]
	Problem solving	[37, 78]

*Outcomes considering satisfaction with the intervention and proxy outcomes were not included in the analyses of outcome measures