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Review article

Exploring effectiveness and effective components of self-management interventions for young people with chronic physical conditions: A systematic review

Marjolijn I. Bal[a,b,*], Jane N.T. Sattoe[a,c], Pepijn D.D.M. Roelofs[a], Roland Bal[c], AnneLoes van Staa[a,c], Harald S. Miedema[a]

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

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ABSTRACT

Objective: To systematically explore the effectiveness and effective components of self-management interventions.
Methods: Study selection criteria were: Original articles in English published between 2003 and 2015; focusing on youth with chronic conditions; describing self-management interventions; with clear outcome measures; using RCT design. The random effects analysis was applied in which standardized mean differences per study were calculated.
Results: 42 RCTs were included. Interventions focused on medical management, provided individually in clinical settings or at home by mono-disciplinary teams showed a trend in improving adherence. Interventions delivered individually at home by mono-disciplinary teams showed a trend in improving dealing with a chronic condition.
Conclusions and practical implications: Adherence could be improved through interventions focused on medical management, provided individually in a clinical or home setting by a mono-disciplinary team. Interventions focused on dealing with a chronic condition might be provided individually, through telemedicine programs facilitating peer-support. These intervention elements seemed effective irrespective of diagnosis, and may therefore act as good starting points for further research into and for improvement of self-management support for youth with chronic conditions in pediatric care. Results underlined the need to systematically develop and evaluate self-management interventions, since this may provide more evidence for effectiveness and effective intervention components.
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* Corresponding author at: Rotterdam University of Applied Sciences, Research Center Innovations in Care, P.O. Box 25035, 3001 HA Rotterdam, The Netherlands.
E-mail addresses: m.i.bal@hr.nl (M.I. Bal), j.n.t.sattoe@hr.nl (J.N.T. Sattoe), p.d.d.m.roelofs@hr.nl (P.D.D.M. Roelofs), r.bal@bmg.eur.nl (R. Bal), a.van.staa@hr.nl (A. van Staa), h.s.miedema@hr.nl (H.S. Miedema).

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1. Introduction

Advancements in medical care result in increasing numbers of young people with chronic conditions making the transition into adulthood [1,2]. This transition, which implies becoming an independent adult fulfilling different roles in society, requires complicated life changes [3,4]. For these young people the transition may be more complicated, however, as they often lag behind in social and emotional development compared to healthy peers [5,6]. Furthermore, they are expected to take over the task of medical management from their parents, but this does not always come with ease [7,8]. It seems crucial, therefore, to help them develop self-management skills in all life areas [9–11]. Barlow et al. define self-management 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]". As such, self-management and self-management support encompass three elements: medical management (considering the treatment), role management (considering participation in society), and emotion management (considering emotional consequences of being ill) [13]. This broad definition of self-management is widely used, as it fits with the World Health Organization's definition of health in terms of physical, mental and social well-being [14].

A range of interventions is available for healthcare providers to support young people's self-management in chronic disease [9–11,15,16]. These interventions are developed for young people aged between 7 and 25 years. The age of seven years is considered as a developmentally appropriate age to start the development of independence and young adults are still developing their full potential [17,18,19]. Self-management interventions have been reviewed in some studies [20,21], but solid evidence on effectiveness of self-management interventions (SMI) for young people with chronic conditions in general, i.e. irrespective of diagnosis, is still lacking [20–26]. Specifically, Kirk et al. [21] restricted themselves to asthma, cystic fibrosis and diabetes, while Lindsay et al. [20] restricted themselves to physical disabilities, excluding people with somatic chronic conditions. Moreover, although Kirk et al. [21] reviewed effective components of SMI for young people with asthma, cystic fibrosis and diabetes, insights into effective intervention components of self-management support for young people with a variety of chronic conditions are still lacking [20].

Still, looking at self-management support through a non-categorical approach is important [27]. Despite disease-specific differences, there are many commonalities between young people with chronic conditions, as they face comparable challenges and similar adaptive tasks while growing up [22]. A non-categorical approach to self-management support may benefit both health service delivery and research [28]. First, because it could allow pediatric teams to learn from other specialist teams, for instance by using (partly) the same SMI. Second, it could stimulate the use of same outcomes measures, which could enhanced the evaluation of effectiveness of these programs [28].

In a parallel paper including SMI evaluation studies using all kinds of study designs, a systematic overview of self-management support for youth with chronic conditions in general with respect to content, formats, theories, and evaluated outcomes is provided [29]. This systematic overview showed that most interventions were aimed at medical management, and that no theoretical base was provided for most of the included interventions. Although a variety of outcomes was evaluated, outcomes were conceptually related to specific content [29]. No results about effectiveness of SMI were included in this overview. Therefore, in the current paper, we reviewed published randomized controlled trials (RCT) of these SMI elaborating on (a) evidence regarding effectiveness of SMI focused on youth with chronic conditions; and (b) effective intervention components of these SMI, by employing a non-categorical approach to chronic conditions. Such insights may provide understanding of what elements of self-management support might be effective across a variety of chronic physical conditions, and hence may be valuable to further improve self-management support in health care.

2. Methods

2.1. Study design

We applied a systematic review methodology which Grant and Booth defined as "systematically searching for, appraising and synthesizing research evidence, often adhering to guidelines for conducting a review" [30]. Methodological characteristics according to the 'Search, Appraisal, Synthesis and Analysis' (SALSA) framework are: exhaustive and comprehensive searching, quality assessment, narrative synthesis with tabular accompaniment, results of uncertainty around findings, recommendations for practice and future research [30]. This type of review allows for exploration of effects and effective intervention components of self-management support. The PRISMA statement guided the review process [31].

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2.2. Search strategy

The search strategy employed variations and Boolean connections (AND, OR) of subject headings and keywords relating to self-management, children and adolescents, chronic illness, and intervention. For example, MESH terms (Medical Subject Headings) included: "Self care", "Self medication", "Intervention studies", Program evaluation", "Chronic disease", "Disabled person", "Adolescence", "Child". Key words included: "self help" "clinical effectiveness"; "evaluation"; "congenital disorder"; "handicapped child"; "youth"; "teenage". Relevant variations of search terms were derived from database thesauruses and relevant review articles. An information specialist helped define the final search strategy. Six databases were searched: Embase; Medline; PsycINFO; Web-of-Science; CINAHL; and Cochrane. Two researchers (MB; JS) completed the database searches by scrutinizing relevant reviews' references for additional relevant publications.

2.3. Inclusion criteria

- Study design: studies using a randomized controlled study design.
- Study types: original research articles in English language published from 2003 to April 2015, because the focus in literature on self-management rapidly increased since 2003 [32].
- Interventions: studies focusing on the evaluation of SMI and describing the SMI or referring to previous description(s) of the intervention.
- Outcome measures: studies considering clearly defined outcome measures.
- Participants: studies focusing on young people aged 7–25 years with somatic chronic conditions or physical disability. The age of seven years is considered a developmentally appropriate age to start the development of independence [17]. As young adults are still developing their full potential, the age range was extended from 18 to 25 years [18,19].

Studies had to meet all inclusion criteria to be included for further analysis.

2.4. Selection, quality assessment, and data extraction

Retrieved records ($n = 7505$) identified in databases and relevant reviews' reference lists were imported into Endnote X7.2®. Two reviewers (MB, JS) independently categorized studies into: 'include', 'exclude' or 'not clear' based on title and abstract. Thereafter, the reviewers discussed the studies for which inclusion/exclusion was unclear and aimed to reach consensus on the decision. If doubt remained, a third reviewer was consulted (PR). Full texts of all agreed-upon articles ($n = 562$) were retrieved. Then, the two reviewers independently decided on the inclusion of articles based on the full text, resulting in 85 publications. For this paper we were interested in effects and effective intervention components, in contrast to the parallel paper [29], and therefore selected studies with RCT design ($n = 42$) from the included publications. The selection process and reasons for exclusion are presented in Fig. 1. Three reviewers (MB, JS, PR) independently assessed methodological quality of all included studies using the methodology checklists of the Scottish Intercollegiate Guidelines Network (SIGN) for randomized controlled trials [33]. Methodological quality was defined as high when at least eight out of ten criteria were met; as moderate when from five till eight were met; and as low when fewer than five criteria were met [33]. Any discrepancies in assessment of methodological quality were resolved by discussion. Two reviewers (MB, JS) extracted data on study design; study sample; self-management domain considered during the intervention; interventions' theoretical base, format, discipline, interventionist, element, setting, outcome measures and study results [34]. Data was recorded on an electronic extraction form.

2.5. Analysis

The following seven categories of outcome measures were inductively derived from the data: (1) symptoms; (2) disease knowledge; (3) adherence; (4) dealing with the chronic condition (including self-efficacy, coping and problem-solving); (5) psychological outcomes (including depression, stress, anxiety); (6) school attendance; and (7) quality of life. The reviewers (MB, JS) independently clustered the specific study outcome measures into these categories.

The overall quality of evidence for each outcome measure was independently rated by two researchers (MB&JS) using the GRADE approach, a method for rating the quality of evidence and grading the strength of recommendations per particular outcome [35]. Basically, evidence of randomized controlled trials (RCT's) is rated as high but may be modified downwards on the basis of five different criteria: (1) risk of bias: assessment of methodological quality; (2) inconsistency: heterogeneity or variability in results across studies; (3) indirectness of evidence: indirect comparison of interventions within the studies; (4) imprecision of results: wide confidence intervals around the estimate of the effect; and (5) likeliness of publication bias: underestimating or overestimating of the effect due to the selective publication of studies [36–40]. Problems on a criterion was defined as serious when 60–80% of the studies showed limitations, and very serious when >80% of the studies showed limitations on the criterion. The quality of evidence per outcome measure (high) was single downgraded for serious study limitations to moderate quality of evidence, and double downgraded for very serious study limitations to low quality of evidence.

Analyses to explore the effectiveness and the effective intervention components of self-management support were performed for each outcome measure separately. The random effects analysis was applied in which standardized mean differences per study were calculated [41]. In this way, we could compare effect sizes of statistically heterogeneous studies and provide an overview of effects on an outcome measure measured with different measurement instruments. Pooled estimates were not calculated, because interventions were clinically diverse, i.e. consisted of different intervention elements, and studies were statistically diverse, i.e. different instruments were used to evaluate the interventions. In addition, to evaluate the effective intervention components, we compared the effect sizes of included studies that differed on particular intervention components. For instance, effect sizes of individual intervention programs were compared with effect sizes of group intervention programs. Likewise, effect sizes of interventions focusing on different self-management domains, or provided by different disciplines, interventionists, and in various settings were compared. We speak of 'a trend in favor of', because we could not perform a meta-analysis (due to the heterogeneity in measurement instruments) and thus cannot state whether an intervention or its components are indeed effective or not. We only described a pattern of effects when *at least* three studies were included, and used the cut-off point of two out of three studies (67%) as a minimum number of studies indicating effects in the same direction. Otherwise, the pattern was described as showing no clear effects. When drawing conclusions, we downgraded the level of evidence for those issues where the number of available studies was low [38]. Individual studies that showed a significant effect were weighted twice and individual studies that showed a trend (but not a significant effect)

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were weighted once. Review Manager version 5.1 software was used for the analyses.

3. Results

3.1. Paralell paper

A detailed overview of the focus and content of the interventions presented in the parallel paper, showed a variety in the operationalization of self-management support [29]. Most SMI were aimed at medical management, neglecting psychosocial challenges. Although a variety of outcomes was evaluated, outcomes were conceptually related to specific content [29]. In order to explore the effectiveness and effective components of SMI, we selected the studies with RCT-design from the included studies ($n = 42$). In the current paper results on effectiveness and effective components of SMI are described.

3.2. General study characteristics (n = 42)

- Countries: Most, studies were performed in the USA ($n = 27$), followed by Australia ($n = 3$), Canada ($n = 2$), Taiwan ($n = 2$), the Netherlands ($n = 2$), the United Kingdom ($n = 2$), China ($n = 1$), Germany ($n = 1$), and Jordan and Australia ($n = 1$).
- Chronic conditions: Study participants were patients with asthma ($n = 16$), diabetes ($n = 6$), cystic fibroses ($n = 3$), cancer ($n = 2$), human immunodeficiency virus infection ($n = 2$), sickle cell disease ($n = 2$), or other diseases (e.g. spina bifida, haemophilia and juvenile fibromyalgia) ($n = 9$).
- Methodologicalquality: The methodological quality of 25 studies was rated as moderate, of 11 studies as high and of 6 studies as low.

3.3. Intervention components (n = 42)

Many interventions were solely aimed at medical management (61.9%). Medical management was either disease-specific or more general. Disease-specific medical management refers to tasks or topics associated with or related to a specific diagnosis, e.g. self-monitoring of blood glucose values in diabetes. 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. One intervention considered only role management (2.4%), referring to topics related to social participation, such as communicating, assertiveness and keeping up with peers. None of the interventions considered emotion management separately. Interventions considering emotion management could refer to young person's feelings and intrinsic characteristics. Topics covered are stress-management and relaxation techniques. The other interventions addressed multiple domains, for example both on medical and role management (35.7%). Studies did not mention a theoretical base for the intervention (64.3%), referred to learning

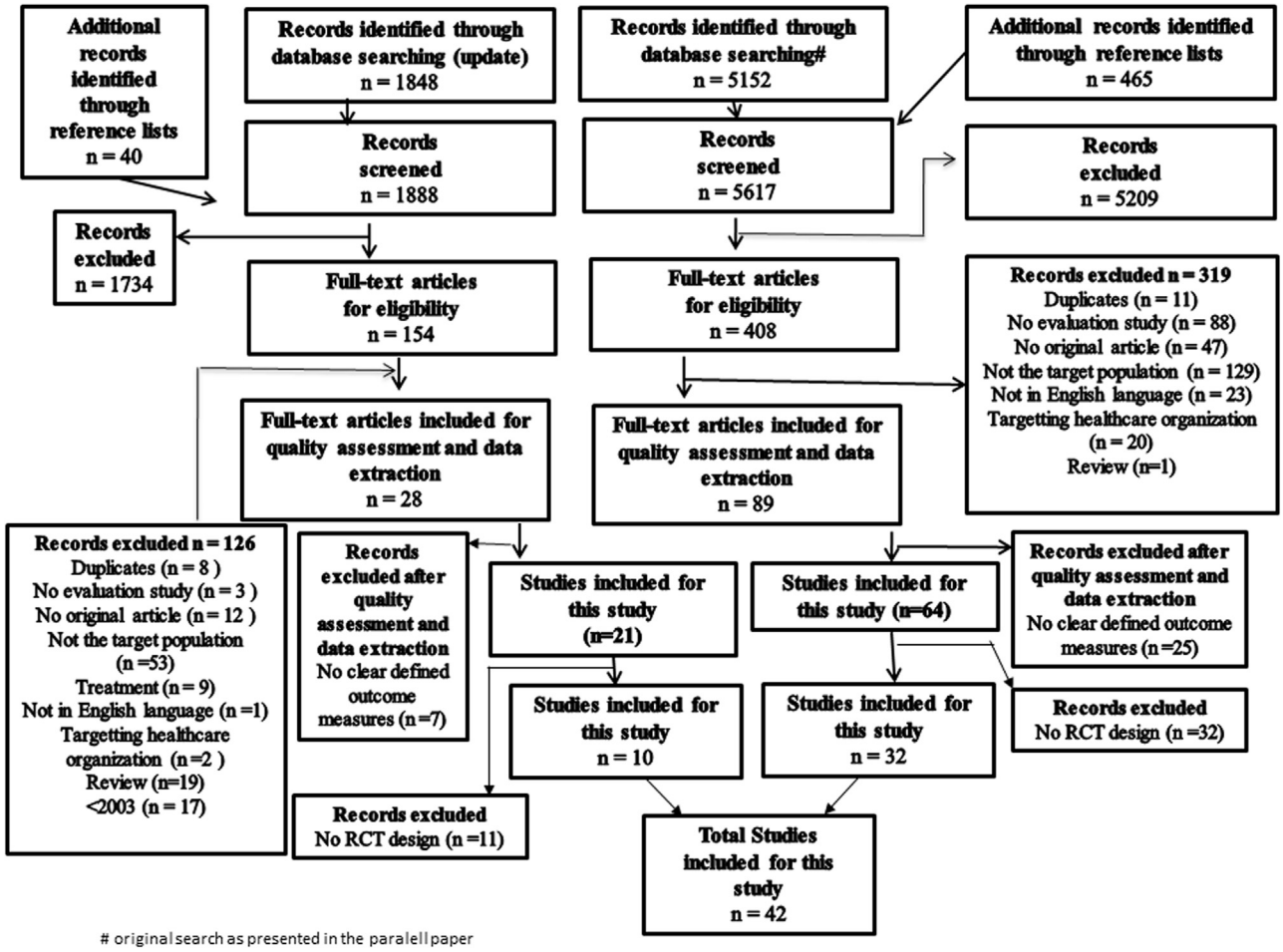


Fig. 1. Selection process.

theories like Bandura's (cognitive) social learning theory (11,9%), cognitive behavioral theory (4,4%) or a combination of these (2,4%). Interventions were either applied at individual level (69.0%), at group level (23.8%) or both (7.1%). Most interventions were provided by a mono-disciplinary team (70%). Interventions included education (88.1%), peer-support (23.8%), problem solving (23.8%), relaxation training (21.4%), cognitive restructuring (e.g. cognitive behavioral therapy) (19.0%), or self-monitoring, (e.g. keeping a diary with blood glucose values) (19.0%). In general, neither the domain of self-management considered during interventions nor the other intervention elements were specifically linked to certain theoretical frameworks. Intervention settings were inpatient or outpatient clinics (31.0%), home (23.8%), online (14.3%), school (14.3%), home and clinic (7.1%), camping sites (4.8%), or home and school (2.3%). Settings were not exclusive for formats and elements of interventions.

A detailed description of study characteristics and intervention components per study is presented in Appendix A.

3.4. Exploration of effectiveness and effective components of self-management interventions

3.4.1. Outcome measure symptoms

Twenty-four studies focused on the severity of symptoms as an outcome measure [43,49–51,54,56,58–60,63–67,70,72,74,76–83]. In general, SMI showed a trend in favor of the control condition. Specifically, nine studies showed a trend in favor of intervention; twelve studies reported a trend in favor of the control condition; and three studies showed a significant effect in favor of the control condition. The quality of evidence was very low (Table 1).

Of all interventions that aims to reduce the severity of symptoms, the interventions focused on medical management, medical and role management, or medical management, emotion management and role management showed a trend in favor of the control condition. The same pattern held for interventions delivered by a psychologist. Also, interventions provided in a clinic, online, or at home and in a clinic showed a trend in favor of the control condition. In contrast, interventions provided at home showed a trend in favor of intervention (Fig. 2a–c).

3.4.2. Outcome measure disease knowledge

Nineteen studies focused on disease knowledge as an outcome measure [42,43,45,47,48,52–55,57,61–63,66,71,73,76,78,82]. In general, SMI showed a trend in favor of intervention. Specifically, nine studies revealed a significant effect in favor of intervention; five studies showed a trend in favor of intervention and five studies showed a trend in favor of the control condition. The quality of evidence was moderate (Table 1).

Of all interventions that aims to improve disease knowledge, interventions focused on medical management, or medical management, emotional management and role management, showed a trend in favor of intervention. The same pattern revealed for interventions provided individually and interventions provided in a clinic or at home. Mono-disciplinary interventions showed a trend in favor of the control condition, but this was also the case for multi-disciplinary interventions (Fig. 3a and b).

3.4.3. Outcome measure adherence

Nine studies focused on adherence as an outcome measure [45,53,54,61,67,68,78,82,83]. Overall, SMI showed a positive trend on adherence. Specifically, four studies showed a significant effect in favor of intervention, five other studies showed a positive tendency. The quality of evidence was very low (Table 1).

Of all interventions that aims to improve adherence, interventions focused on medical management showed a trend in favor of intervention. The same pattern held for interventions provided individually and in a clinic or at home and interventions delivered mono-disciplinary (Fig. 4a and b).

3.4.4. Outcome measure dealing with the chronic condition in daily life

Eleven studies focused on dealing with the chronic condition in daily life as an outcome measure [42,43,47,48,52,54,57,61,69,73,78]. Overall, no clear effects of SMI were found on dealing with the chronic condition in daily life. Specifically, two studies had a significant effect in favor of intervention; five studies had a trend in favor of intervention. In contrast, three studies revealed a trend in favor of the control condition and one study showed a significant effect in favor of the control condition. The quality of evidence was very low (Table 1).

Of all interventions that aims to improve dealing with chronic condition in daily life, interventions focused on medical management, showed a trend in favor of intervention. The same pattern

Table 1
Evidence profile.

Outcome (no. of studies)	Quality assessment					Number of patients		Quality of the evidence
	Limitation in design	Inconsistency	Indirectness	Imprecision	Publication bias	C[a]	I[b]	
Symptoms (24)	No serious limitation	Serious inconsistency	No serious indirectness	Very serious imprecision	Unlikely	1019	1085	Very low
Disease knowledge (19)	No serious limitation	Serious inconsistency	No serious indirectness	No serious imprecision	Unlikely	771	626	Moderate
Adherence (9)	No serious limitation	Serious inconsistency	No serious indirectness	Very serious imprecision	Unlikely	333	387	Very low
Dealing with chronic condition in daily life (11)	No serious limitation	Very serious inconsistency	No serious indirectness	Serious imprecision	Unlikely	395	535	Very low
Psychological outcomes (9)	No serious limitation	Serious inconsistency	No serious indirectness	Very serious imprecision	Unlikely	367	378	Very low
School attendance (5)	Serious limitation	Serious inconsistency	Very serious indirectness	No serious imprecision	Unlikely	305	285	Very low
Quality of life (13)	No serious limitation	No serious inconsistency	No serious indirectness	No serious imprecision	Unlikely	705	757	High

[a] Number of patients that participated in the control condition.
[b] Number of patients that participated in the intervention condition.

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A

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Std. Mean Difference IV, Random, 95% CI
1.1.1 MM							
Palermo et al. 2009 (H)	3.54	2.42	23	4.76	1.84	21	-0.55 [-1.16, 0.05]
Laffel et al. 2003 (M)	8.2	1.1	50	8.7	1.5	50	-0.38 [-0.77, 0.02]
Shames et al. 2004 (M)	267.4	118.6	59	294.5	123.9	60	-0.22 [-0.58, 0.14]
Joseph et al. 2007 (M)	2.1	3	162	2.8	3.4	152	-0.22 [-0.44, 0.00]
Chiang et al. 2009 (M)	6.93	1.51	20	7.24	1.71	17	-0.19 [-0.84, 0.46]
Kashikar et al. 2012 (H)	4.9	2.2	57	5.3	2.1	55	-0.18 [-0.56, 0.19]
Krishna et al. 2003 (M)	39.4	71.2	67	53.7	89.3	84	-0.17 [-0.50, 0.15]
Franklin et al. 2006 (M)	10.1	1.7	32	10.3	1.7	27	-0.12 [-0.63, 0.40]
Kumar et al. 2004 (M)	7.9	1.1	18	8	0.7	19	-0.11 [-0.75, 0.54]
Walders et al. 2006 (M)	0.81	0.74	61	0.79	0.83	63	0.03 [-0.33, 0.38]
Jan et al. 2007 (M)	0.07	0.24	82	0.05	0.17	71	0.09 [-0.22, 0.41]
Mcpherson et al. 2006 (M)	3.97	13.99	50	2.41	13.46	51	0.11 [-0.28, 0.50]
Mulvaney et al. 2010 (M)	9.1	1.8	34	8.5	1.3	18	0.36 [-0.22, 0.93]
Barakat et al. 2010 (L)	16.71	23.03	13	7.84	12.31	21	0.51 [-0.20, 1.21]
Wiecha et al. 2005 (L)	1.5	1.09	28	0.9	1.09	14	0.54 [-0.11, 1.19]
1.1.2 RM							
Christian et al. 2006 (H)	83.78	17.73	58	80.43	18.68	58	0.18 [-0.18, 0.55]
1.1.3 MM + EM							
Staab et al. 2006 (M)	23.4	12.6	70	35.2	15.2	50	-0.85 [-1.23, -0.47]
Connelly et al. 2006 (H)	72.97	84.99	17	117.31	91.23	20	-0.49 [-1.15, 0.17]
1.1.4 MM + RM							
Wysocki et al. 2007 (M)	8.8	1.5	28	9.1	1.8	26	-0.18 [-0.71, 0.36]
Velsor et al. 2005 (L)	0.2621	0.22	28	0.278	0.31	24	-0.06 [-0.60, 0.49]
Rhee et al. 2011 (M)	100.8	13.7	43	97.7	11	41	0.25 [-0.18, 0.68]
1.1.5 MM + EM + RM							
Stule. et al. 2005 (H)	30.2	16.8	35	44	13.4	34	-0.90 [-1.39, -0.40]
Stinson et al. 2010 (H)	2.17	1.34	22	3.47	2.12	24	-0.71 [-1.31, -0.12]
Ng et al. 2008 (M)	110.33	13.17	18	104.64	15.97	14	0.38 [-0.32, 1.09]
1.2.1 Individual							
Stule. et al. 2005 (H)	30.2	16.8	35	44	13.4	34	-0.90 [-1.39, -0.40]
Walders et al. 2006 (M)	2.17	1.34	22	3.47	2.12	24	-0.71 [-1.31, -0.12]
Shames et al. 2004 (M)	3.54	2.42	23	4.76	1.84	21	-0.55 [-1.16, 0.05]
Connelly et al. 2006 (H)	72.97	84.99	17	117.31	91.23	20	-0.49 [-1.15, 0.17]
Laffel et al. 2003 (M)	8.2	1.1	50	8.7	1.5	50	-0.38 [-0.77, 0.02]
Stinson et al. 2010 (H)	267.4	118.6	59	294.5	123.9	60	-0.22 [-0.58, 0.14]
Joseph et al. 2007 (M)	2.1	3	162	2.8	3.4	152	-0.22 [-0.44, 0.00]
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Palermo et al. 2009 (H)	1.84	1.33	33	1.6	1.16	37	0.19 [-0.28, 0.66]
Mulvaney et al. 2010 (M)	9.1	1.8	34	8.5	1.3	18	0.36 [-0.22, 0.93]
Barakat et al. 2010 (L)	16.71	23.03	13	7.84	12.31	21	0.51 [-0.20, 1.21]
Wiecha et al. 2005 (L)	1.5	1.09	28	0.9	1.09	14	0.54 [-0.11, 1.19]
1.2.2 Group							
Staab et al. 2006 (M)	23.4	12.6	70	35.2	15.2	50	-0.85 [-1.23, -0.47]
Rhee et al. 2011 (M)	100.8	13.7	43	97.7	11	41	0.25 [-0.18, 0.68]
Ng et al. 2008 (M)	110.33	13.17	18	104.64	15.97	14	0.38 [-0.32, 1.09]
1.2.3 Individual + group							
Velsor et al. 2005 (L)	0.2621	0.22	28	0.278	0.31	24	-0.06 [-0.60, 0.49]
Christian et al. 2006 (H)	83.78	17.73	58	80.43	18.68	58	0.18 [-0.18, 0.55]

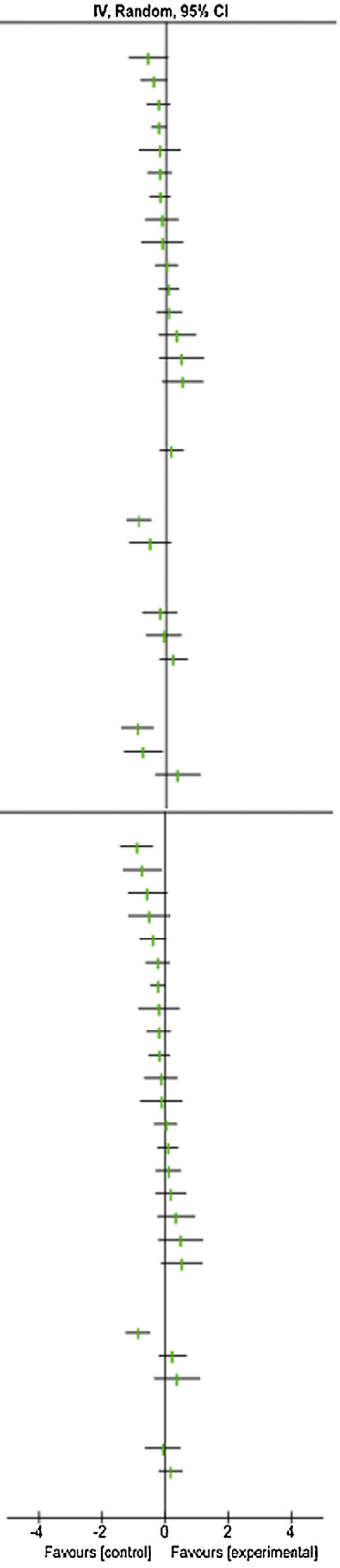


Fig. 2. (A) Effectiveness of intervention component domain of self-management and format on symptom reduction. (B) Effectiveness of intervention component discipline and setting on symptom reduction. (C) Effectiveness of intervention component interventionists on symptom reduction.

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B

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Std. Mean Difference IV, Random, 95% CI
1.3.1 Monodisciplinary							
Stule. et al. 2005 (H)	30.2	16.8	35	44	13.4	34	-0.90 [-1.39, -0.40]
Stinson et al. 2010 (H)	2.17	1.34	22	3.47	2.12	24	-0.71 [-1.31, -0.12]
Palermo et al. 2009 (H)	3.54	2.42	23	4.76	1.84	21	-0.55 [-1.16, 0.05]
Laffel et al. 2003 (M)	8.2	1.1	50	8.7	1.5	50	-0.38 [-0.77, 0.02]
Chiang et al. 2009 (M)	6.93	1.51	20	7.24	1.71	17	-0.19 [-0.84, 0.46]
Kashikar et al. 2012 (H)	4.9	2.2	57	5.3	2.1	55	-0.18 [-0.56, 0.19]
Wysocki et al. 2007 (M)	8.8	1.5	28	9.1	1.8	26	-0.18 [-0.71, 0.36]
Velsor et al. 2005 (L)	0.2621	0.22	28	0.278	0.31	24	-0.06 [-0.60, 0.49]
Barakat et al. 2010 (L)	16.71	23.03	13	7.84	12.31	21	0.51 [-0.20, 1.21]
1.3.2 Multidisciplinary							
Staab et al. 2006 (M)	23.4	12.6	70	35.2	15.2	50	-0.85 [-1.23, -0.47]
Shames et al. 2004 (M)	267.4	118.6	59	294.5	123.9	60	-0.22 [-0.58, 0.14]
Krishna et al. 2003 (M)	39.4	71.2	67	53.7	89.3	84	-0.17 [-0.50, 0.15]
Franklin et al. 2006 (M)	10.1	1.7	32	10.3	1.7	27	-0.12 [-0.63, 0.40]
Walders et al. 2006 (M)	0.81	0.74	61	0.79	0.83	63	0.03 [-0.33, 0.38]
Wiecha et al. 2005 (L)	1.5	1.09	28	0.9	1.09	14	0.54 [-0.11, 1.19]
1.4.1 Clinic							
Stule. et al. 2005 (H)	30.2	16.8	35	44	13.4	34	-0.90 [-1.39, -0.40]
Staab et al. 2006 (M)	23.4	12.6	70	35.2	15.2	50	-0.85 [-1.23, -0.47]
Laffel et al. 2003 (M)	8.2	1.1	50	8.7	1.5	50	-0.38 [-0.77, 0.02]
Kashikar et al. 2012 (H)	4.9	2.2	57	5.3	2.1	55	-0.18 [-0.56, 0.19]
Wysocki et al. 2007 (M)	8.8	1.5	28	9.1	1.8	26	-0.18 [-0.71, 0.36]
Krishna et al. 2003 (M)	39.4	71.2	67	53.7	89.3	84	-0.17 [-0.50, 0.15]
Franklin et al. 2006 (M)	10.1	1.7	32	10.3	1.7	27	-0.12 [-0.63, 0.40]
Walders et al. 2006 (M)	0.81	0.74	61	0.79	0.83	63	0.03 [-0.33, 0.38]
Jan et al. 2007 (M)	0.07	0.24	82	0.05	0.17	71	0.09 [-0.22, 0.41]
Ng et al. 2008 (M)	110.33	13.17	18	104.64	15.97	14	0.38 [-0.32, 1.09]
1.4.2 Home							
Connelly et al. 2006 (H)	72.97	84.99	17	117.31	91.23	20	-0.49 [-1.15, 0.17]
Mcpherson et al. 2006 (M)	3.97	13.99	50	2.41	13.46	51	0.11 [-0.28, 0.50]
Barakat et al. 2010 (L)	16.71	23.03	13	7.84	12.31	21	0.51 [-0.20, 1.21]
Wiecha et al. 2005 (L)	1.5	1.09	28	0.9	1.09	14	0.54 [-0.11, 1.19]
1.4.3 Online							
Stinson et al. 2010 (H)	2.17	1.34	22	3.47	2.12	24	-0.71 [-1.31, -0.12]
Palermo et al. 2009 (H)	3.54	2.42	23	4.76	1.84	21	-0.55 [-1.16, 0.05]
Kumar et al. 2004 (M)	7.9	1.1	18	8	0.7	19	-0.11 [-0.75, 0.54]
Mulvaney et al. 2010 (M)	9.1	1.8	34	8.5	1.3	18	0.36 [-0.22, 0.93]
1.4.4 Home + clinic							
Shames et al. 2004 (M)	267.4	118.6	59	294.5	123.9	60	-0.22 [-0.58, 0.14]
Chiang et al. 2009 (M)	6.93	1.51	20	7.24	1.71	17	-0.19 [-0.84, 0.46]
Christian et al. 2006 (H)	83.78	17.73	58	80.43	18.68	58	0.18 [-0.18, 0.55]
1.4.5 School							
Joseph et al. 2007 (M)	2.1	3	162	2.8	3.4	152	-0.22 [-0.44, 0.00]
Velsor et al. 2005 (L)	0.2621	0.22	28	0.278	0.31	24	-0.06 [-0.60, 0.49]
1.4.6 Camp							
Rhee et al. 2011 (M)	100.8	13.7	43	97.7	11	41	0.25 [-0.18, 0.68]

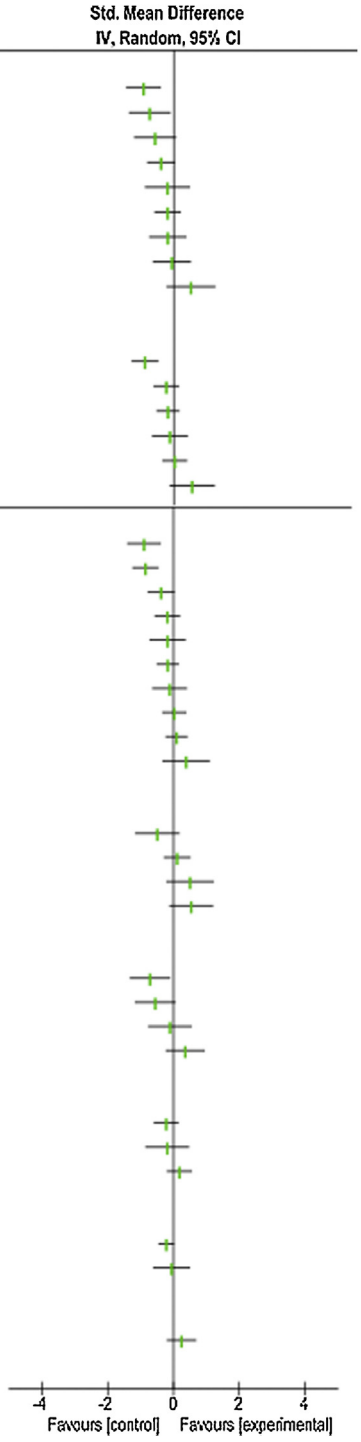


Fig. 2. (Continued)

held for mono-disciplinary interventions provided individually and at home. In contrast, interventions provided online showed a trend in favor of the control condition (Fig. 5a and b).

3.4.5. Outcome measure psychological outcomes

Nine studies focused on psychological outcomes [44,46,49,59–61,69,72,75,78]. In general, no clear effects of SMI were found on this outcome measure. Specifically, one study had a significant effect in favor of intervention; two studies showed a positive tendency; and six others showed a trend in favor of the control condition. The quality of evidence was very low (Table 1).

Of all interventions that aims to improve psychological outcomes, interventions focused on medical management, showed a trend in favor of the control condition. The same pattern was revealed for mono-disciplinary interventions and interventions provided individually by a psychologist and online. In contrast, interventions provided in groups showed a trend in favor of intervention (Fig. 6a–c).

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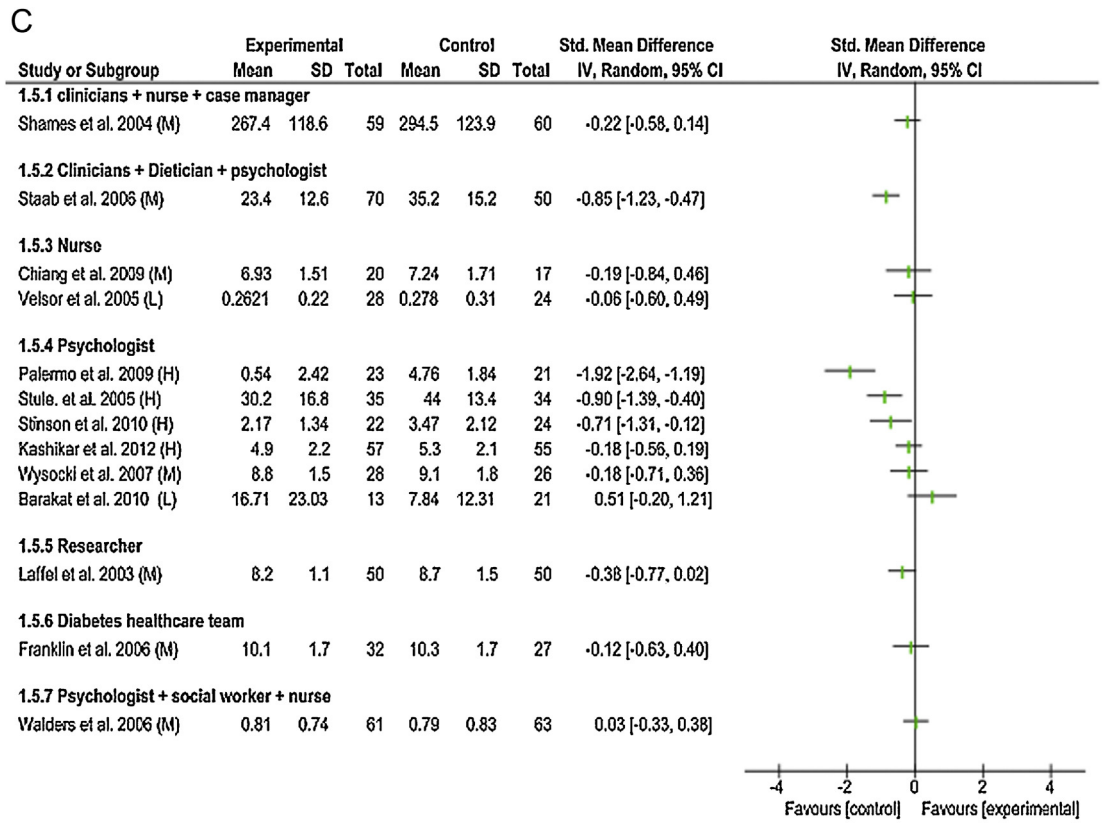


Fig. 2. (Continued)

3.4.6. Outcome measure school attendance

Five studies focused on school attendance as an outcome measure [43,58,62,63,79]. SMI showed a trend in favor of the control condition: two studies showed a significant effect in favor of the control condition one study showed a negative tendency, while two studies showed a trend in favor of intervention. The quality of evidence was very low (Table 1).

No clear pattern was revealed for intervention components.

3.4.7. Outcome measure quality of life

Thirteen studies focused on quality of life as an outcome measure [42,44,47–50,57,58,61,65,70,74,78]. Overall, no clear effects of SMI were found on quality of life. Four studies had a significant effect in favor of intervention; three studies showed a trend in favor of intervention; one study showed a significant effect in favor of the control condition; four studies showed a trend in favor of the control condition. The quality of evidence was high (Table 1).

Of all interventions that aims to improve quality of life, interventions focused on medical management showed a trend in favor of intervention (Fig. 7).

4. Discussion and conclusion

4.1. Discussion

We reviewed randomized controlled trials to explore the effectiveness and effective intervention components of SMI. In contrast to existing literature, we looked at pediatric SMI in general, i.e. irrespective of type of condition. Our findings suggests that pediatric SMI might be effective at influencing disease knowledge, adherence, but not at symptom severity and school attendance. Conflicting evidence was found for effectiveness of SMI on dealing with the chronic condition, psychological outcomes and quality of life. However, results about effectiveness should be interpreted with some caution, because the quality of evidence for most outcome measures was rated as low. In addition, some evidence was found for effective intervention components, but this differs per outcome measure.

4.1.1. Effectiveness of SMI

Possible evidence for effectiveness of SMI on disease knowledge was also reported in previous reviews on SMI for adult patients [12,84]. Others showed possible evidence for effectiveness of SMI on disease knowledge of youth with spina bifida, arthritis, asthma, or diabetes [17,18,85–87] and for effectiveness of pediatric SMI on adherence [88–90]. Moreover, earlier studies on youth showed that both knowledge about the condition and medication adherence are important to maintain health [91].

Although Kirk et al. [21] underlined the need to incorporate patient-centered outcomes such as quality of life and psychosocial well-being into SMI evaluation studies, conflicting evidence for effectiveness of SMI on these outcome measures was found and inconsistent results have been reported by others [12,84]. Nolte et al. [92] pointed out that patient reported outcomes measures (e.g. quality of life and psychosocial well-being) are highly variable, since these require the highest degree of personal appraisal. Specifically, people may define depression or quality of life very differently before SMI compared to after intervention, influencing the reliability of measurements. These biases could have influenced the results of included studies and, thus, our results. However, patient reported outcomes do provide insights into patients' lived experiences and are therefore highly relevant for studying self-management. Therefore, future studies designed to explore response shifts are recommended. For instance, qualitative methods may shed light on how a patient's context interacts with

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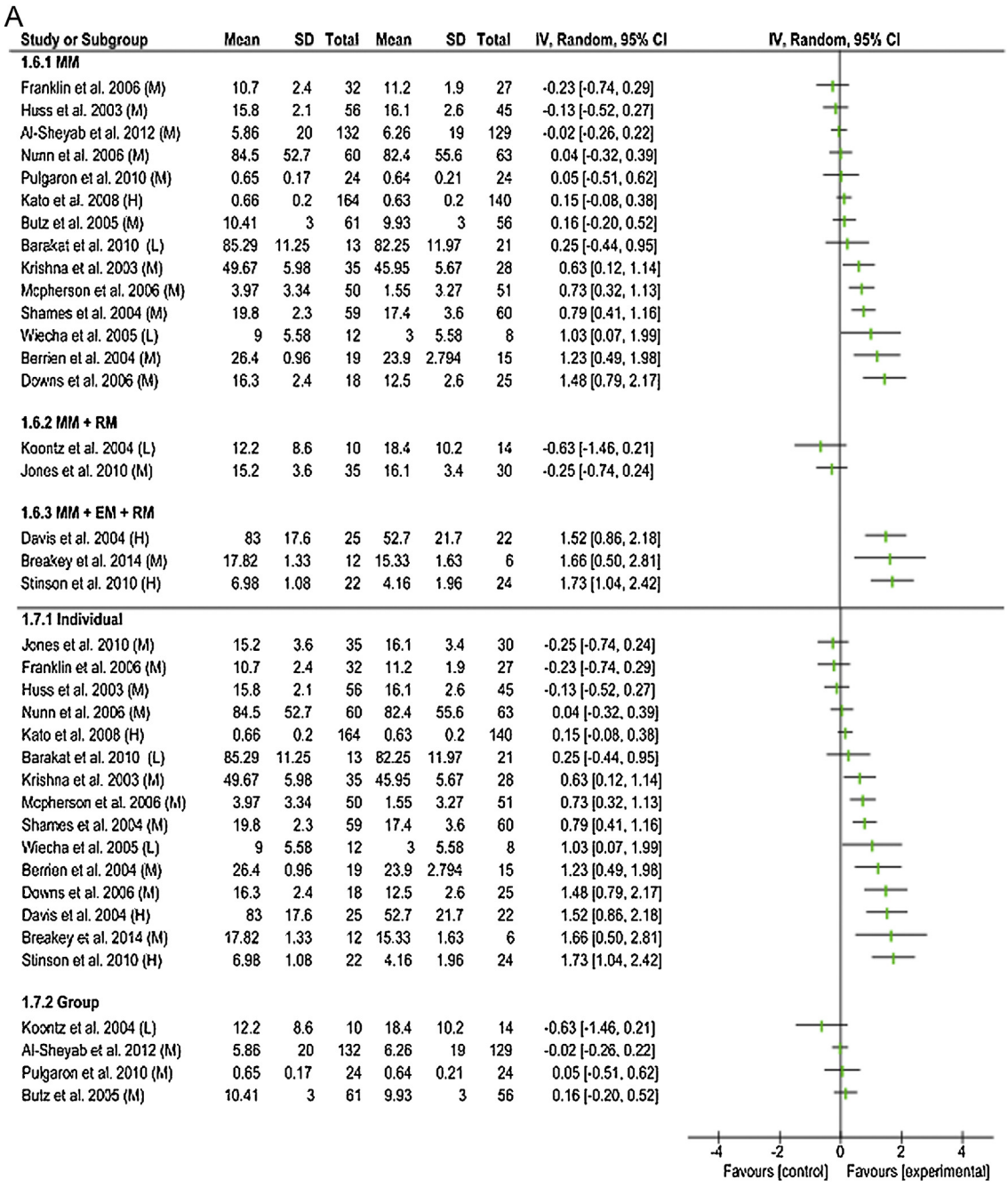


Fig. 3. (A) Effectiveness of intervention component domain of self-management and format on disease knowledge. (B) Effectiveness of intervention component discipline and setting on disease knowledge.

their lived experiences. This is in line with the recently posed notion that patient's context is important to consider when researching self-management [93].

4.1.2. Effective components of SMI

In addition to previous research on effectiveness of SMI [17,18,21], this review revealed some suggestions about components of SMI to be effective. Specifically, SMI aimed to improve adherence might be effective when focused on medical management and provided individually in a clinic or at home by a mono-disciplinary team. This is not surprising, since adherence is part of medical management and individual attention of one professional may enhance insights into personal barriers to adherence.

We found some evidence that SMI aiming to support young people to deal with the chronic condition in daily life should focus on medical management, emotion management and role management, i.e. should consider a holistic view on self-management [13,22]. This conclusion is in line with earlier findings showing that one's illness behavior depends on one's perception of symptoms and on the extent to which symptoms interfere with daily life [94], i.e. one's lived experiences [95,96]. In this light, the support need on dealing with chronic conditions in daily life is influenced by lived experiences, and SMI on this outcome measure should therefore include role management and emotion management, besides medical management [13]. In addition, our review suggests that these SMI might be mono-disciplinary programs, provided individually and at home. These findings are somewhat

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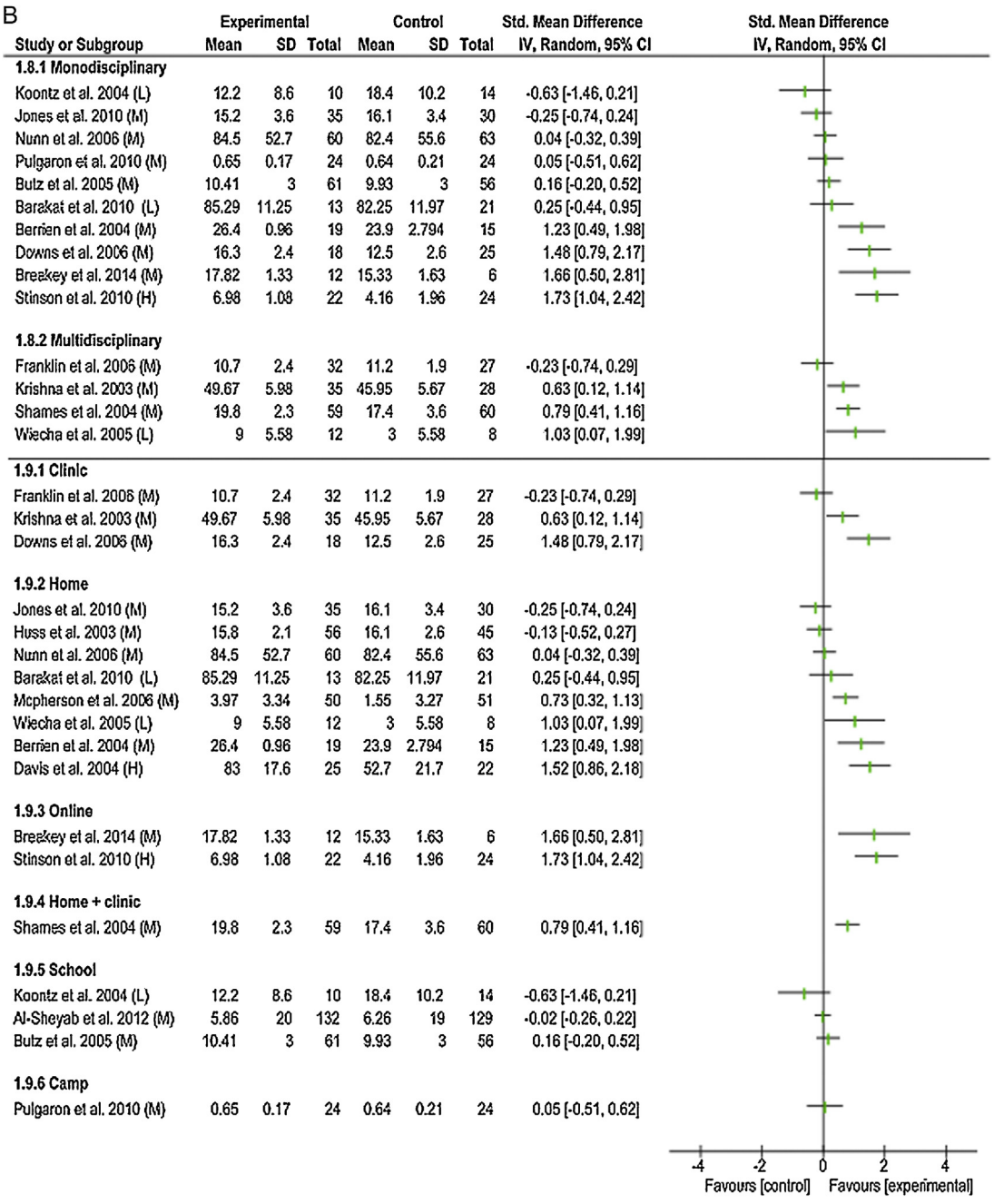


Fig. 3. (Continued)

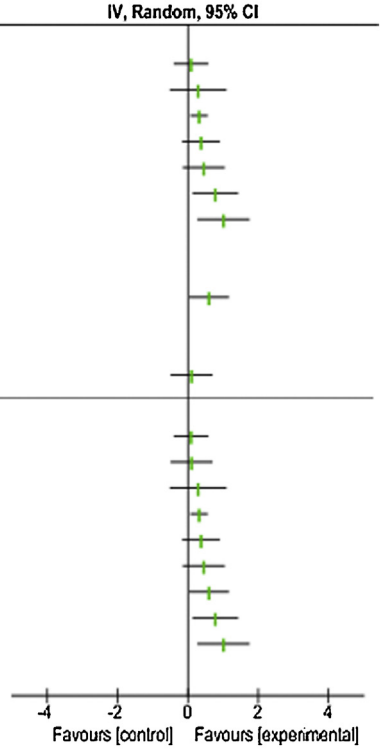
unexpected since peer-support was found to be an appropriate element to stimulate dealing with the chronic condition in daily life, i.e. enhance self-efficacy, and therefore we expected group sessions and a clinical setting to be effective intervention elements [97,98]. However, taking a closer look at elements used in these SMI, we conclude that these individually provided programs facilitate peer-support using telemedicine element. This indicates that online peer-support could also be an appropriate element to improve self-efficacy, problem solving skills and pro-active coping behavior, as was earlier mentioned in literature [18]. However, more research is needed to further validate this hypothesis, since we found some evidence that interventions provided online without a peer-support element might not be effective.

Our review suggests, too, that a mono-disciplinary team, an online setting and an individual format might not be effective intervention components of self-management support focused on psychological outcomes, i.e. stress, anxiety and depression. In contrast, we found some evidence for group sessions to be an effective intervention component. Earlier research showed the perceived distress of people with chronic conditions and their need for social support [99]. It might be necessary, therefore, to incorporate elements that promote people's sense of empowerment into SMI, if aiming to improve psychological outcomes [100,101]. In addition cognitive behavioral therapy is commonly used in the treatment of depression. According to the rationale behind the therapy, cognitive social learning theory, people should adapt their maladaptive cognitions and modify their behavior to reduce the depressive symptoms [102]. Group meetings may help to discuss maladaptive cognitions and behaviors, and may help to change these into more adaptive ones. Also, our review suggests

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A

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Std. Mean Difference IV, Random, 95% CI
1.10.1 MM							
Naar-King et al. 2013 (H)	70.27	41.31	33	66.61	40.35	36	0.09 [-0.38, 0.56]
Wiecha et al. 2005 (L)	49.2	25.8	21	41.5	25.8	9	0.29 [-0.49, 1.08]
Kato et al. 2008 (H)	81	8.7	163	78.4	7.5	140	0.32 [0.09, 0.54]
Franklin et al. 2006 (M)	77.2	16.1	32	70.4	20	27	0.37 [-0.14, 0.89]
Mulvaney et al. 2010 (M)	3.9	0.4	34	3.7	0.5	18	0.45 [-0.13, 1.03]
Downs et al. 2006 (M)	98.5	22.6	18	77.5	28.9	25	0.78 [0.15, 1.41]
Berrien et al. 2004 (M)	34.8	1.79	19	31.9	3.72	15	1.01 [0.29, 1.73]
1.10.2 MM + RM							
Wysocki et al. 2007 (M)	57.1	7.6	28	52.1	8.8	26	0.60 [0.05, 1.15]
1.10.3 MM + EM + RM							
Stinson et al. 2010 (H)	8.14	8.14	22	7.5	2.96	24	0.10 [-0.47, 0.68]
1.11.1 Individual							
Naar-King et al. 2013 (H)	70.27	41.31	33	66.61	40.35	36	0.09 [-0.38, 0.56]
Stinson et al. 2010 (H)	8.14	8.14	22	7.5	2.96	24	0.10 [-0.47, 0.68]
Wiecha et al. 2005 (L)	49.2	25.8	21	41.5	25.8	9	0.29 [-0.49, 1.08]
Kato et al. 2008 (H)	81	8.7	163	78.4	7.5	140	0.32 [0.09, 0.54]
Franklin et al. 2006 (M)	77.2	16.1	32	70.4	20	27	0.37 [-0.14, 0.89]
Mulvaney et al. 2010 (M)	3.9	0.4	34	3.7	0.5	18	0.45 [-0.13, 1.03]
Wysocki et al. 2007 (M)	57.1	7.6	28	52.1	8.8	26	0.60 [0.05, 1.15]
Downs et al. 2006 (M)	98.5	22.6	18	77.5	28.9	25	0.78 [0.15, 1.41]
Berrien et al. 2004 (M)	34.8	1.79	19	31.9	3.72	15	1.01 [0.29, 1.73]



B

Study or Subgroup	Experimental Mean	SD	Total	Control Mean	SD	Total	Std. Mean Difference IV, Random, 95% CI
1.12.1 Monodisciplinary							
Stinson et al. 2010 (H)	8.14	8.14	22	7.5	2.96	24	0.10 [-0.47, 0.68]
Wysocki et al. 2007 (M)	57.1	7.6	28	52.1	8.8	26	0.60 [0.05, 1.15]
Downs et al. 2006 (M)	98.5	22.6	18	77.5	28.9	25	0.78 [0.15, 1.41]
Berrien et al. 2004 (M)	34.8	1.79	19	31.9	3.72	15	1.01 [0.29, 1.73]
1.12.2 Multidisciplinary							
Wiecha et al. 2005 (L)	49.2	25.8	21	41.5	25.8	9	0.29 [-0.49, 1.08]
Franklin et al. 2006 (M)	77.2	16.1	32	70.4	20	27	0.37 [-0.14, 0.89]
1.13.1 Clinic							
Franklin et al. 2006 (M)	77.2	16.1	32	70.4	20	27	0.37 [-0.14, 0.89]
Wysocki et al. 2007 (M)	57.1	7.6	28	52.1	8.8	26	0.60 [0.05, 1.15]
Downs et al. 2006 (M)	98.5	22.6	18	77.5	28.9	25	0.78 [0.15, 1.41]
1.13.2 Online							
Stinson et al. 2010 (H)	8.14	8.14	22	7.5	2.96	24	0.10 [-0.47, 0.68]
Mulvaney et al. 2010 (M)	3.9	0.4	34	3.7	0.5	18	0.45 [-0.13, 1.03]
1.13.3 Home							
Naar-King et al. 2013 (H)	0.27	41.31	33	66.61	40.35	36	0.09 [-0.38, 0.56]
Wiecha et al. 2005 (L)	49.2	25.8	21	41.5	25.8	9	0.29 [-0.49, 1.08]
Berrien et al. 2004 (M)	34.8	1.79	19	31.9	3.72	15	1.01 [0.29, 1.73]

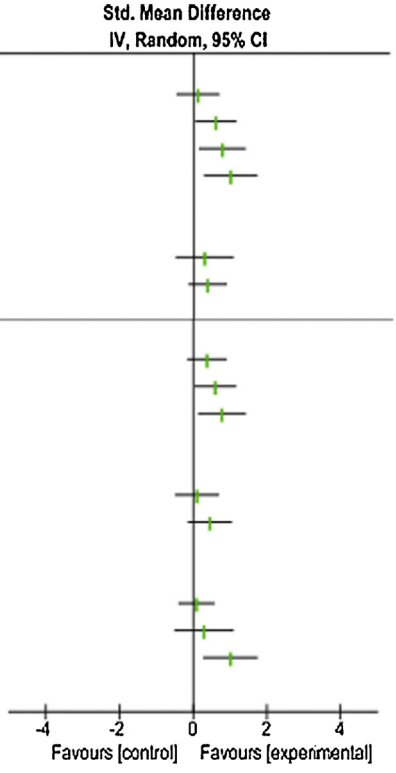


Fig. 4. (A) Effectiveness of intervention component domain of self-management and format on adherence. (B) Effectiveness of intervention component discipline and setting on adherence.

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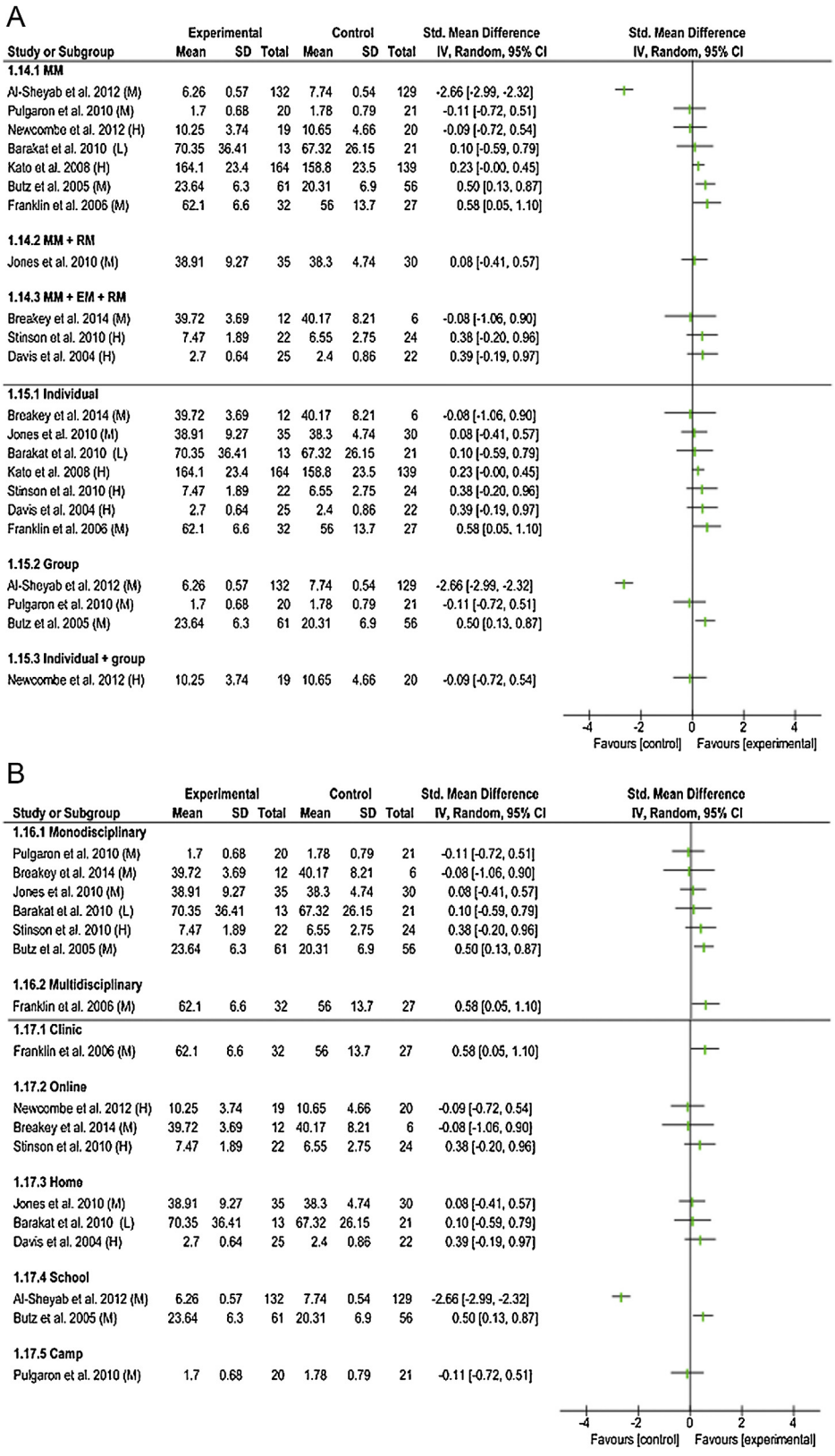


Fig. 5. (A) Effectiveness of intervention component domain of self-management and format on dealing with a chronic condition in daily life. (B) Effectiveness of intervention component discipline and setting on dealing with a chronic condition in daily life.

that SMI aimed to target psychological outcomes might not be focused on medical management. This is not unexpected, because emotion management or a combination of emotion management with role and/or medical management might be a more appropriate content for SMI aiming to reduce stress, anxiety and depression.

Furthermore, we found that programs on symptom reduction should be provided at home instead of in a clinic, home and clinic

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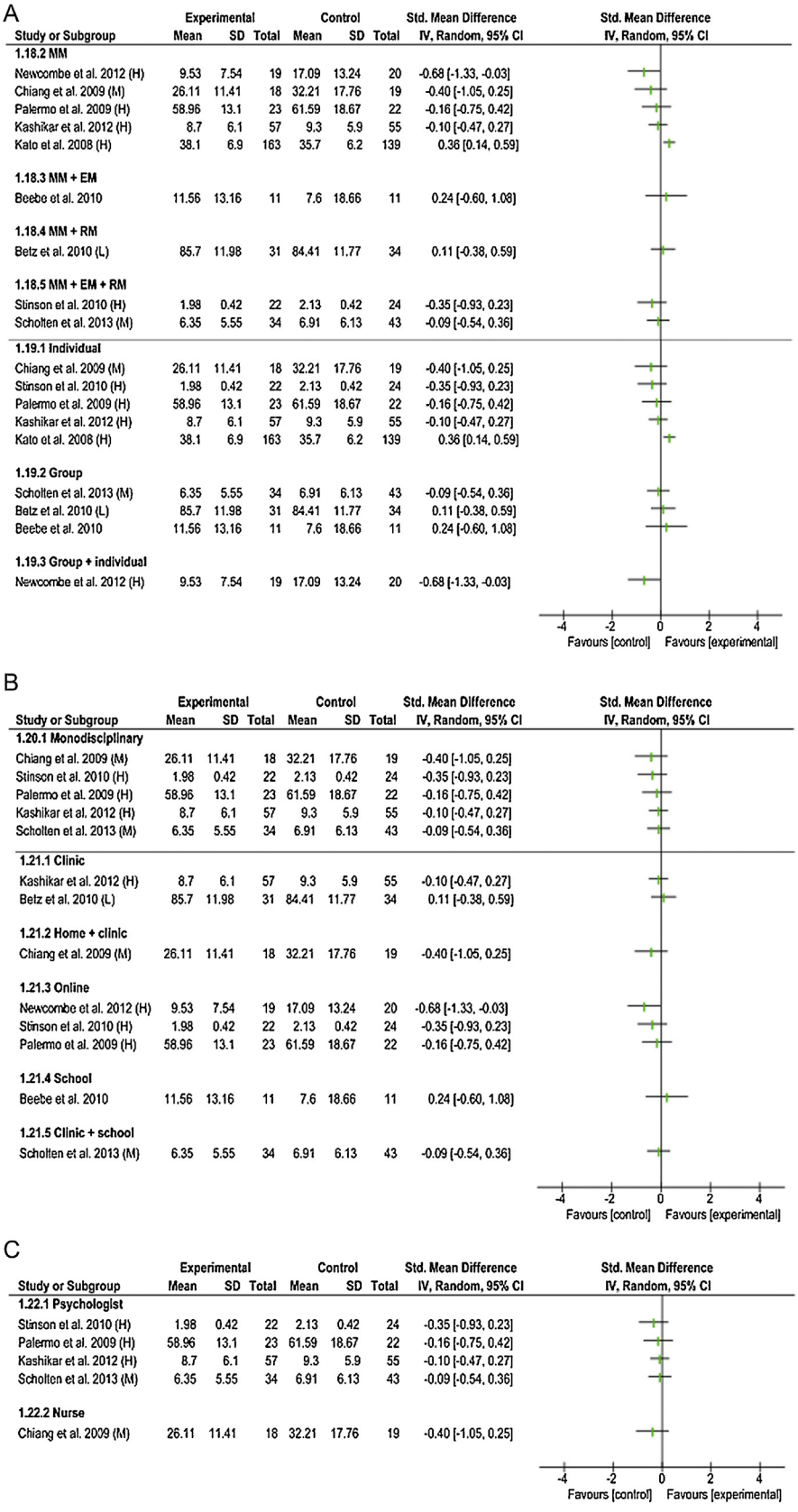


Fig. 6. (A) Effectiveness of intervention component domain of self-management and format on psychological outcomes. (B) Effectiveness of intervention component discipline and setting on psychological outcomes. (C) Effectiveness of intervention component interventionists on psychological outcomes.

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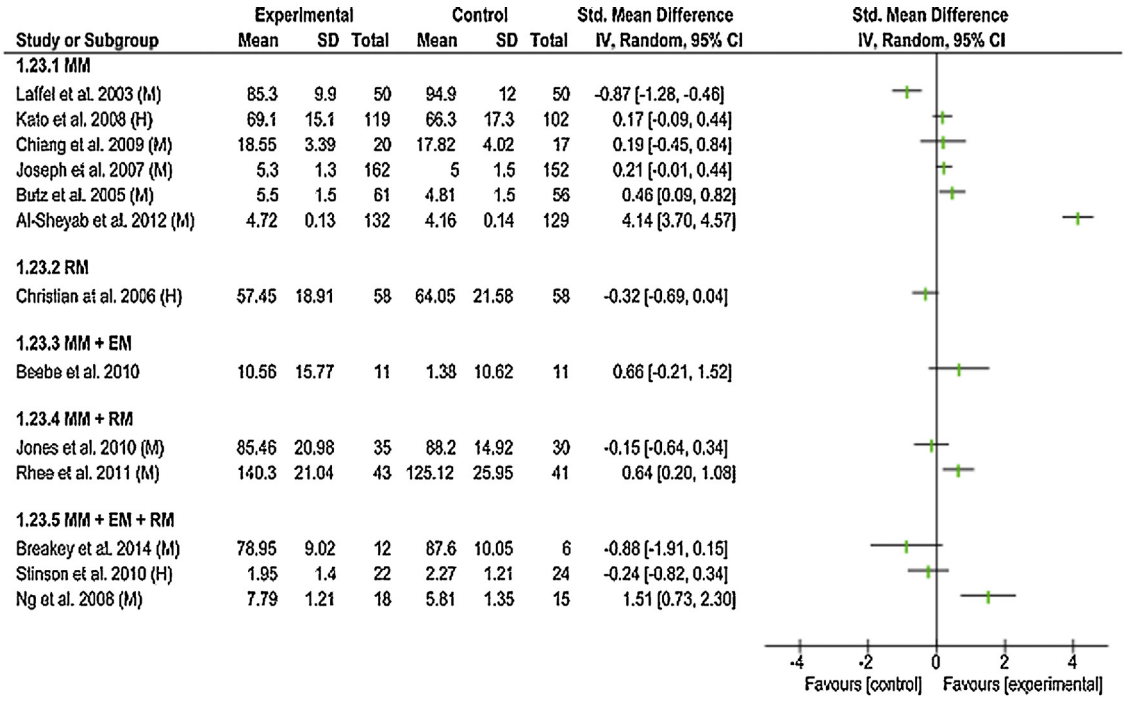


Fig. 7. Effectiveness of intervention component domain of self-management on quality of life.

or online. An explanation for this finding could be that symptoms arise in interacting with the social context. In line with this reasoning, SMI could be more effective when provided in people's daily life. For example, Reeves et al. [103] indicated the importance of social community to fulfill self-management tasks. However, Krieger et al. [104] reviewed pediatric asthma interventions and found both home and clinical settings to be effective for symptom reduction. Also, no clear effects were found for any other intervention components. Elements of SMI on symptom reduction seem to be too diverse and sample sizes are too small, which hampers the evaluation of working elements of these interventions. It seems that the development of SMI is often not based on theories [21,24,25,29]. Therefore, it is recommended to further standardize the development of SMI, and thus to explicitly use theoretical frameworks when designing interventions. Also, it could be that symptoms are too disease-specific and therefore effects on symptom reduction could not be appropriately analyzed in a review of SMI focusing on a variety of chronic conditions. Therefore it would be favorable to employ a disease specific approach, when exploring effects of SMI on symptom reduction.

4.1.3. Strengths limitations and other considerations

SMI for young people across the wide age range of 7–25 years were included, while content or themes obviously are not applicable to the whole age range, e.g. vocational participation pertains to older adolescents only. It would be advisable, therefore, to distinguish between age groups. However, a systematic overview of the content of SMI for young people aged between 7 and 25 years showed that interventions' theoretical base, formats and elements did not differ for different age groups [29].

This study looked at many types of SMI across a wide range of chronic conditions. The breadth of this study is a potential strength. The findings enable researchers and healthcare professionals to look at general self-management support, which goes beyond particular chronic conditions. In addition, subgroup analyses – not presented in this paper – showed no differences in effects between interventions focused on a distinctive diagnosis.

Last, the, in general, low quality of evidence for most outcome measures as rated using the GRADE methodology [35], downgrades the strength of recommendations per outcome measure. The low quality of evidence was mainly caused by the variability and heterogeneity of study results. Also it was not possible to perform a meta-analysis on the effects of SMI, since the outcome measures and intervention programs were very heterogeneous. Therefore, results about effectiveness should be interpreted with some caution. Different conceptualizations of self-management might be one explanation for the diversity of elements and content of SMI and the variety of outcome measures used in SMI evaluation studies, which points at a more fundamental challenge to provide precise definitions [105]. Others, too, recommended to further standardize the development and evaluation of self-management interventions [16,17,84]. Intervention mapping methodology [98] is a recommended stepwise approach for theory and evidence-based development and implementation of interventions that helps to fit intervention goals with program development and program evaluation. In addition, a theoretically derived intervention would make for a more effective SMI, using components that have been found to be effective in changing that specific outcome [106].

4.2. Conclusions

Our review suggests that pediatric SMI might be effective at influencing disease knowledge and adherence across a wide range of conditions. There are indications that SMI aimed to improve *adherence* should be focused on *medical management*, and should be provided *individually in a clinical setting or at home by a mono-disciplinary team*. Furthermore, a *holistic view on self-management*, *individual format and home setting* combined with *online peer-support* might be effective intervention components for SMI focused on *dealing with the chronic condition* in daily life. These combinations of expected outcomes, focus and intervention elements seemed effective irrespective of diagnosis, and may therefore act as good starting points for further improvement of and research into self-management support of young people with

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chronic conditions in health care. Results underlined the need to systematically develop and evaluate self-management interventions, since this may provide more evidence for effectiveness and effective intervention components.

4.3. Practical 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. Our systematic overview of effectiveness and effective intervention components may assist clinicians and other healthcare professionals in determining the focus, content and components of self-management support they provide. More specifically, to improve patient's adherence, healthcare professionals should focus their SMI on medical management, and they should provide the intervention individually in a clinical setting or at home by a mono-disciplinary team. Furthermore, a holistic view on self-management, individual format and home setting combined with online peer-support might be appropriate intervention components to select for SMI focused on dealing with the chronic condition in daily life.

Conflict of interest

The authors have no potential conflicts of interests to declare, including relevant financial interests, activities, relationships, and affiliations.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.pec.2016.02.012.

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