



The Development of Self-Management in Young People with Chronic Conditions: A Transitional Process

3

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3.1 Introduction

The developmental context of young people with chronic conditions makes their situation different from people who are being diagnosed with a chronic condition at a later age. This also reflects in their challenges for learning and practicing self-management and the support they need. In Chap. 1, the broad definition of self-management was outlined as follows: “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” [1].

Growing up with a childhood-onset chronic condition implies that children do not only have to cope with their condition and its consequences for their daily life, but also need to reach various developmental milestones while passing through childhood, early adolescence, late adolescence and eventually attaining young adulthood. Young people are, for example, expected to leave their parents’ or caregivers’ homes eventually, pursue educational and vocational or professional careers, start their own families and thus, as autonomous adults, they are expected to participate and fulfill meaningful roles in society. This multifaceted life-stage transition to adulthood is already challenging but is extra demanding for those with (childhood-onset) chronic conditions [2]. These young people have to balance the usual developmental tasks of growing up with additional adaptive tasks related to their chronic condition. Fulfillment of these tasks is important for adjustment to adult life [3]. Moos and Holahan [4] described the following adaptive tasks for people with chronic conditions: managing symptoms, managing treatment, forming relationships with health care providers, managing emotions, maintaining a positive self-image, relating to family members and friends and preparing for an uncertain future

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[4]. Note that these tasks relate to the medical, role and emotional domains of self-management [5], and require specific self-management skills (see also Table 3.1). Balancing and navigating between normal developmental and additional adaptive tasks related to the chronic condition is complex. A chronic condition and its treatment can have manifold effects on development and daily life, while at the same time developmental changes can affect both the condition and its treatment [7–9].

3.2 Growing Up with a Childhood-Onset Chronic Condition

Growth, physical appearance, relationships with relatives and peers, social participation and emotional wellbeing may all be influenced by a chronic condition [8–11]. Several studies showed that young people with chronic conditions reach developmental milestones later and are at risk for less favourable psychosocial development compared to their healthy peers [12, 13]. Adolescents confirm that having a chronic condition complicates school participation and the development of friendships through frequent hospitalizations and disclosure issues [14]. Mental health is often compromised as well. Young people with chronic conditions report elevated levels of anxiety and depressive symptoms and lower self-esteem compared to healthy peers [15–17]. On the other hand, usual developmental changes, like the onset of puberty, may negatively influence disease patterns and symptoms. Hormones may for example negatively impact disease parameters like growth hormone does for blood values in diabetes [8]. Young people are reported to have poorer disease control than other age groups, and to show problem behaviours or risk-taking behaviours [8, 18, 19], complicating management of the condition and its treatment. Another change young people have to deal with is the transfer from paediatric to adult care. Suboptimal transfer may result in no-show in adult care or poor treatment adherence, accompanied by a risk of complications and deterioration of health [20]. Self-management in young people with chronic conditions is thus complicated by the reciprocal impact of transitioning to adulthood and having a chronic condition.

Furthermore, the additional adaptive tasks for people with chronic conditions require specific self-management skills that young people have to acquire while becoming adults. While doing so, they ideally and gradually take over the responsibility of caring for their chronic condition from their parents or caregivers. This initial dependency followed by a gradual shift in responsibility is also part of their development and unique to the case of young people with chronic conditions [21]. They, for instance, have to build up a relation with new healthcare professionals in adult care and have to engage in shared decision-making. Gall et al. [22] introduced the Shared Management Model (also see Chap. 8) in which they outline that, ideally, young people gradually transform from *receivers of care* to their own *managers or supervisors of care*. In this last stage, parents take on the role of consultants and healthcare professionals become resources instead of having the major responsibility [22]. The role of parents in this process is further highlighted in Chap. 6.

Table 3.1 Self-management tasks along the adaptive tasks of living with a chronic condition and the domains of self-management^a

Self-management domains	Medical management	Role management	Emotional management
Adaptive tasks of living with a chronic condition			
Managing symptoms and treatment	<ul style="list-style-type: none"> • Understanding: the disease; (the necessity of) medication and treatment regimen; and side effects 		
	<ul style="list-style-type: none"> • Use of specific treatment devices or techniques 		
	<ul style="list-style-type: none"> • Dealing with symptoms 		
	<ul style="list-style-type: none"> • Self-monitoring of clinical outcomes 		
	<ul style="list-style-type: none"> • Drafting an individualized care plan 		
	<ul style="list-style-type: none"> • Knowing where to find information about the disease 		
	<ul style="list-style-type: none"> • Knowing about the risks of risk behaviours (e.g. alcohol abuse). 		
Forming relationships with healthcare professionals	<ul style="list-style-type: none"> • Accessing healthcare 		
	<ul style="list-style-type: none"> • Communication with healthcare professionals 		
	<ul style="list-style-type: none"> • Managing doctor visits 		
	<ul style="list-style-type: none"> • Coping with hospitalizations 		
	<ul style="list-style-type: none"> • Knowing when to ask for medical help 		
	<ul style="list-style-type: none"> • Having organizational skills 		
Relating to family members and friends	<ul style="list-style-type: none"> • Child–parent sharing/ teamwork 	<ul style="list-style-type: none"> • Social initiation and friendship making; having a social network; maintaining family and romantic relationships (sexuality) 	
	<ul style="list-style-type: none"> • Knowing when to ask for (medical) help 	<ul style="list-style-type: none"> • Participating in normal social activities; keeping up with peers (e.g. via internet or social media) 	
		<ul style="list-style-type: none"> • Disclosure (educating peers) 	
		<ul style="list-style-type: none"> • Communication and social problem-solving 	

(continued)

Table 3.1 (continued)

Self-management domains	Medical management	Role management	Emotional management
Preparing for an uncertain future	<ul style="list-style-type: none"> • Setting goals for healthcare transition 	<ul style="list-style-type: none"> • Setting goals and having dreams for the future related to school, work, community, living, housing, recreation and leisure 	
		<ul style="list-style-type: none"> • Setting life goals 	
		<ul style="list-style-type: none"> • Independent living 	
		<ul style="list-style-type: none"> • Traveling/staying abroad • Having organizational skills 	
Managing emotions			<ul style="list-style-type: none"> • Dealing with fear-related thinking
			<ul style="list-style-type: none"> • Sharing feelings and experiences, also feelings related to the condition
			<ul style="list-style-type: none"> • Accepting the condition
			<ul style="list-style-type: none"> • Healthy expressions of anger and transforming or managing anger
			<ul style="list-style-type: none"> • Stress management; having helpful positive thoughts
			<ul style="list-style-type: none"> • Managing the impact of or decreasing negative thoughts
			<ul style="list-style-type: none"> • Spirituality
Maintaining a positive self-image			<ul style="list-style-type: none"> • Self-confidence/ self-esteem building
			<ul style="list-style-type: none"> • Developing a positive body image/body esteem
			<ul style="list-style-type: none"> • Building self-efficacy/ self-appreciation

^aAdapted with permission from Sattoe et al. [6]

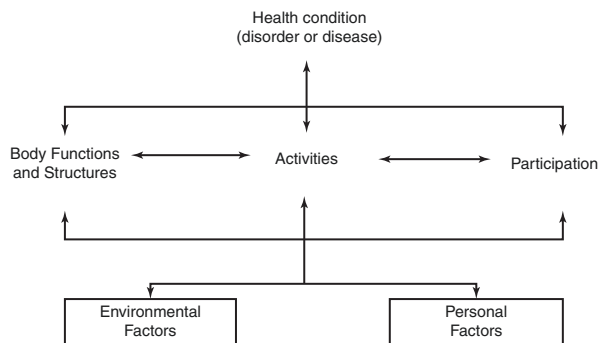
Taking up an active role in healthcare is not self-evident for young people. While adolescents want to be involved as equal partners in their care, this wish often remains unfulfilled in daily practice. During consultations, they mostly act like bystanders because their participation is not requested, nor encouraged [23, 24]. Also, preferences of young people often are not met by their actual experiences, which can have negative emotional consequences [25]. This difficulty in becoming independent and gaining autonomy is also present outside healthcare. A qualitative study comparing the views of adolescents and their parents, showed that life beliefs of young people and their parents can clash, leading to child–parent conflict [26] and resulting in negative outcomes regarding lived experiences, social participation, and the overall transition to adulthood [27, 28]. A recent review focusing on how children assume self-management responsibility from their parents showed that this includes a complex process that is influenced by multiple contextual factors [29]. Self-management in young people with chronic conditions is thus complicated by the shift from dependency to independency.

The developmental context of young people with chronic conditions hence impacts self-management and that is why self-management should be seen as transitional process [30] that is inevitably linked to their overall transition to adulthood [3]. Also, while the challenges are manifold, young people are generally motivated and confident about their ability to learn new skills. They often embrace the prospect of becoming autonomous adults, and many have an optimistic outlook on the future [2].

3.3 Frameworks for Self-Management and Self-Management Support of Young People

There are different frameworks that may be useful in addressing the challenges of self-management in young people with chronic conditions. A general framework that is often linked to self-management is the World Health Organization’s International Classification of Functioning, Disability and Health (ICF; Fig. 3.1) [31]. While the ICF is not specifically designed for use in case of young people, it has been applied successfully to young people with chronic conditions in various

Fig. 3.1 International classification of functioning, disability and health



studies [21, 32–35]. The ICF is a biopsychosocial model that pretends to combine both the medical model of disease and the social model of disability. It considers three core components of functioning, i.e. body functions, activity and participation, within the sphere of an individual’s health condition and contextual factors (environmental and personal factors). The ICF emphasizes the importance of *capacity* and *performance* in functioning. Capacity refers to the ability of a person to complete a task or action in a standard environment, while performance refers to performing this task or action in his or her own environment [31]. Regarding self-management of young people, the gaps between capacity and performance may help professionals (and others) to understand the support needs of these young people [21]. The ICF presumes that by addressing these barriers, functioning can be improved. Although the presence of mutual influences of an individual’s health condition and context on daily functioning is described in the model, the ICF remains a general framework that does not specify self-management processes and tasks and the context in which self-management takes place. Also, the ICF has been criticized for being normative and not paying enough attention to people’s lived experiences and the enhancement of their agency [36].

A more specific framework is the conceptual model of Modi et al. named the Paediatric Self-management Model (PSM) [37]. The PSM is a socio-ecological model that embeds self-management behaviours of young people with chronic conditions within four different domains: individual, family, community, and health-care system. The underlying notion is that modifiable and non-modifiable factors in each domain determine self-management behaviours through cognitive, emotional and social processes. These self-management behaviours affect adherence and so influence outcomes (at both individual and system level) [37]. In this context, adherence is defined as “the extent to which a person’s behaviour coincides with medical or health advice” [37]. The importance given to adherence as a mediating construct shows that the PSM focuses on medical treatment (outcomes). The developers mention that “self-management behaviours, which are conducted by a child or family member, are performed in the context of care for the chronic condition. This does not assume positive or negative impact, only that the behaviour was conducted for the purpose of treatment” [37]. The assumption that self-management behaviours are solely conducted for the purpose of treatment, however, does not concur with the holistic view on self-management.

The shifting importance of the medical, role and emotional domains is emphasized in the Self-management Support Model for Young People (SSMYP; Fig. 3.2) [3]. The SSMYP does not elaborate on specific self-management processes and outcomes, but tries to depict the unique context of young people growing up with chronic conditions and their specific self-management challenges. The SSMYP conceptualizes self-management as a dynamic process that requires flexibility in shifting between different *content* (the domains of self-management) and *roles* (of the people involved) [3]. The interaction between healthcare professionals and young people is shown as a continuum of directivity, acknowledging that sometimes professionals will take the lead and sometimes patients will—and that young people will have to learn forming partnerships with their healthcare professionals. The

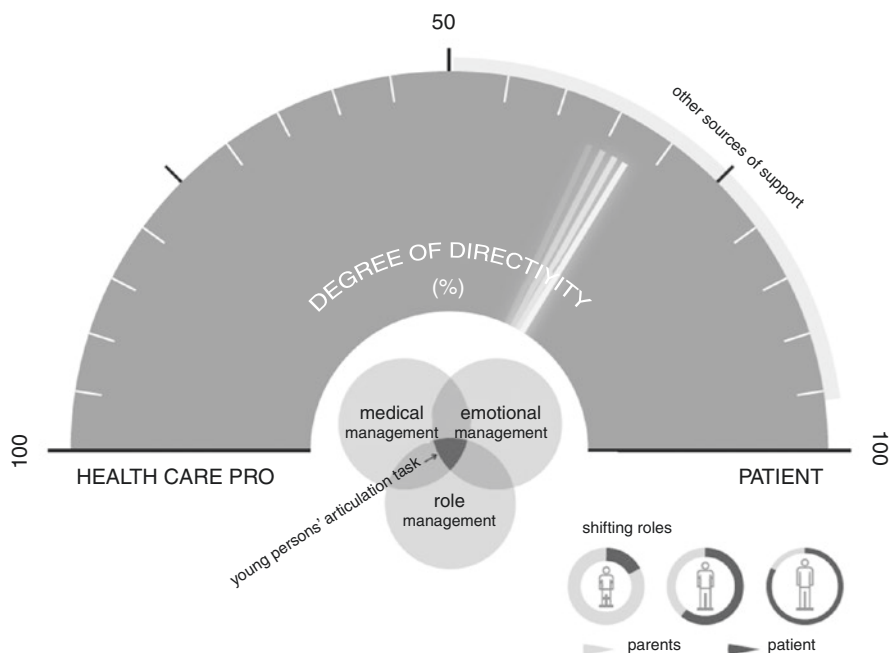


Fig. 3.2 Self-management support model for young people. (Sattoe, J.N.T. (2015). *Growing up with a Chronic Condition: Challenges for Self-management and Self-management Support*. Rotterdam: Erasmus University Rotterdam. ISBN: 978-94-6169-684-7)

(development of the) patient–provider relationship will be further explored in Chap. 5. The model also points towards shifting roles and autonomy of youth and their parents, which will be further explored in Chap. 6; and the fact that support may also come for others as is the case in peer support, as will be elaborated upon in Chap. 7. Finally, the SSMYP mentions an “articulating task” for young people when shifting between domains of self-management. This has to do with the inter-relatedness of the medical, role and emotional domains. Young people have to learn how to coordinate the tasks and priorities related to each domain within their capacities, this articulating task is the core of self-management [3].

The ICF, PSM and SSMYP are different models that may be seen as complementary to each other. Still, there are some similarities between the models that may further enhance our understanding of self-management of young people with chronic conditions. First, all three conceptualize self-management as a dynamic process rather than a fixed ability. This is in line with seeing self-management of young people with chronic conditions as a “transitional process” [30]. Second, the ICF and the SSMYP both endorse a biopsychosocial view, underlining the important of all three domains of self-management. Finally, the ICF and the PSM both emphasize that self-management is influenced by contextual factors and all three models recognize the importance of others (e.g. parents, family, friends) in the process. There are also some points raised by the different models individually that

deserve further exploration. First, the ICF distinguished the constructs of capacity and performance. Second, the PSM emphasizes that factors influencing self-management processes (and ultimately behaviour) can be either modifiable or unmodifiable. Third, the SSMYP points towards articulation work as the core self-management task. Before further exploration of these points, we review the theories and theoretical constructs underlying self-management.

3.4 Theories and Theoretical Constructs Underlying Self-Management

The theory that is most often linked to self-management is the social learning theory or social cognitive theory of Bandura [38], both in young people [6, 39, 40] and in adults with chronic conditions [41–44]. This theory implies that self-management is something that (young) people learn through information given by others (social persuasion by an authority), by observing others (social modelling) and by trial and error (mastery experiences). An important construct in the social cognitive theory of Bandura is self-efficacy. Self-efficacy refers to an individual's belief in his or her capacity to execute and control over certain tasks [45]. The idea is that higher self-efficacy will lead to "better" self-management, and that self-management interventions (SMI) should foster self-efficacy [44]. Often, instead of referring to the theory, studies use individual theoretical constructs to inform SMI [39, 41]. In this light, self-efficacy is often related to self-management [5, 46] and used as an outcome in the evaluation of SMI [6].

Another theory that is regularly linked to self-management is the theory of self-regulation. Again, this is both in young people [6, 39] and in adults with chronic conditions [42]. This theory is generally labelled as the self-regulation theory, but some more specifically refer to Bandura's social cognitive theory of self-regulation. The main idea is that people self-regulate to achieve previously set goals. Goals-setting is thus an important aspect of the theory, and Bandura [38] mentions three elements of self-regulation: (1) self-monitoring (of behaviour, its determinants and its outcomes), (2) judgement of the behaviour considering the context (e.g. is this behaviour in this context beneficial for me?), and (3) affective self-reaction (e.g. problem-solving) [38]. Barlow and colleagues (2002, p. 178) describe self-management as "... to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life" and define self-management as "a dynamic and continuous process of self-regulation...". The construct of self-efficacy is also seen as an important mechanism in the self-regulation theory [38]. Whereas self-regulation is more like the strategy to achieve pre-set goals, self-efficacy refers to the extent to which people think they will succeed in achieving these goals.

Another construct that is essential in the self-regulation theory is "self-determination", which is defined as "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour" [47]. The last part of this definition emphasizes that self-determination has to do with individual agency, e.g. having own priorities and making own decisions.

Apart from a construct, self-determination is also mentioned as a theory in itself. The self-determination theory emphasizes three basic needs: (1) having a sense of personal competence, (2) social relatedness (e.g. good relationships with others) and (3) autonomy [48, 49]. These are all in line with self-management. Notable is that self-efficacy, again, seems to be an important construct (although not explicitly mentioned as such). Summarizing, all the mentioned theories show that self-efficacy, competency, social context and relatedness, and autonomy determine how young people perform self-management. We now explore the specific tasks and skills required for learning how to self-manage, the influencing factors, and self-management interventions.

3.5 Self-Management Tasks of Young People and Required Skills

Self-management of people with chronic conditions is about living with a chronic condition and thus is a lifetime task [50]. Each domain of self-management comes with its own adaptive tasks and required corresponding skills. For young people, the uptake of these tasks is extra challenging because they have to deal with additional developmental tasks that may interfere or even overlap with their self-management tasks [3]. Also, young people have less (life) experience than older adults which can make self-management more challenging. Therefore, they have a wider range of self-management tasks than adults [37]. Yet, literature on what these self-management tasks of young people entail is scarce.

In adults with chronic conditions, Schulman-Green et al. [51] specify processes, tasks and skills of self-management [51]. The list is long and self-management tasks evolve around the chronic condition and health needs, navigating healthcare, spirituality and social roles, and emotional adjustment. Corresponding skills vary from general life skills like “carrying out normal tasks and responsibilities” or “advocating for self” to specific skills like “monitoring and managing symptoms” and “coordinating services/appointments and insurance” [51].

In a systematic overview of SMI for young people with chronic conditions, the content of these interventions was reviewed [6]. This gives insight into what is seen as important for young people to learn to self-manage their chronic condition. In Table 3.1, we present it alongside the domains of self-management and the adaptive tasks of living with a chronic condition as described by Moos and Holahan [4]: managing symptoms, managing treatment, forming relationships with healthcare professionals, managing emotions, maintaining a positive self-image, relating to family members and friends and preparing for an uncertain future.

Another recent review of interventions for young people with chronic conditions has found similar content of interventions [52]. Corresponding self-management skills are problem-solving skills, decision-making skills, resource utilization skills, social and communication skills and goal setting skills [5, 52]. On top of these comes the articulation task, which Lorig and Holman [5] describe as the core self-management skill of “self-tailoring” [5], i.e. using one’s skills to know and prioritize needs (and act accordingly). Required self-management skills are summarized in Table 3.2.

Table 3.2 Required self-management skills

Skills	In relation to self-management
Problem-solving	Solving problems by assessing situations and finding appropriate solutions
Decision-making	Being able to make the right decisions on the right time and in the right order
Resource utilization	Knowing when and how to utilize resources like finding and using the right information; and being able to involve others in time
Social relations and communication	Managing relationships with healthcare professionals: being an active partner in healthcare, reporting changes in health and discussing these with healthcare professionals, and being able to make argued decisions and share these with healthcare professionals
Goal setting	Being able to set goals and make a realistic planning to achieve these goals; also, being able to go from planning to practicing
Articulation or self-tailoring	Monitoring the course of disease, being able to prioritize accordingly, being flexible, and initiate timely adjustment when needed

3.6 Factors That Influence Self-Management of Young People

Different factors can influence self-management of young people with chronic conditions. Modi and colleagues [37] visualized that these can be both modifiable and non-modifiable and can operate at different levels: the individual level, the family level, the community level and the healthcare system level. In a review of barriers and facilitators of self-management among young people with chronic conditions different influencing factors were found [53], as well as in other studies [54–59]. These are summarized in Table 3.3 and placed alongside the categorisation and levels mentioned in the PSM. To complete the list the extra level “chronic condition” was added.

At the individual level, modifiable factors mostly cover the way young people see themselves and if they feel competent enough to manage their condition. Most factors can influence self-management both negatively and positively. Wanting to lead a “normal” life for instance, can be a motivation for some young people, while at the same time it can create pressure for others. Findings about the influence of non-modifiable personal factors are mostly mixed and thus unclear [53]. Parental involvement in self-management can as well be both positive and negative for young people. If parents leave room for young people to develop autonomy and eventually grow independent, this is beneficial. On the other hand, if they worry about letting go and want to force their own involvement upon their child’s life, it often creates child–parent conflicts, complicating self-management. Similarly, relationships with peers and teachers can be supportive or not. This is likely also true for relationships with colleagues and supervisors in the work environment. Finally, on the healthcare system level, relationships with providers, perception of ownership of care and shared management can be important. Financial costs and difficult treatment regimens can complicate self-management. The list of influencing factors in Table 3.3 is not exhaustive and it is noteworthy

Table 3.3 Factors that influence self-management of young people

	Modifiable	Non-modifiable
Individual	Self-concept (normalization)	Age
	Health beliefs	Gender
	Self-efficacy	Intrapersonal characteristics, e.g. intellectual/cognitive capacity
	Knowledge (about the chronic condition)	
	Feeling of autonomy	
	Problem-solving skills	
Psychosocial functioning		
Family	Parental involvement and support in self-management	Socioeconomic status
	Parental attitudes towards chronic condition	Ethnicity/culture
		Marital status of parents
Community	Peer relationships/support	Social stigma
	Interactions with teachers (e.g. understanding of teachers)	
Healthcare system	Support by healthcare providers	Financial costs
	Patient–provider relationship	Access to healthcare
	Shared management with providers and parents	
	Ownership of care	
Chronic condition	Attitude towards condition	Visibility
	(Complicated) regimen/treatment	Age at onset of condition
		Predictability
		Complicated regimen/treatment

that most studies into influencing factors and experiences of young people only included adolescents. Studies about young adults are scarce. Also, little is known about the interaction between different factors.

3.7 Self-Management Interventions

A wide variety of SMI exist for young people with different chronic conditions [6], although the self-management challenges are similar across conditions [40]. Most individual intervention studies are conducted in the United States [6, 52], focus on a particular diagnosis with asthma and diabetes on top of the list [6, 39, 40, 52], and are conducted in young people in the age from 12 to 18 year old [6]. Interventions aim at different areas of self-management. Eighty-one SMI for young people (7–25 years) were reviewed, and most SMI solely aimed at medical management, while very few consider emotional management [6, 60]. This finding is in contrast with the notion that self-management is a broad concept and encompasses more than medical management and indicates that the translation from theory to practice

is slow. Yet, a shift seems to be noticeable. In an update of the review (see Chap. 4), we found new interventions aiming at emotional management, while no new interventions were included that were solely targeted at medical management.

Regarding the format, SMI can be applied at individual level or group level and sometimes parents of young people with chronic conditions also participate in interventions. Formats include among others educational sessions, skills training sessions, motivational interviewing sessions, cognitive behavioural therapy sessions, family sessions, telemedicine systems, peer support activities and art therapy sessions [6, 52]. Saxby et al. [40] recommended eight key educational components for SMI (regardless of the format): structured and sequenced curricula, reinforcement, active participation, collaboration, autonomy, feedback, multiple exposures and problem-solving [40]. These seem appropriate as they link to the theoretical assumptions underlying self-management. Professionals that facilitate self-management support are, among others, trained interventionists, nurses, clinicians, psychologists and therapists, and can also include whole healthcare teams [6, 52]. The setting of interventions also varies. While they are mostly conducted in outpatient clinics of hospitals, they can also take place at home, schools, public environments, and online [6, 52].

3.8 Evaluation and Outcomes of Self-Management Interventions

As the types and content of SMI vary, so do the outcome measures used in evaluation studies [6, 39, 52, 61]. Studies for instance measure adherence, disease knowledge, clinical outcomes, self-efficacy, quality of life, self-management skills and behaviours. Although this could logically be attributed to the different areas interventions focus on, mismatches between content of interventions and outcome measures used in evaluation studies are not uncommon [6]. This hampers conclusions about the effectiveness of SMI for young people with chronic conditions in meta-analyses [3].

The uncritical use of outcome measures was also mentioned by others, and the establishment of a core set of measurement instruments for SMI is recommended [61–63]. So far, we only found one study that identified a core outcome set for clinical trials of interventions for young adults with type 1 diabetes. Eight outcomes were recommended: (1) measures of diabetes-related stress, (2) diabetes-related quality of life, (3) number of severe hypoglycaemic events, (4) self-management behaviour, (5) number of instances of diabetic ketoacidosis (DKA), (6) objectively measured glycated haemoglobin (HbA1C), (7) level of clinic engagement, and (8) perceived level of control over diabetes [64]. Both medical and emotional management seem to be covered in these, but role management is not. An outcome measure related to role management could be the Rotterdam Transition Profile, that measures the attainment of independence in areas such as education, work, independent living, sexuality and intimate relations, etc. [65, 66].

Predefined outcome sets do not exist. One could also wonder whether it would be feasible and helpful to define core outcomes for every diagnosis separately.

Therefore, current studies would benefit from a more systematic approach to the evaluation of SMI. Steps in such an approach could be [3]:

1. Review the content of interventions: Which domains of self-management are targeted?
2. Establish content-related criteria for the selection of participants: Who needs the intervention?
3. Select theory- and content-related outcome measures: What is expected to change?
4. Decide on measurement instruments: Disease-specific or generic?

Despite the heterogeneity in interventions and outcome measures used and the methodological limitations of evaluation studies, some evidence on the effectiveness of SMI for young people with chronic conditions has been extracted in recent reviews. This will be reviewed in the next chapter.

3.9 Key Recommendations

- Acknowledge that balancing and navigating between normal developmental and additional adaptive tasks related to the chronic condition, is complex for young people and parents alike.
- Be aware that growth, physical appearance, relationships with relatives and peers, social participation, and emotional wellbeing may all be influenced by the chronic condition and that being “different” may cause additional emotional strain on young people.
- View the development of self-management skills as a necessary prerequisite for an optimal transfer from paediatric to adult care. It is an intrinsic part of transitioning to adulthood and to adult care.
- Include parents or caregivers in the process of building self-management skills, as young people gradually need to take over the responsibility of caring for their chronic condition from them.
- Involve children and adolescents in all healthcare-related decisions and encourage that they participate in their healthcare as much as possible.
- Use holistic, biopsychosocial models to describe self-management tasks and do not only focus on the medical domain and tasks.
- Self-efficacy is an important determinant of self-management. Therefore, facilitate environments that allow young people to learn from others and to gain mastery experiences.
- In developing self-management interventions for young people with chronic conditions, both disease-specific and generic self-management tasks should be addressed.
- Use theory to build self-management interventions and use a systematic approach for the evaluation.

- Make sure that the selected outcomes in the evaluation of self-management interventions match both the goal and the content of the intervention.
- Be aware that there is no “one size fits all” approach, as the development of self-management is a dynamic and individualized process.

3.10 Conclusion

Growing up with a childhood-onset chronic condition implies that young people do not only have to cope with their condition and its consequences in daily life, but also need to reach various developmental milestones in order to achieve autonomy in adulthood. Learning to perform self-management tasks is a challenge for young people, their families, and healthcare professionals alike. This is a complex process that requires flexibility, trust, and support on the part of parents and professionals so that adolescents can build self-confidence and enhance their self-efficacy. The development of self-management is influenced by many factors, both on the level of the individual, the family, the community and the healthcare system. Self-management does not only involve medical tasks, but also involves managing the psychological and social consequences of living with a chronic condition. Self-management skills are often complex and include problem-solving, decision-making, resource utilization, building social relations, goal setting and self-tailoring. Many of such adaptive tasks are not disease-specific but represent generic challenges. Still, at present, most interventions aiming at enhancing self-management skills in young people only target medical management skills. Very few focus on the emotional trials that are inherent to living with chronic conditions. Furthermore, the evaluation of self-management interventions is often comprised by the fact that there seems to be little consensus on suitable outcomes.

Adolescence is often described as a stormy period with multiple transitions in various life domains. Still, young people themselves generally have an optimistic view of the future and embrace the possibilities of adulthood. This offers healthcare professionals and parents the opportunity to empower young people in their journey towards adulthood. Self-management does not imply doing it all by yourself; but it starts with the acknowledgement of the right and the need to include young people in (decisions about) their own care and life.

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