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Perceived Social Support of Children with Severe Chronic Physical Health Conditions

A Systematic Literature Review

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ABSTRACT

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Severe chronic physical illnesses are often accompanied by extensive stress and lowered psychosocial well-being. To protect severely ill children from negative outcome resulting from this, supporting them to increase their psychosocial well-being and thus physical health is important. Especially significant social support is necessary for better outcomes. Perceiving social support can differ from what is actually provided and misconceptions about what children need and perceive are possible. Thus, asking children what they perceive as provided social support and as helpful is crucial. A systematic literature review was conducted in February 2016. 11 articles on perceived social support from child perspectives were found thought a data base search. Participants ranged from five to 12 years of age with cancer, cystic fibrosis, asthma, HIV, and diabetes. Findings showed that family, and especially parents, are the major support source for emotional and instrumental support at this age. Peer and professional support increase with age, while spiritual social support might be important for individual children. Types of perceived social support were mainly emotional and instrumental support from all support providers, with emerging informational support from professionals and sometimes family, and partly appraisal support from spiritual powers and peers. Areas of unmet needs are opportunities for meeting similarly affected peers for social support, and community support and education. The high importance of family for pediatric patients is suggestively due to strong emotional bonds with and reliance on close family and especially parents in early years. Implications are fostering family relationships and well-being, facilitating old friendships while providing possibilities for new ones, and educating communities for better social support opportunities. This study highlights the need for more research on child perceptions of social support. Future suggestions are studying perceived support from a whole-family approach, and studying outcome measurements such as physical health and participation.

Keywords: Perceived social support, psychosocial support, child's perspective, children, chronic illness, physical health condition, cancer, cystic fibrosis, CF , HIV, diabetes, asthma

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1 Introduction

The increased quality of health services has caused survival rates of previously fatal illness, such as cancer, to recently increase to 80% for children, which makes their course more chronic (American Cancer Society, 2010). Ten to thirty percent of all school-aged children will have some kind of chronic illness or health problem at one point in their lives with a significant portion of them being severely affected (Canter & Roberts, 2012). Adaptation to and living with a severe illness and its treatment for a prolonged period of time becomes a daily challenge. In addition to the physical complaints and treatments, psychosocial well-being is increasingly important with this chronic development. Severe long-term illnesses cause significant stress, demanding adaptation and effective coping (Bilfield, Wildman, & Karazsia, 2006). People with such chronic illnesses are in need of social support for successful handling of the permanent demands of their illness (Varni & Katz, 1997). Especially children face the strains of a severe illness on top of the developmental struggle of childhood (Kyngäs et al., 2001).

Social reintegration in school and family life, as well as enhancing the overall quality of life for chronically ill children is the primary concern next to physical treatments (Varni & Katz, 1997). Good psychosocial well-being is a major factor of social reintegration. In order to socially reintegrate, children have to participate in various social life situations (Mattson & Hall, 2011). This is facilitated by internal coping mechanisms, such as resilience, and positive social support. Children with chronic illnesses have been shown to often possess such important resources for successful coping and resilience (Hampel, Rudolph, Stachow, Laß-Lentzsch, & Petermann, 2005). However, interventions are needed to strengthen these individual resources. Positive social relationships with supportive characteristics facilitate well-being and help children to cope with severe stress and strains (Corey, Haase, Azzouz, & Monahan, 2008). Providing appropriate social support adds an important contribution to the physical and psychosocial well-being of a sick child. It is, however, also necessary that the child perceives the support as provided and helpful. Limited up-to-date research is currently present on how children with severe chronic diseases cope with social and psychological strains in daily life and how children themselves perceive the provided support. Keeping this in mind, the question arises: How can professionals and the social community of the chronically ill best support these children in terms of psychosocial well-being in daily life?

1.1 Severe physical health conditions

Severe physical long-term illnesses are health conditions primarily with bodily problems lasting longer than a year, or having a longer impact on life, such as diabetes, cystic fibrosis, and cancer (Bedroussian & DeVol, 2007). This usually includes having at least one prolonged hospital inpatient stay with recurrent visits to health professionals and on-going therapies over a long period of time. These health conditions often bring extensive stress in daily life with them. The duration, prolonged treatment and extensive stress are

compounded by the severity of the condition and are often related to a terminal progress or imminent danger of death. The terms illness and disease, as well as health conditions are used interchangeably in this paper.

Chronic diseases have a large negative impact on a child's mental health and well-being (Kiliś-Pstrusińska et al., 2013; Varni & Katz, 1997). Negative developmental outcomes and a heightened risk for psychosocial problems, such as decreased social contact and participation, following a severe health condition have been identified (Bilfield et al., 2006; Dumas et al., 2015; Li, Chung, & Chiu, 2010). Parents have reported lower quality of life (QoL) in children with chronic diseases. Social rejection, not attending school for prolonged periods, and facing death and painful treatments are common stressors for children with chronic conditions like cancer, HIV, cystic fibrosis, and cardiovascular diseases. The significant stress provoked by a long-term illness might have a hindering effect on healing and rehabilitation (Klosky et al., 2014; Malecki & Demaray, 2002; Zebrack et al., 2014).

Despite diversity in physical problems of chronic illnesses such as cancer, HIV, cystic fibrosis, or diabetes, children with these conditions experience similar psychosocial problems, as suggested by previous literature (e.g.: Çavuşoğlu & Sağlam, 2015; Kiliś-Pstrusińska et al., 2013; Malecki & Demaray, 2002; Varni & Katz, 1997; Zebrack et al., 2014). Learning how to cope with intense illness-related emotions, changing behaviors for better treatment and health, and managing disruptions in daily life are major tasks (Institute of Medicine, 2008). To tackle prominent psychosocial problems and coping difficulties of pediatric patients with severe chronic conditions, social support can be of help.

1.2 Social support

Social support is the "process of interaction in relationships which improves coping, esteem, belonging, and competence through actual or perceived exchanges of physical and psychosocial resources" (Cohen et al., 2000, p. 28). Hereby, the emphasis is on communication and the interaction between both parties of providing and receiving support. Social support is seen as the perception and actualization of being cared for, receiving assistance from other people, and being part of a supportive social network (Cohen et al, 2000).

Different support providers have been identified: Apart from support provided by professionals, hospitals or other institutions, social support provided by family, friends and the community can additionally support children's well-being effectively. The benefits of social support depend on relational, personal, situational, and emotional characteristics of the interaction between support provider and receiver (Cohen et al., 2000). Social support can generally be divided into four categories: emotional, instrumental, informational, and appraisal support (see Table 1) (Decker, 2007; Malecki & Demaray, 2002). Emotional support refers to drawing support from social relationships that provide feelings of love, trust, empathy, and a sense of being cared for. If others provide active help by doing things for someone it is understood as instrumental support. Informational support contains helpful information, advice and suggestions received from others. Lastly,

appraisal support is other people providing encouraging feedback that can be used for self-evaluation and constructing a positive self-image.

Table 1

Four types of social support

Construct	Definition
Emotional Support	Expression of love, trust, empathy, and caring
Instrumental Support	Services and tangible aid
Informational Support	Information, advice, and suggestions
Appraisal Support	Information which is useful for self-evaluation, encouraging

Having support that is available and accessible for a person in its social network is crucial (Tardy, 1985). Most studies report on provided social support rather than perceived social support. Provided social support is the provision of objective support. Perceived social support refers to the perception that social support is available for usage. When social support is not perceived as accessible or available, support wishes and needs can arise.

Social support is mainly associated with positive effects, while also bearing some negative outcomes. Positive, stable personality traits and coping mechanisms have been found to be associated with early social support and a good social network (Uchino, 2009). Social support teaches especially children to deal with and decrease stress, as well as to develop and apply coping mechanisms for better well-being (Decker, 2007). Being part of a social community and relying on others further lowers negative health outcomes and mortality rates (Reblin & Uchino, 2008). However, a possible negative effect of social support is the perception of a decrease in privacy because of more time spent with support providers. Pediatric patients for example often feel reluctant to talk about emotions concerning their illness because of the increased closeness of family and others (Decker, 2007). Considering both, positive and negative sides of social support are therefore required.

Using a form of social support and valuing it strengthens one's self-concepts and coping mechanisms in challenging life situations (Varni, Katz, Colegrove, & Dolgin, 1994). Perception of availability of social support often gives patients a feeling of belonging. Moreover, the sole perception of being able to rely on social support when needed provides young patients with the required strength and belief for successful coping. Positive well-being and adjustment to challenging life circumstances (e.g. severe chronic illness) are associated with good social support (Garbarino, Ganzel, & Zigler, 2000; Malecki & Demaray, 2002; Zebrack et al., 2014). Since high levels of stress triggered by chronic developments of severe illnesses demand good coping skills of patients (Decker, 2007; Zebrack et al., 2014) social support has to be stable and perceived as positive over time for positive outcomes (Uchino, 2009).

1.3 Social support and health

Social support influences stress evoked by illness in a multidimensional way. Three theoretical processes on how social support facilitates well-being and health outcomes have been established: social buffering hypothesis, social constructionism, and main effect model. The first perspective is the social buffering hypothesis (Cassel, 1976). It sees social support as buffering stress of health issues by providing coping mechanisms and support (Cassel, 1976; Cohen et al., 2000; Uchino, 2009). Learned coping mechanisms and support drawn from social relationships can be basic things like a better diet, exercise, and other health enhancing behavior (Reblin & Uchino, 2008). Buffering of stress through support relies on the quality and availability of different types of support. According to this theory, in order to be helpful, the received and perceived social support should match the demands of present. Social support that buffers experienced stress promotes a positive health outcome.

Social constructionism is the second perspective, which holds the beliefs that social support promotes self-esteem and self-regulation, which are necessary for coping (Cohen et al., 2000; Lakey & Cohen, 2000; Varni & Katz, 1997). Relationships between support provider and receiver are reliant on the emotional capacities and self-perception of the recipient, while influencing the support receiver's self-concept and self-esteem (Uchino, 2009). The basic idea of the social constructionism theory holds that cognitive appraisal derived from social relationships helps to develop relevant self-concepts, which are coping strategies, and promote resilience.

According to the third theoretical perspective, the main effect model, social relationships are seen as essential to well-being and thus as directly promoting health outcomes (Cohen & Wills, 1985). When social relationships that provide a sense of caring and belonging, less stress is experienced (Uchino, 2009; Varni & Katz, 1997). Social support is hereby seen to be highly effective regardless of how much stress is experienced. This main effect of social support on well-being and health is exemplified by a study by Kyngäs et al. (2001) who found that social support itself was the most common used coping strategy for tackling health related problems in adolescent cancer patients.

Apart from how social support promotes well-being, other issues related to the relationship among social support, health and well-being have to be kept in mind. A severe diagnosis in itself usually has a great impact on the social relationships in a child's life (Helgeson & Cohen, 1996). An intense life-event, such as a severe illness, often causes anxiety and elevated stress in parents and emotionally close others. Support providers are most often parents for children. Their experienced increased anxiety may hinder retrieval of effective supporting skills (Gottlieb, 2000). It impacts the whole family, poses a threat to the child-parent relationship, and can have negative effect on well-being and thus health for the child (Kiliś-Pstrusińska et al., 2013). The chronic illness puts a strain on the social network and might even destroy relationships, as well as make social support unavailable.

If and how support has an effect is dependent on whether it is perceived as support or not. Emotional support is especially important for a positive outcome in uncontrollable events, such as a severe illness (Uchino, 2009). Nevertheless, the social environment can be of harming character (DiMatteo, 2004; Mäntymaa et al., 2003). Received social support can have a variety of outcomes, while perceived support mainly results in positive effects on health (Uchino, 2009; Wills & Shinar, 2000). To promote positive well-being of chronically ill children, social support that they perceive as helpful should be considered.

1.4 Perceived social support

Received and perceived support are separable constructs (Tardy, 1985; Wills & Shinar, 2000). On the one hand, received social support largely relies on situational factors, such as availability, type of support and timing. Perceiving social support, on the other hand, is learned in early development and depends on family interactions (Uchino, 2009). This makes it relatively stable over time. The cognitive perception that one is valued and cared for, and that support from others is available makes up perceived social support (Varni & Katz, 1997). It is primarily dependent on a person's ability to perceive support and can be solely described, or evaluated, as either positive or negative based on what is considered as needed by the individual (Norris & Kaniasty, 1996; Tardy, 1985)

Nevertheless, situational factors, such as actual provided support, can also impact an individual's perception of available support (Uchino, 2009). Stressful life-events often alter social interactions and demand extensive social support (Norris & Kaniasty, 1996; Uchino, 2009). These needs can be hard to live up to and actual available support is often lacking. Strains resulting from a stressful life-event can provoke anxiety and denial in potential support providers which might lead to a failing of actually providing support (Gottlieb, 2000). If no social support is provided, it cannot be perceived.

Exactly how perceived and received social support are interlinked and why they are separable units is yet unknown. One possible explanation is that people with a higher ability to perceive support are more likely to acknowledge received support. Moreover, Uchino (2009) argued that perceiving support constructs self-esteem and makes an individual feel more secure. Better coping might result from this which makes the actual use of received support unnecessary. To study perceived social support, self-reports of the support receiver are required.

1.5 Children's perceptions

Investigating a child's perception calls for asking the child for its opinion. Children with the cognitive and linguistic abilities to communicate are able to voice their opinions and thoughts (Nilsson et al., 2015). Varni and Katz (1997) conclude that a child's report about their perceptions provides a unique perspective and insights that would not be accessible through external sources. Children's personal experiences, perceptions and satisfactions might differ to a great extent when compared to adults' ratings (Falkmer, Granlund, Nilholm, & Falkmer, 2012; King, 2013). A child's view, as opposed to a parental or professional

point of view, gives a more thorough, and possibly more significant, indication of what children really need. Thus, self-reports of children are of high importance when it comes to investigating how to optimally support them in the course of their illness and development.

When doing research with children, special ethical considerations are requires apart from those made in research with adults (Nilsson et al., 2015). While children are too young to be seen as fully accountable parents have to be asked for permission for research. However, children themselves still have to agree to be studied (Chaplin, 2012). Assuring the rights of the child and respecting it in research is of highest importance. Children can be highly involved in research when adapting techniques to their needs and seeing research from a child's perspective rather than a child perspective (Nilsson et al., 2015). Data collected in qualitative questionnaires for example require a careful interpretation that is based on an understanding of what children mean and refer to with their answers. Quantitative research can be conducted with children who have developed reading and writing skills, when a child-like understanding is kept in mind for developing the questionnaire. To support such data, letting children illustrate their ideas with pictures, puppets, or play is suggested for younger children.

Children start to develop more abstract ways of thinking and communicating their thoughts and feelings with the onset of school. In many countries, this is between the age of five and seven. The following big milestone in a child's cognitive development is moving to secondary school and becoming a teenager, around the age of 13 years. The age range of five – 12 years conforms to the idea of Piaget's "concrete operational stage" (initially 7 – 11 years) of cognitive development which brings emerging cognitive and linguistic abilities with it (Piaget, 1977). Children at this stage start to form deep relationships to others and move from the exclusive context of relying on family support to seeking social support in others (e.g. peers, other significant adults) (Hwang & Granlund, 2013). The change in social relationships paired with developing cognitive and linguistic communication skills makes it possible to ask children at this stage for their own perceptions about social support in their emerging relationships with others.

1.6 Ill children's perceived social support

Helping young patients with a severe chronic health condition cope is important. Children have internal coping strategies to deal with their illnesses like returning to their "normal life" as soon as possible, hoping, and believing in God (Kyngäs et al., 2001). Further, for young adults, a sense of sustaining one's personality and independence is highly rated (David, Williamson, & Tilsley, 2012). Strengthening these internal coping mechanisms through external social support with, for example, positive reinforcement and perspectives from others helps many patients stay positive (Helgeson & Cohen, 1996; Hokkanen, Eriksson, Ahonen, & Salantera, 2004; Kyngäs et al., 2001). Social support is based on patients' perceived relations to family, friends, and professionals (Hokkanen et al., 2004).

Young people perceive family as the most important social support provider in their lives (Çavuşoğlu & Sağlam, 2015; Ishibashi, 2001). The primary responsibility of parents and legal guardians is to assure a good

upbringing and healthy development of a child (§18 UN, 1989). Therefore, the development, behavior and mind of a child are highly connected to the family environment (Earls & Buka, 2006). Emotional, physical and social demands that accompany having a chronically ill child create additional stress to the role of parenting. These children require supplementary support in their everyday lives when it comes to basic human needs and participation in family and social life. During a severe course of illness, adolescents have defined maintaining good relationships with their parents and siblings as the most important social support for them (Decker, 2007; Haluska, Jessee, & Nagy, 2002; Woodgate, 2006), especially in times of relapse (Çavuşoğlu & Sağlam, 2015). More specifically, Haluska et al. (2002) found that young cancer patients were overall satisfied with perceived social support and valued their parents' support more than their healthy peers. Especially mothers are often valued as a major support provider (Decker, 2007), due to the fact that mothers are more often the primary care taker for school-aged children and thus are more closely emotionally connected to the child.

Furthermore, having close, supportive relationships with peers is important (Decker, 2007). Juvenile cancer patients have identified either a close friend that stood by them throughout their illness or a new friend with similar experiences as their biggest and most important supporter within the friends group (Decker, 2007; Woodgate, 2006). The need for friend-support is highlighted in the acute treatment phase and decreases over time (Decker, 2007). Many children with a severe, physical, chronic condition perceive social emotional support from their friends and family, but the majority would like to have more contact with others who are similarly affected. Seeking health related information from peers with similar illnesses is especially important (Decker, 2007; Martin et al., 2014). This seeking for peer support can be connected to their need of individuality and personality building in childhood. Peers help to develop one's own identity while understanding and relating to the situation one faces. Possibilities to provide the needed peer contact and to create an environment where young patients feel safe enough to share their experiences, participate, and bond with others are specially designed summer camps (McCarthy, 2015; Zebrack, 2011), or internet support groups (Hokkanen et al., 2004; Martin et al., 2014).

Next to family and peer support, health professionals also play an important role when it comes to social support. Woodgate (2006) found that many adolescents report having a supportive relationship with one particular member in their health care team. Often these supporters are nurses who are there for them and help them keep a positive attitude. The availability of a stable staff member is hereby very important (Decker, 2007; Kyngäs et al., 2001). The social aspect of supportive relationships to health care professionals is defined by discussing health related coping behavior and emotions (Kyngäs et al., 2001). Patients often find it easy to talk to health professionals about these topics, because it allows them to keep a sense of autonomy and anonymity due to a less personal level of relationship with professionals. Professionals informal help is often valued and perceived as being helpful when it comes to motivating and reminding children to follow their treatment plan and daily exercises at home (Happ, Hoffman, DiVirgilio, Higgins, & Orenstein, 2013), as well as directly providing individualized information (Ishibashi, 2001). Health care professionals were rated as

increasingly important for emotional support by providing information in the course of adolescents' illness (Decker, 2007; Kyngäs et al., 2001). A literature review revealed that information was most valued when it came from health professionals and less from family and friends (Helgeson & Cohen, 1996).

Apart from the importance of support providers, a number of factors related to perceived social support are to be considered. Helgeson and Cohen (1996) showed that possible support providers have many misconceptions about social support needs of cancer patients. Providers believed that cheering patients up, avoiding talks about the illness, and avoidance of the patient were appropriate, whereas patients themselves saw these behaviors as unhelpful and hurting. Instead, emotional and informational support are overall rated as most important (Helgeson & Cohen, 1996; Kyngäs et al., 2001). These support types in social relationships increase psychosocial well-being, which facilitates participation in social situations (King et al., 2006), while leading to social integration (Reblin & Uchino, 2008). Woodgate (2006) found that for pediatric cancer patients the social component of participation, the "being there", of close others was highly important. "Being there" has to be understood in terms of not only being there physically, but also being present in a more mental and spiritual way, namely being engaged, or the psychological component of participations. The presence of significant others comforted patients, gave them a feeling of belonging and not being alone, and kept them positive by reminding them that they had a life apart from their illness (Helgeson & Cohen, 1996). This personal feeling of belonging and being socially included is a part of participating in social situations (Falkmer, Granlund, Nilholm & Falkmer, 2012).

When children perceive a higher level of social support their negative affectivity tends to be lowered (Varni & Katz, 1997). When participating in social school settings, especially classmates' social support has been found to be positive for better self-esteem, lowering illness-related anxiety, and depressive symptoms (Mattson & Hall, 2011; Varni, Setoguchi, Rappaport, & Talbot, 1992). Moreover, perceived parental, peer and teacher social support has been found to be negatively related to psychological distress and positively to self-esteem (Varni et al., 1994). Thus, perceived support is crucial for a positive well-being and development in childhood.

Positive relationships of a sick child with family, health professionals, and peers are essential when it comes to its well-being are important (Darcy et al., 2015). Many studies can be found on perceptions of parents and health professionals when it comes to helpful social support for ill children. Further, adolescents' and young adults' perceptions have been studied more thoroughly than younger children when it comes to perceived social support. What young children themselves really perceive as being helpful however is rarely investigated. The question arises: What do young children perceive as social support and what do they value in the course of their severe and chronic illness? Gaining insights into perceived social support for young patients can help to develop intervention strategies for these children, and educate and support the significant support providers in their surroundings. Especially since children and youth surviving severe or fatal long-

term health conditions have been found to be at a heightened risk for poor social development and adverse effects (Dumas et al., 2015) tailored social support for this group is crucial.

1.7 Aim

The aim of this literature review is to explore how children with severe physical long-term health conditions perceive and evaluate social support as reported in the literature.

1.8 Research questions

1. According to literature, what characterizes social support that children with severe physical long-term health conditions perceive as provided?
2. What characterizes social support that these children perceive as being helpful for them?

2 Method

A systematic literature review was performed. This taxonomy refers to a systematic and transparent collection process of scientific articles. The process of a systematic literature review starts with mapping the field of knowledge, conducting a comprehensive and replicable search, extracting data and synthesizing results (Jesson, Matheson, & Lacey, 2011). Additionally, a quality assessment of reviewed articles is performed to minimize the bias of individual studies.

2.1 Preunderstanding

The author of this paper has a background of psychology and social aspects of dealing with a severe long-term illness. Preunderstanding influences and constrains the way one understands information (Nyström & Dahlberg, 2001). The phenomenology of the author suggests the understanding of and search for social aspects within the illness context (SBU, 2014). By being aware of this, the author attempts to control for this bias by "avoiding projective interpretations" (Nyström & Dahlberg, 2001, p. 344).

2.2 Search strategy

The database search for this systematic literature review was conducted in February 2016 using AcademicSearchElite, Pubmed, and PsychINFO. These databases integrate articles from the fields of psychology, social sciences and health. Search terms were chosen according to their theoretical and practical significance, and with help of database thesauruses. Terms addressed population-age, as well as concepts of perceptions, social support and health conditions. Truncations of terms by adding asterisks to the word stem were used for a greater variety of results.

Search words used were (child* OR pediatric*) AND (perce* OR attitude* OR opinion*) AND (help* OR support*) AND (informal* OR social*) AND (ill* OR disease* OR cancer* OR heart* OR cardio*) AND (physical* OR medical*) AND (terminal* OR chronic* OR "long-term" OR severe*). A first search included the selected search words separately. After the first search process, a second search was conducted due to unsatisfactory results in the first search. Results of both searches combined were used for this review. For the second search, search terms that were associated with each other were combined in strings to achieve more significant results. Search strings were: (child* OR pediatric*) AND (perce* OR attitude* OR opinion*); (help* OR support*) AND (informal* OR social*); and (ill* OR disease* OR cancer* OR heart* OR cardio*) AND (physical* OR medical* OR terminal* OR chronic* OR "long-term" OR severe*). Additionally the search term "child's view" was added in the first string concerning children and perceptions: (child* OR pediatric*) AND (perce* OR attitude* OR opinion* OR "child's view").

Publications published in peer-reviewed journals, dates between January 1st, 2000 and December 31st, 2016, publications in English, and available free full-text were additional inclusion criteria added to the searches (see Table 2). Age range of populations of articles was set to five – 12 years of age within the

population age options of each database in the second search procedure. After articles were chosen in the process of title/abstract and full-text screening, a hand search was performed. For this, reference lists of included articles were searched for other significant studies.

Table 2

Inclusion and exclusion criteria for title and abstract screening

Inclusion criteria	Exclusion criteria
Publication type - Articles published as full texts in peer-reviewed journals - Full text available - Published in English - Published between 1.1.2000 and 29.2.2016	- Abstracts, conference papers, theses, books, other literature - Published in languages other than English - Published before 1.1.2000
Population - Age range of participants 5-12y - Severe physical long-term health condition	- Physical disabilities - Mental health conditions - Long-term survivors older than 18
Measure - Perceived social support - Child's view	- Parental/families OR caretaker's perception
Design - Qualitative AND/OR quantitative studies - Case studies	- Literature reviews - Protocols

2.3 Selection criteria

A detailed list of in- and exclusion criteria can be found in Table 2. This systematic review aimed at studying a population of pediatric patients with physical long-term health conditions. Therefore, studies with physical long time effects of at least one year or requiring on-going care were selected. Severity relates to extensive stress in daily life, or the terminal or fatal course of a condition. Severe physical illness are often also termed disorders. However, since database thesauruses suggested the word disease instead of disorder, only disease was used as a search word.

Because of the need of children's self-reports studied children needed to be able to voice their perceptions autonomously. Thus, studies dealing with children younger than the age of five were excluded (Nilsson et al., 2015). The age of five was chosen as it is the starting point of school in many countries, which brings a change in a child's life with it that distinguishes their cognitive abilities and their perceived needs from children younger than five years of age. The maximum age in included articles was set to 12 years. This is the age where children often transfer to secondary school. Children above the age of 12 years are usually referred to as teenagers and are thus a different sample. Teenage years hold a fundamental change in social relations and teenagers rely more and more on peers than solely on family bonds. The chosen age range from the years

five to 12 is congruent with the "child" definition offered by the used databases. As many articles have varying age ranges in populations, at least 50 % of samples of included articles had to be within the age range set by the author, or a sub-sample of children was used in the analysis.

Articles not studying perceptions of children themselves were excluded. Studies reporting descriptions of perceived social supports (who, how, and what) and evaluations of perceived support by children were included. To ensure that important information was not missed, quality of life (QoL) measures were included when social support was a secondary study objective.

2.4 Selection process

The three steps in the data collection process (article selection, data extraction, and quality assessment) were performed by one researcher. The detailed search process is illustrated in a flowchart (see Appendix 1). Two searches were implemented in February 2016 where a total of 1641 articles were found. Elimination of non-peer-reviewed articles led to 1341 included articles. Limiting the publication date till after the first of January 2000 decreased the number of results by 156 (n=1185). By additionally setting the article search to only English publications, 1153 articles were included. Of these, 724 full-texts were available (search 1: n=275; search 2: n=449). Finally for the second search, the participant age range was set to five-12 years which resulted in a final total number of n=110 articles within the second search. The remaining combined 385 articles in both searches were first screened on title and abstract level, as well as on full-text level for the included articles.

After screening titles and abstracts of the 385 articles, a total of 39 articles were selected for full-text review. Full-text screening resulted in 13 articles. Three of these articles were removed as they were duplicates and appeared in both searches. A hand-search was performed and reference lists of selected articles were scanned for relevant articles to assure that no important information was missed. This resulted in one additional article. Finally, 11 articles were selected for data extraction.

2.4.1 Title/Abstract screening

A short checklist based on in- and exclusion criteria, as presented in Appendix 2, was used for title and abstract screening. The screening process was performed separately in the two search processes, as can be seen in the flowchart (see Appendix 1). However, numbers of excluded articles are reported combined in this section.

104 articles were excluded due to health conditions that were either not chronic, not severe in that they were not life-threatening or causing significant clinical distress, not physical, or could be categorized as some kind of disability. Disorders often refer not only to biological, but also behavioral, psychological dysfunctions (American Psychiatric Association, 2000), which can bring altered cognitive functions with it. Therefore, mental and neurological disorders that affect cognitive functions were excluded. 79 articles were excluded because of not studying social support, and 79 because of missing self-reports of children. 56 of the

remaining articles did not include participants within the anticipated age-frame of age five to age 12. Lastly, 28 articles were duplicates and were thus excluded. Duplicates were discovered with the help of the online tool Covidence (Mavergames, 2013). Full-texts of the remaining 39 articles were collected for the next stage of the screening process.

2.4.2 Full-text screening

A detailed protocol (see Appendix 3) which was further based on the in- and exclusion criteria was applied for full-text screening. Included articles were read and their data was used to advance the categories and protocol for full-text review. Four conditions for significance of inclusion of an article to this particular literature review were studied in depth at this stage: child report, perceived social support, age group, and study design. Articles had to report children's own perceptions, whereby 9 studies failed to report this and were thus excluded. Measurement of perceived social support was not reported by 9 more articles which were thus excluded. Three articles reported social support within an initially formal support setting, such as summer camp or a befriender program (Kiernan, Guerin, & MacLachlan, 2005; MacDonald & Greggans, 2010). These articles were kept for data extraction as they reported social aspects that exceeded the formal support characters of the programs.

Some articles that were screened at full-text level had only few participants within the required age-group. To increase the significance of the results and to make the results more age specific, articles with a sample that consisted of at least 50% of children within the ages of five-12 years, or with a mean age within this age frame were included. Articles with more than 50% of their sample not conforming to the age requirements were excluded (n=5). Two articles did not report the percentage of participants within this age frame, but reported no statistical significance in answers between age groups. Hence, these studies were kept for the analysis.

At this stage, the researcher decided to exclude literature reviews, due to not being appropriate to answer the research questions. Therefore, three articles had to be excluded. After conducting the full-text screening separately within the two search processes the remaining 13 articles were combined and three duplicates were identified. Ten articles from the screening process plus one additional article found through hand-search were used for data extraction.

2.4.3 Peer-review

A second researcher assessed a random sample of five articles (3 included, 2 excluded) at full-text level for significance to the research questions. The second reviewer agreed to the first reviewer's choice on three articles (2 included, 1 excluded). The two remaining articles were discussed thoroughly. Hereby the two parties agreed that one article (Kamper, Van Cleve, & Savedra, 2010) should be included due to appropriate description of social support within a spiritual setting. A second article (Williams, Mukhopadhyay, Dowell, & Coyle, 2007) was excluded, as support described in this article did not fit this paper's definition of social

support. Overall, after discussing differences in opinions, this resulted in an overall coherent agreement on the in- and exclusion of articles.

2.5 Data extraction

Data was extracted with the help of a data extraction tool (combined full-text protocol and quality assessment, see Appendices 3 & 4*).* Studies' information was extracted by authors' names, year of publication, country of publication, and title. Extracted data included information about the sample, social support and perceptions. Details about the study design, setting, and measurement tools were also recorded. Information about the sample contained sample size, mean age and age range, gender, ethnicity, and health condition. Results about descriptive information of perceived social support, evaluations of support and relationship of social support to other variables were obtained from the articles.

2.6 Quality assessment

To assess the quality of reviewed articles (qualitative, quantitative and mixed methods) the review checklist COREQ-32 (Tong, Sainsbury, & Craig, 2007) for qualitative studies was adapted for use of all three types of empirical studies. "The criteria included in the checklist can help researchers to report important aspects of […] study methods, context of the study, findings, analysis and interpretations" (Tong et al., 2007, p. 356). As it is suggested to adapt this reviewing tool for individual application for one's review (Jesson et al., 2011), the researcher chose applicable items and added criteria for quantitative studies. Finally, quality of included studies was assessed based on 17 items on study design, data collection, analysis, and findings (see Appendix 4).

Since this review dealt with children of young age, special ethical considerations had to be considered (Nilsson et al., 2015). Parental permission, as well as children's own agreement for research had be collected (Chaplin, 2012). While ethical considerations were upheld by all articles, children in the reviewed articles were highly involved by adapting techniques that conformed to their needs and communication abilities (e.g.: drawings, interviews, play) (Nilsson et al., 2015).

For each of the 17 items one quality point was assigned for reporting or conforming to the requirement. Studies with 15 to 17 quality points were rated as high, 12 to 14 quality points as medium, and 0 to 11 quality points as low quality. Seven of the chosen articles were rated to have high quality of research (see Appendix 5) (Battles & Wiener, 2002; Eiser, Vance, Horne, Greco, & Glaser, 2004; Kamper et al., 2010; Kiernan et al., 2005; Mitchell, Clarke, & Sloper, 2006; Pendleton, Cavalli, Pargament, & Nasr, 2002; Pendley et al., 2002). Three more articles were rated as having medium quality (Einberg, Svedberg, Enskär, & Nygren, 2014; Martin, Beebe, Lopez, & Faux, 2010; Stewart, Masuda, Letourneau, Anderson, & McGhan, 2011). Reasons for this were missing control groups, small sample size, or missing reliability of measurements. The remaining study (MacDonald & Greggans, 2010) was rated as being of low quality due to very small sample sizes ($n < 20$), no reported measurement tool, reliability of measures, and no reported limitations.

Despite these quality ratings, all selected studies were used for the results of this paper. Reasons for this were limited number of articles on children's perceived social support. Emphasis was put on studies of high and medium quality based on this evaluation.

2.7 Data analysis

During and after the data extraction process, the analyzing process was performed. With help of the construct of perceived social support, categories representing factors that make up social support emerged: social support types, providers, behaviors, ratings, and wishes. Categories are based on columns in the protocol for full-text (see Appendix 3). Results will be presented according to identified categories and relations drawn between them.

Categories answered the questions where, what, who, how, as well as ratings, effects and wishes concerning perceived social support. More precisely, areas and life situations in which social support was perceived were identified. Secondly, categories of social support providers were analyzed. Hereby, not only humans and pets in a child's proximal surrounding were included, but also perceived support of God or another spiritual power. Reason for this inclusion is that God/higher power can be perceived as an active agent that provides support. A third category contains perceived sources that provide social support for children. Fourthly, the specific support actions or interpersonal relationships were analyzed within the protocol category "how". Children's evaluations of perceived social support and connections to other outcome variables were further identified.

3 Results

Based on carefully selected in- and exclusion criteria 11 articles were used for answering the research questions, of what characterizes social support that children with severe physical long-term health conditions perceive (1) as provided and (2) as helpful to them. Results of this systematic literature review were structured according to different factors of social support. All study samples included children between the ages of five-12 years and are from here onwards only referred to as "children". An overview of authors, publication years, sample with age group and diagnoses, aim, major finding, and quality rating of the included articles is presented in Appendix 5. Difference between results based on diagnoses or ethnicity were not found.

Four articles had children's perceived social support as a primary outcome (Einberg et al., 2014; Mitchell et al., 2006; Pendley et al., 2002; Stewart et al., 2011). Two articles measured children's perceived social support explicitly as a secondary measure (Battles & Wiener, 2002; Kiernan et al., 2005). Study outcomes of the remaining five articles were self-reported overall or spiritual quality of life with a component of social support (Eiser et al., 2004; Kamper et al., 2010; Pendleton et al., 2002), and outcomes associated with psychosocial adjustment and learning within the family and peer environment (MacDonald & Greggans, 2010; Martin et al., 2010). Tools used were focus groups with three or four children (Einberg et al., 2014; Martin et al., 2010), unstructured interviews, or previously designed questionnaires (SSSC, Harter, 1985; DSSI, La Greca, Swales, Klemp, & Madigan, 1988) with follow-up interviews, which were sometimes supported by children's drawings for better understanding (Pendleton et al., 2002).

3.1 Perceived social support providers

Four major groups of social support providers as perceived by children were found: family, peers, professionals, and spiritual powers. Hereby, some support providers were more prevalent in specific life areas. Life areas in which social support was perceived were grouped into (1) everyday life, (2) coping with illness and being in the hospital, (3) school context, and (3) within summer camps. Perceived social support sources in relation to areas of social support are reported in Appendix 6.

3.1.1 Family

The major source of social support as perceived by children with various kinds of severe chronic diseases was their family. Compared to other social support providers, family was especially important within everyday life and dealing with ones' illness in hospitals and in daily life. Six of the studied articles reported the importance of family (Eiser et al., 2004; Kamper et al., 2010; Martin et al., 2010; Mitchell et al., 2006; Pendley et al., 2002; Stewart et al., 2011), whereby five of them stressed the importance of parents as support providers. Mothers were mentioned as the most important social support providers by children in one study (Stewart et al., 2011). Apart from parents, siblings and other relatives were also mentioned (Kamper et al., 2010; Pendleton et al., 2002).

3.1.2 Peers

The other major social support provider group was made up by peer relations of different kinds. Peers were mentioned and rated as being important by children across all four life situations. Peer relations ranged from friendships with healthy and ill children of similar ages (Battles & Wiener, 2002; Einberg et al., 2014; Pendley et al., 2002) to peer groups in a more artificial setting (i.e. befriender programs, support groups, and summer camps) (Kiernan et al., 2005; MacDonald & Greggans, 2010; Mitchell et al., 2006; Stewart et al., 2011) to relations with people in one's community (Kamper et al., 2010; Martin et al., 2010; Pendleton et al., 2002). One study also mentioned children perceiving social support from pets (Kamper et al., 2010).

3.1.3 Professionals

Children in two studies perceived social support from health staff, like doctors and nurses (Mitchell et al., 2006; Stewart et al., 2011) in coping with their illness in hospital settings and returning back home and to school. Perceived social support from professionals within the school setting was also reported by two articles (Martin et al., 2010; Mitchell et al., 2006).

3.1.4 Spiritual power

Two articles studied support perceived by children through believing in and interacting with God or another spiritual power (Kamper et al., 2010; Pendleton et al., 2002). This social support was mainly perceived for coping with one's illness and in everyday life.

3.2 Perceived types of social support

Perceived social support, as reported by severely chronically ill children in various studies, covered all four subtypes of social support: emotional, instrumental, informational, and appraisal support (see Appendix 7). Some articles also provided ratings of perceived social support.

3.2.1 Emotional support

Children in all reviewed studies reported their perceived social support as being relational to significant others in their life. Companionship from family, friends, and pets with aspects of love, caring, and empathy were most important (Battles & Wiener, 2002; Einberg et al., 2014; Kamper et al., 2010). The feeling of not being alone with their illnesses and being able to rely on others (e.g.: family, God/spiritual power) for support was a repeating concept reported by these children (Einberg et al., 2014; Eiser et al., 2004; Kamper et al., 2010; Kiernan et al., 2005; Pendleton et al., 2002). Understanding children (Mitchell et al., 2006), acknowledging their fears and concerns, and providing emotional support were perceived as supportive (Kamper et al., 2010; Pendley et al., 2002; Stewart et al., 2011). God/spiritual power was seen as providing children with social support by being with them, protecting them, and comforting them (Pendleton et al., 2002). Children felt like they could rely on God/spiritual power to help them. Praying, going to church or just thinking of God were mentioned as having contact to God/spiritual power (Kamper et al., 2010; Pendleton et al., 2002)

Children perceived close relationships as especially supportive when they contained certain components: common interests and experiences, mutual empathic actions, and mutual trust and understanding (Einberg et al., 2014; Kiernan et al., 2005). More specifically, having a connection to a friend via shared time and preferences, respecting and supporting each other, and being able to rely on the other person are important. For developing these equal and mutual commitments digital and face-to-face interactions are used.

3.2.2 Instrumental support

Children reported parental supervision and active support in health-related issues, like medication taking (Martin et al., 2010; Pendley et al., 2002). Mitchell et al. (2006) further reported that children perceived family support for helping care for them especially in the hospital setting. Health staff was of help to become independent.

Children perceived the significance of social support in a faith community or religious affiliate, like prayers, rituals and tangible aids brought by others, and God himself. For example, family members, friends, or religious affiliates mediated in the relationships to God and prayed for the sick children (Kamper et al., 2010; Pendleton et al., 2002). Available tangible aid was perceived in food, clothes, or presents from the faith community (Pendleton et al., 2002). This spiritual social support derived from a faith community was reported by 72% of the sample in Pendleton et al.'s study (2002). Direct support from God/spiritual power was perceived as God making children feel better and acting on their requests (Pendleton et al., 2002).

Instrumental support derived from peer relationships were commonly spent activities and mutual helping (Kiernan et al., 2005; MacDonald & Greggans, 2010). Activities were considered to be welcome distractions from everyday things and relieving boredom during hospitalization.

3.2.3 Informational support

The domain of informational support was characterized by advice and information from other's in similar situations, family, and health staff. Informational support about the disease and management strategies was mostly perceived from health care professionals (Mitchell et al., 2006) and partly by family/mothers (Pendley et al., 2002; Stewart et al., 2011). Information was often reported as provided by health staff directly in an understandable language (Mitchell et al., 2006). Nurses and doctors were perceived to spend a lot of time on explaining issues, providing advice concerning treatment and side-effects and considering patients' wishes and feelings. This was seen as social support as it extended the required level of information by additional possibilities for coping mechanisms and time (Mitchell et al., 2006). Lastly, children perceived hospital staff to help them become more independent when returning home after a hospital stay.

3.2.4 Appraisal support

Appraisal was perceived from peers saying positive things to the children instead of displaying negative attitudes (Einberg et al., 2014). From this, children drew social comparisons (Eiser et al., 2004) and learned being more confident and seeing that they were not alone in their fight against their illness (Kiernan et

al., 2005). Peers further helped children to dare to do more things, than they would have with their parents (MacDonald & Greggans, 2010).

When disclosing to others about their illness, children perceived more social support (Battles & Wiener, 2002). Children perceived speaking about personal and illness-related issues to other children in similar illness situation as helpful support and advice (Eiser et al., 2004; MacDonald & Greggans, 2010; Stewart et al., 2011). Talking to and receiving reassurance from healthy peers was also indicated to be social support for severely sick children (Mitchell et al., 2006).

Further guidance was perceived from spiritual powers, such as God (Pendleton et al., 2002). Appraisal support drawn from faith was believing in an afterlife, praying for normalcy, and using spiritual reappraisal of negative events, such as being tested with their illness (Kamper et al., 2010). Appraisal social support was barely reported as being of importance by children between five and 12 years of age.

3.3 Evaluations of perceived social support

Evaluations were presented in some of the reviewed articles. Table 3 contains the evaluations based on combined ratings by children and frequency of mentioning of the four social support types and support providers.

Table 3

Children's perceived social support types according to support providers

	Emotional support	Instrumental support	Informational support	Appraisal support
Family	**X** [a]	**X**	x	
Peers	x	x		x
Professionals		x	**X**	
Spiritual power	x	x		x

[a] Bold letters indicate which support provider was indicated as being most important in a specific support type.

3.3.1 Family support.

As depicted in Table 3, family was perceived as most important for providing emotional and instrumental support (Mitchell et al., 2006; Pendley et al., 2002; Stewart et al., 2011). Statements as "Seeing my mom […]" and "Knowing that there is someone out there who cares" (Kamper et al., 2010, p. 4) exemplify the importance of relations to other's for children's well-being. Parental social support as perceived by children appears to have a more constant course than the social support from friends or classmates (Battles &

Wiener, 2002). Especially parents staying with them and helping care for them in health-related matters was regarded with satisfaction by children (Martin et al., 2010, Mitchell et al., 2006).

3.3.2 Peer support

The perceived reciprocity of friendships helped children cope better (Eiser et al., 2004; MacDonald & Greggans, 2010; Mitchell et al., 2006) (e.g. "you can cope better in life when you have friends that are loyal to you, even when you are not in a good mood") (Kiernan et al, 2005; p. 738). Activities with peers were evaluated as being fun and enjoyable (MacDonald & Greggans, 2010) and were often welcome distractions from their illnesses and daily struggles. Faith communities were further rated as beneficial in that children felt part of a group and thought other's prayers helped them.

Some children, however, had neutral or negative views on peer support. Kiernan et al. (2005) found that about one third of their sample reported not learning and deriving anything from social interactions with friends, while the other two thirds in this study had enduring positive outcomes related to their personal growth in daily life and dealing with their illnesses. Being harassed and bullied due to one's illness was further negatively evaluated and led to feelings of exclusions and fear of confiding in others (Stewart et al., 2011).

3.3.3 Professional support

Children evaluated perceived information and advice from professionals as especially helpful and valuable when it was directly conveyed to them (Mitchell et al., 2006). Doctors and nurses making time to give advice about making treatment more bearable (80%) and possible side effects was perceived as helpful. Listening to the children's wishes and feelings was significant. When it came to leaving the hospital to go back home, children perceived hospital staff as supporting them to reach their anticipated degree of independence (75%, Mitchell et al., 2006).

Teacher support was perceived as being fairly constant over time and thus helpful, especially when compared to peer support (Battles & Wiener, 2002). 74% of children perceived teachers as understanding and positive about changed appearances when returning to school (Mitchell et al., 2006).

3.3.4 Spiritual support

Of those children that reported to pray or meditate 82% reported that it helped them (Kamper et al., 2010). Pendleton et al. (2002) reported that children perceived God as supportive in health related issues by making them feel better mentally and physically.

3.4 Support needs, wishes and fears

3.4.1 Emotional needs

Meeting other children with and without similar diagnoses was reported as an unmet need by some children (Kiernan et al., 2005; Mitchell et al., 2006), as opportunities were perceived to be scarce. Support from hospital staff to provide or facilitate meetings was wished for. Stewart et al. (2011) reported that 75% of

interviewed children in their study preferred peer contact with older children in similar situations to derive emotional support from them.

3.4.2 Informational needs

Children's wishes concerning education and information were mostly on community level (Martin et al., 2010). Educating teachers and community about health risks for ill children like smoking cessation education and reduction of general smoking in public places were identified. While Stewart et al. (2011) reported wishes for information from older peers, Kiernan (2005) found that children wanted similar aged peers to interact and talk with.

3.4.3 Instrumental needs

Related to community education, children wished for more active support from individuals in their healthy community (e.g. smoking cessation). The wish for recognition of their illness and readily availability of support from others was insufficient for many (Martin et al., 2010).

3.4.4 Fears

Perceived fears related to social support were "not finding peers" for social interactions and support (5.3%) and being without one's family-support (8.1%) (Kiernan et al., 2005). Further, children feared harassment and bullying in schools because of their illness (Stewart et al., 2011).

4 Discussion

This paper aimed at reviewing literature in order to find out what severely chronically ill children perceive as provided and what they consider as helpful social support. Results indicate that these children perceive many different available or accessible social support types (i.e.: emotional, instrumental, informational and partly appraisal support) from support providers as helpful and important in dealing with their illnesses and everyday life. Perceived providers are mainly family and peers, and to a lesser degree professionals and God. Despite much perceived social support more possibilities to meet peers with similar experiences, as well as education and acknowledgment within the community are unmet needs that require attention.

Children's relationships account for most of their perceived emotional support coupled with a sense of belonging, caring, and love (Battles & Wiener, 2002; Einberg et al., 2014; Kamper et al., 2010). Existing close connections of pediatric patients are mostly within families, which suggest a strong emotional bond and reliance on close others for their well-being. Instrumental, informational and appraisal support are often connected to perceived emotional relationships children had with family, peers, professionals, and god. They perceive others providing all four types of support when they have a feeling of trust and care from others (e.g. Einberg et al., 2014; Martin et al., 2010; Pendley et al., 2002). This brings up the idea that any social support children perceive is connected to emotional support and their recognition of provided support.

Most social support was perceived as being actively provided instead of solely knowing that it is available. Children's focus on perceiving actively provided support instead of implicit support is not surprising, since the studied age range from five to 12 years only just begins to think in abstract forms (compare Piaget, 1977). The only social support that was perceived as being mostly available instead of actively provided in reviewed studies was spiritual support (Kamper et al., 2010; Pendleton et al., 2002), since it is based on beliefs. Closely connected to children's perceptions of perceived social support is their consideration of helpfulness of this support (e.g. Eiser et al., 2004; Kiernan et al., 2005; Mitchell et al., 2006; Stewart et al., 2011). Children between the ages of five-12, in reviewed articles, only rated perceived support as helpful and never mentioned unwanted and unhelpful social support. This might be linked to children solely perceiving, focusing, and reporting social support that they use for themselves, as it helps them cope with their illnesses.

4.1 Perceived social support

To illustrate how different perceived social support types influence children's mental and physical well-being, existing models of how social support influences well-being are combined with the four types of social support (emotional, informational, instrumental, and appraisal). The mechanisms are illustrated in Figure 1.

Main effect model	Emotional support		→	Well-being	
Buffering model	Instrumental & informational support	→	Coping strategies	→	Well-being
Social constructionism	Appraisal support	→	Self-concept Self-esteem	→	Well-being

Figure 1. Explaining social support mechanisms in combination with social support types.

The major aspect of provided social support as perceived by children is having social relationships with others (family, peers, professionals, and spiritual power) in order to gain a sense of belonging and not being alone (e.g.: Battles & Wiener, 2002; Cohen et al., 2000; Einberg et al., 2014; Kamper et al., 2010; Woodgate, 2006). This is captured under the category of emotional support. The direct effect of supportive relationships as provided by family and close friends (e.g.: Kamper et al., 2010; Mitchell et al., 2006) on well-being describes a direct effect between the two units (see Figure 1). The main effect model supports the direct connection between emotional support and positive well-being (Uchino, 2009; Varni & Katz, 1997). This interaction is especially helpful for chronically ill children, since emotional social support is beneficial irrespective of how much stress is present and of how much support is needed.

As depicted in Figure 1, social support can buffer stress resulting from severe health conditions by providing support actions, such as information and instrumental support that make up coping mechanisms. Children perceive parental supervision, advice from others of same or older age that have similar experiences, and professionals' extensive instrumental and informational support for handling their illnesses, as it buffers stress (Martin et al., 2010; Mitchell et al., 2006). Children between the age of five and 12 are dependent on others for such instrumental and informational support in health related issues and daily life. Pediatric patients need help with daily routines, and organizing and implementing their therapies. However, when relying on informational and practical support, quality and availability of such support are crucial (Reblin & Uchino, 2008). Misconceptions of how to talk to patients about their illnesses have been found (Helgeson & Cohen, 1996). Illness related information is often kept from children at younger ages due to adults believing that children cannot handle nor process this kind of information. Nonetheless, informational support leads children to feeling more confident and positive about possible health outcomes by providing ways of coping (Kyngäs et al., 2001). Results of this literature review suggest that some children indeed value receiving information, and feel better socially supported when it is conveyed in a suitable way for them (i.e. understandable language, taking time to convey message, etc.) (Eiser et al., 2004; Mitchell et al., 2006; Stewart et al., 2011). This is of special importance since advice seeking is often not initiated by children themselves (Eiser et al., 2004). Information, advice, and active support from different support providers needs to be

adapted to support needs due to perceived stress: social support has to be perceived as being able to buffer perceived stress for optimal positive effect.

Lastly, the social constructionism model suggests, that appraisal support helps individuals to construct their self-concept and thereby heighten self-esteem. The perception of socially supporting severe chronically ill children with appraisal support was rarely found in the reviewed literature. Appraisal was merely implicitly given by social comparison with other children (Eiser et al., 2004). Scores on self-esteem and global self-worth increased in the course of the summer camp for children between 7 and 12 years of age without specifically defining what caused this increase (Kiernan et al., 2005). Faith helped some children to reattribute reasons for their illness to being tested which helped them cope (Kamper et al., 2010). A suggestion for low emphasis on social appraisal for this population is that children between the ages of five and 12 are not yet being fully able to construct their views in an abstract way based on appraisal support (compare Piaget, 1977). Therefore children rely on other coping mechanisms and only begin to use cognitive appraisal for personal well-being.

The three introduced models of how perceived social support promotes well-being are described as separate constructs influencing well-being with use of specific social support types. However, this process is an overall complex mechanism. Concepts overlap, possibly make use of all four support types, and not only use the main types as described in Figure 1. Emotional support for example is directly influencing well-being, while being essential for support relationships that provide coping mechanisms or appraisal which is understood as buffering stress or constructing well-being. Thus, social support mechanisms are interlinked. Despite this interrelated concept, young children with severe medical health conditions emphasize support by main effects of emotional relationships with family and peers, while also relying on buffering effects of coping mechanisms and practical aid received from family, professionals, God and peers. Opposite to emotional and informational support, instrumental and appraisal support is often identified as being least important for young chronic patients (Helgeson & Cohen, 1996). An exception to this could be support perceived from God/spiritual power which results in trusting on him for recovery helped them stay positive (Kyngäs et al., 2001). Appraisal support was found to merely help children construct positive self-concepts for better coping (Kamper et al., 2010; Kyngäs et al., 2001), but it might increase in significance as age increases.

4.2 Evaluating perceived social support

Children that start primary schooling and are developing more abstract cognitive skills (Piaget, 1977) are still highly dependent on family, specifically parents, for emotional and physical well-being (Haluska et al., 2002). Family support often provides stable relationships (Battles & Wiener, 2002; Uchino, 2009) which makes children in the ages from five to 12 perceive support from family, and more specifically parents, as most important for them (e.g.: Mitchell et al., 2006; Pendley et al., 2002; Stewart et al., 2011). Support providers can best live up to their task of socially supporting children if they are physically and emotionally well. Seeing a child in the context of its family and satisfying family needs is thus important in order to provide sufficient social support and create a fostering family environment (Guralnick, 2006).

Parental guidance and their way of educating and raising their children is one of the most important coping factors in dealing with stress or other problems that may arise in daily life (Shonkoff & Meisels, 2000). Good coping has mostly been detected in children who were affectionate with their parents and share interactions. Therefore, children highly valuing extensive parental support of all kinds is of no surprise (Battles & Wiener, 2002; Gillian King et al., 2006; Mitchell et al., 2006). If a secure relationship cannot be created between a child and a parent, grandparents can be an effective supplement for developing a basic sense of trust and love in the child. Children's perception of sibling and other relatives' support underlines this overall importance of supportive family bonds (Kamper et al., 2010; Pendleton et al., 2002).

Loyalty, caring, and trust are aspects of social support that children find crucial (Decker, 2007). Two articles in this literature review found these aspects in perceived childhood friendships (Battles & Wiener, 2002; Pendley et al., 2002). Articles reporting on important social aspects in friendships proposes the existence of these key features; however the limited number (n=2) puts it into perspective of deep friendships with loyalty and trust just beginning to develop at this age and being more important for older children (Decker, 2007). The emerging importance of intimate friendships for children in the years of primary schooling is exemplified by Einberg et al. (2016). Peers help children to develop a sense of identity and form their character by teaching social skills and forming personal strengths (Kiernan et al., 2005). Children wishing to have more contact and opportunities to meet and seek support of informational and emotional character (Kiernan et al., 2005; Stewart et al., 2011) supports this by showing the increasing importance of peers for personal and social growth.

Peers in this review were understood in a broad sense and also included people in faith and other community settings. For children who are only starting to grow bonds outside of their family context, these kind of peer interactions were in only some situations perceived as supportive (Kamper et al., 2010; Pendleton et al., 2002). Children might interact with their community when family creates contact with community contexts. Without families being involved in communities, children have none to little opportunity to create social bonds with others in a community and thus have little chance for receiving social support. This again supports the importance of family in creating social relations for younger children outside the family. Children that partly relied on communities indicated a need for more education for their community in order to receive more social support from them.

Overall, less importance was generally given to professionals and spiritual social support by children, even though they might be of importance for individual children. Professionals in schools are in regular contact with school-aged children, while health care professionals become an important support source for chronically ill children attending frequent medical care. School staff was barely mentioned in reviewed articles, as focus was not set on school settings. Articles studied children with such severe long-term illnesses, that school and school-reintegration was a minor issue compared to other life areas. Findings of this paper however reported on health staff and showed that children valued health professionals taking time to talk to

them about health related coping, wishes and fears (Mitchell et al., 2006). Kyngäs et al. (2001) suggested that being able to discuss health and personal issues, as well as emotions with health professionals might be perceived as positive due to a sense of autonomy and anonymity. Limited perceptions of social support concerning personal feelings from health care professionals instead of sole health related coping and informational aid are attributable to young children's emotional dependence on family instead of turning emotional needs towards sources outside their family. Mitchell et al. (2006) studied children above the age of ten years and found evolving personal discussions and emotional support from health care professionals. The older age of their sample supports the suggestion that mostly older children form emotional bonds with others outside of their family.

Two studies on spiritual support that were conducted in the US reported that two thirds of children perceived faith and God as helping them emotionally, instrumentally and providing appraisal (Kamper et al., 2010; Pendleton et al., 2002). Studies from other countries on spiritual support were not found. This suggests that relying on spiritual support might not be common across all countries, but still provides interesting suggestions for social support for ill children. Individuals in life-threatening or stressful situations, such as a severe chronic illness, might attribute negative events to God testing them, which helps them cope (Kyngäs et al., 2001). Health outcomes are laid into spiritual hands as faith gives people a sense of hope. It is hence not surprising that some children pray to and interact with God or a spiritual power and perceive God as providing emotional, instrumental, and appraisal support.

4.3 Practical implications

Proximal environments and life circumstances are highly influential on a child's well-being (Darcy et al., 2015). Children between the ages of five and 12 are still deeply rooted in their families and thus when helping a child, supporting the entire family in doing so is of use. A responsive, adaptive and reciprocal environment that acknowledges the needs of a particular child can foster its development (Guralnick, 2011). Strengthening family bonds and routines, educating parents and siblings on how they can support a sick child beyond the usual support, and creating room for active communication between family members to optimally socially support a child is important (Guralnick, 2006; Mitchell et al., 2006). Focusing on mothers as they are often the primary caretaker is also suggested (Decker, 2007; Stewart et al., 2011).

Apart from family support, children perceive friend support. However, children wish for more available opportunities for peer support from healthy and ill children and sometimes even fear not finding friends (Kiernan et al., 2005; Stewart et al., 2011). Facilitating and promoting positive peer interactions and participation, as well as advice within school, hospital, and informal settings is advised for optimal developmental outcomes of this young patient group (Garbarino et al., 2000). Forming new friendships with children that have lived through similar illness scenarios, as well as maintaining old friendships helps children to cope with stressful life-events (Mitchell et al., 2006). Specially designed summer camps, befriender programs, and internet support groups to tackle this support need are suggested (Kiernan et al., 2005;

MacDonald & Greggans, 2010; Martin et al., 2014; McCarthy, 2015). The idea is that formally designed situations provide opportunities for children to meet each other and give them room to participate in social situations (Mattson & Hall, 2011). When having opportunities to participate and interact with others, children have the chance to receive and provide each other with emotional, informational and appraisal support. Face-to-face support can be combined with digital communication services, such as internet support groups (Hokkanen et al., 2004; Martin et al., 2014) as today's youth is increasingly engaging through digital devices and not only through face-to-face interactions (Einberg et al., 2014).

Another wish for peer support is the wish from children for more support in community settings (Martin et al., 2010). According to literature, ill children often feel like their community, teachers and peers are not well enough educated about their illnesses. This often results in feelings of not being recognized or heard. Another problem with this is that children might resign from disclosing to others about their illness because of fear of harassment and being bullied. This is of special significance since disclosure is shown to be positive in terms of perceiving social support and well-being for children (Battles & Wiener, 2002). To overcome this issue, communities in the proximal surrounding of children with severe medical illnesses have to be educated on how they can support physical and emotional well-being for these children. Suggestions from children concerned smoking cessations (asthma) and allergy related food rules in schools (Martin et al., 2010).

4.4 Methodological discussion

The used method of a systematic literature review holds strength and weaknesses. Strengths of this approach were the structured and detailed approach, and documentation of search and analysis processes. This makes it possible to replicate results and strengthens the significance of results. The use of three data bases was chosen according to appropriateness to extent of this paper, but might be too limited for exhaustive and more thorough results.

Selection process, quality assessment, and analysis of results were done by one single researcher. A second reviewer for screening a sample of articles at full-text level helped to increase validity and verified that chosen articles were relevant for anticipated results. However, relying on only one researcher for analyzing results might bias the findings, because the analysis is based on this researchers preunderstanding as a psychologist and emphasis on certain areas (Nyström & Dahlberg, 2001). To minimize these effects, the researcher made herself aware of this bias and attempted to work objectively.

Use of quality assessment of included articles provides some support for significance of results. Emphasis was put on high and medium quality studies. A limitation is posed by the chosen quality assessment tool. An individually adapted assessment tool for qualitative, quantitative, and multimethod studies based on the available COREQ assessment tool (Tong et al., 2007) was chosen, since no tool for the assessment of articles studying perceived social support was found. Using separate quality assessment tools according to study designs and studied concepts would have increased the reliability of this review.

4.5 Limitations and Research Implications

Studying the age group of five – 12 years proved to be important, as many articles in the selection process were excluded due to wrong age groups. The other major reason for excluding articles at title/abstract and full-text level was no self-reports of perceived social support, but parental or professional perspectives which further shows the importance of more research in this area. The limited amount of articles (n=11) found on this specific topic, while only four of these studies primarily looked upon it exemplifies the lack of research in this area. The majority of selected articles (n=7) however were of good quality and often provided comparisons within subjects, to older control groups, or healthy peers. The lack of reliable, significant and up-to-date measurement tools for children's perceived social support is highlighted by used tools in chosen studies. Hence, focusing on self-reported social support perceptions of severely chronically ill children in the age range from five to 12 is still highly needed in the future.

While analyzing some of the selected articles, the researcher found it challenging to extract children's explicit evaluations and feelings on perceived support behavior. Often, perceptions of provided support were not accompanied by explicit individual ratings. Hence, it is advised to distinguish between what a child perceives as social support available to them and what it perceives as being helpful. Discovering what children really value as social support from others is an important indication for improving social support for chronically ill children. However, it is possible that children only report what is relevant and helpful to them. Thus, looking more into and distinguishing between what children perceive as provided and perceive as helpful is suggested.

Measurement tools for perceived social support of young children have to be selected carefully and have to be adapted to children's needs and ways of thinking (Nilsson et al., 2015). Most reviewed articles in this paper used open-ended interviews or quantitative questionnaires. This might not be the optimal way of studying children's perceptions as it is highly dependent on the researcher's child-understanding and interpretation of data. Some articles adapted more to younger children and used focus groups with three or four children, or let children draw what they had in mind. These methods might be helpful to understand what children perceive and what they value. Based on this, it is suggested to carefully select measurement tools when involving children in research in the future.

After examining what children perceive as helpful social support, the question arises how social support is related to physical and psychosocial outcomes. Some articles suggest relations to decreasing negative outcomes, as well as increasing positive ones: perceived social support from teachers, peers, and family is associated with decreases in behavior problems, such as aggression, delinquency, anxiety, depression, and health-related conflicts (Kiernan, Gormley, & MacLachlan, 2004; Pendley et al., 2002). While some articles already draw connections to outcome behavior, physical and psychosocial well-being, and resulting social participation are seldom studied. However, both, better health and social participation were shown to be related to psychosocial well-being and are thus relevant outcome measures (Kiliś-Pstrusińska et al., 2013;

King et al., 2006; Reblin & Uchino, 2008; Varni & Katz, 1997). Measuring positive, as well as negative outcomes such as physical symptoms and participation after providing social support is a way of evaluating the effectiveness of social support (Kiernan et al., 2004, 2005). If social support is provided within a form of intervention such as a summer-camp, support-groups or digital support (Kiernan et al., 2004, 2005; Stewart et al., 2011), the effectiveness of such an intervention should be measured to test the efficacy of an intervention (Bornman & Granlund, 2007). It is important to know how exactly certain social support types improve children's well-being and on which situational factors it depends to know how and where to support children.

Further, studying the connection of children to family needs is important. A child develops within its family and is thus highly dependent on family well-being (Earls & Buka, 2006). Moving from only focusing on the child to considering the whole family and empowering individual family members in the process of social support is important (Dunst & Trivette, 2009; Ylvén & Granlund, 2013). This paper only explored needs of children however future research might combine this with the experiences and needs of the whole family for a more thorough picture.

Lastly, while the most common studied illness was cancer, the group of severe medical long-term health conditions described in this study also included cystic fibrosis, asthma, diabetes and other illnesses (see Appendix 5). Results for these illness groups were combined in this review due to similar expected social needs; however more research on various severe medical long-term health conditions is needed in order to be able to generalize results outside of pediatric cancer patients.

5 Conclusion

Children with severe chronic health-conditions experience extensive stress that can lead to lowered emotional and thus physical well-being. Providing these children with social support for better well-being is advised. Support providers can have misconceptions about what social support children might actually need. Thus, relying on children's perceptions of what social support is perceived and valued by them is important for optimal outcomes. The youngest children with emerging cognitive and linguistic skills that can provide such sufficient self-reports (aged five – 12 years) are rarely studied despite this extensive need.

Most social support that is perceived as available and as being helpful by young children is emotional and instrumental support derived from family. This is suggestively due to strong emotional bonds with and reliance on close family and especially parents in early years. Apart from the importance of emotional support from family, with increasing age peers are perceived as another major provider group for emotional support. Types of perceived social support are mainly emotional and instrumental support from all four groups of support providers, with emerging informational support from professionals and sometimes family, and partly appraisal support from spiritual powers and peers. Supportive actions through emotional, instrumental, informational, and appraisal support either directly influence well-being, provide children with useful coping mechanisms, or help them to social construct their self-concepts. Due to emerging abstract cognitive skills the mechanism of socially constructing self-concepts for better well-being is just marginal. Based on these findings it is suggested to foster family relationships and well-being, facilitate old friendships while providing possibilities for new ones, and educate communities for better social support opportunities.

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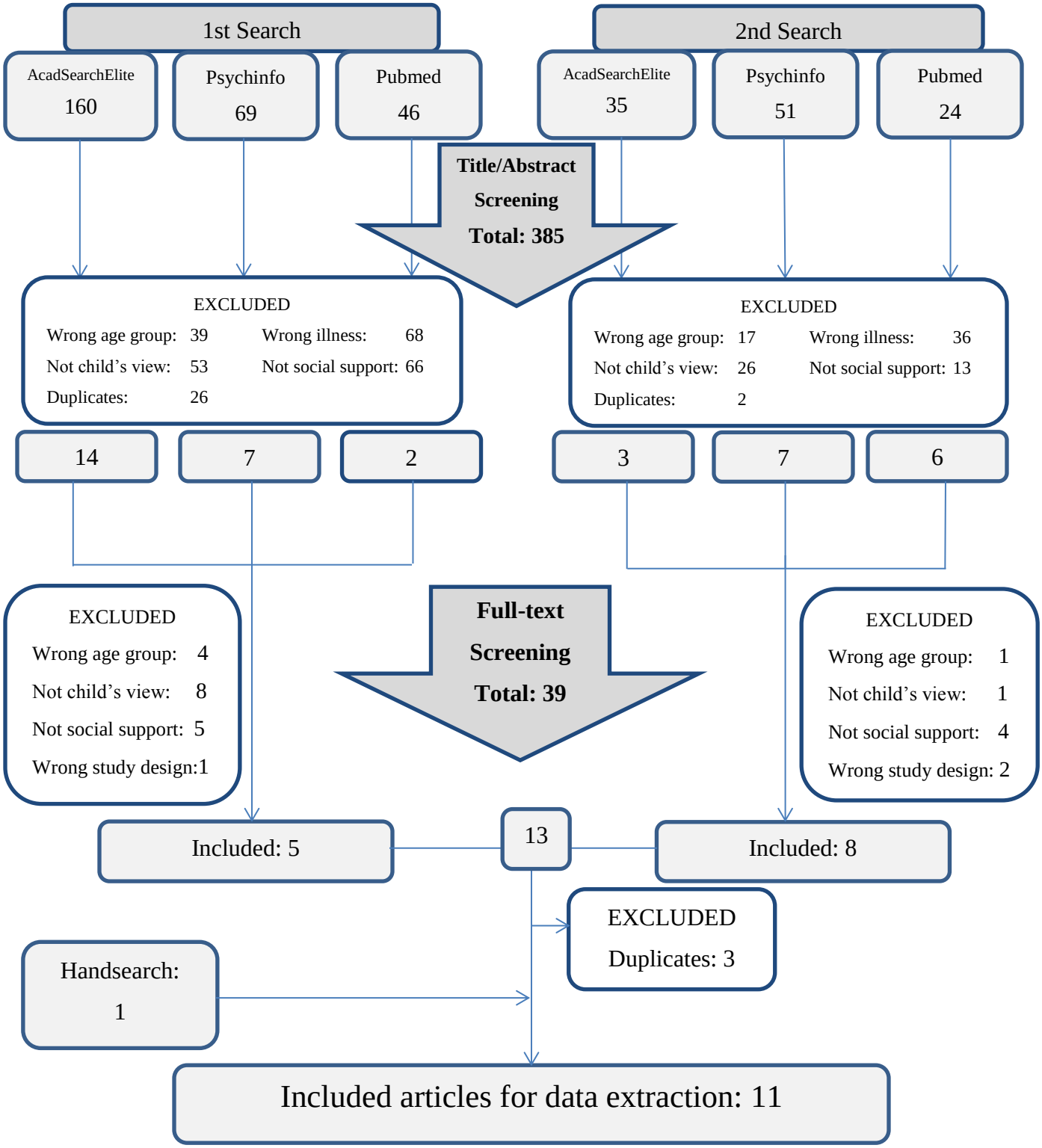
Appendix I

Flowchart visualizing the search process



Appendix 2

Checklist for title/abstract screening

Inclusion Criteria	Included?
Title & Author	
Participants with severe long-term health condition Social support is measured Child's perspective Participants between 5 & 12 years of age Published in English	

Appendix 3

Protocol for full-text screening

Inclusion criteria	Included? If so, report here:
Title & Author	
Section 1: Sample	
Child's report	
Age frame (with mean age)	
% of 5-12 year olds	
Diagnoses of sample	
Current health status	
Section 2: Study information	
Study design	
Purpose/aim	
Research question	
Why: rational	
Setting	
Country	
Time frame	
Social support explicitly measured?	
Explicitly asks for perception of social support?	
How is perception of social support asked for?	
Explicitly asked for consequences/evaluations of social support?	
How are consequences/evaluations of social support asked for?	
Section 3: Social support	
Where: life area of support	
What: kind of social support	
Who: support sources	
How: support behavior	
Support wishes/needs	
Ratings/evaluation of perceived social support	
Other information	

Appendix 4

Protocol for quality assessment of included studies [a]

Criteria	Report data here:
Title & Authors	
Section 1: Study design	
1. Methodological construct and theory	
2. Sampling	
3. Method of approach (e.g. interview, focus group)	
4. Sample size [b]	
Section 2: Data collection	
5. Setting of data collection	
6. Presence of non-participants (parents etc.)	
7. Description of sample	
8. Interview guide/assessment tool	
9. Repeat interviews/control group	
10. Ethical considerations	
11. Audio/visual/written recording	
Section 3: Data analysis and findings	
12. Number of data coders/analyzers	
13. Software	
14. Quotations	
15. Data and findings consistent	
16. Clarity of major themes	
17. Clarity of minor themes	

[a] Based on COREQ quality assessment tool for qualitative studies

[b] sample size was considered small when n=/< 20.

Appendix 5

Studies of Perceived Social Support

Study	Sample/ Setting	Diagno-sis	Purpose	Major finding	Quality Rating [a]
Battles and Wiener (2002)	80 children 8-18y, M= 11.8y 56,3% male 72.2% white	HIV	"to examine the psychosocial factors associated with long-term survival of pediatric HIV infection" (p 161)	Relationship between perceived social support and a child's psychological distress; adult's support is more constant than peer support	High
Einberg et al. (2016)	15 children 8-12y 67% male	Cancer	"to describe perceptions of friendship from the perspective of children undergoing cancer treatment, in order to build knowledge that can be used in a health promotion intervention for these children" (p 154)	Children perceive friendships with common interests and experiences, mutual empathic actions, and mutual trust and understanding	High
Eiser et al. (2004)	76 children 8-20y, combined age-groups because of no sig. differences in responses	Cancer	"to contribute further to our understanding of the QoL implications for survivors of childhood cancer by comparing two groups differing in cancer diagnosis (ALL and CNS tumor)" (p 18)	Less social and family discrepancies when good perceived social well-being; Seeking social support is not major coping strategy	High
Kamper et al. (2010)	60 children 6-17y, 52% 6-12y 42% male	Cancer	"to describe the responses of children with advanced cancer to a spiritual quality of life (SQL) interview" (p 301)	Children draw happiness and well-being from relations with family, friends, and pets	High
Kiernan et al. (2005)	119 children 7-16y, M=11.5y, only 7-12y used for this review 54,6% male Recreational summer camp	Various health conditions	"to gain additional insight into children's expectations of the camp's programme, their experiences of the programme, and what they learnt during their time there" (p 735)	Peer interactions taught children to cope with their illness, social skills, and the importance of friends; Overall satisfaction with camp situation	High
Mac-Donald & Greggans (2010)	10 children 8-18y, majority below 12y	Cystic Fibrosis	"to evaluate the impact of a community youth befriending program on a group of young people	Activities with befrienders are fun and welcome distractions	Low

	Befriending program		with chronic illness and their carers" (p 2406)		
Martin et al. (2010)	32 children 9-19y; 52% 9-13y 60% male Puerto Rican	Asthma	"to describe asthma self-management behaviors in Puerto Rican youth" (p 464)	Overall satisfaction with parental support for health issues; More education and support in community necessary	Medium
Mitchell et al. (2006)	112 children 10-19y (combined age-groups because of no sig. differences in responses) 55% male	Cancer	"providing an overview of parents' and children's views of psychosocial support they receive at different stages of the illness" (p 806)	Family support is most important; Professional support is good; More contact to peers wished for	High
Pendleton et al. (2002)	23 children 5-12y 39% male	Cystic Fibrosis	"to understand the role of religiousness/spirituality in coping in children with CF" (p 1)	Children reported the importance of a faith community and god supporting them	High
Pendley et al. (2002)	34 children 8-12y 38% male Older comparisons	Diabetes	"to examine social support and peer and family involvement in relation to diabetes management within a developmental context" (p 429)	Family support high, peer support lower for 8-12y olds than for 13-17y olds)	High
Steward et al. (2011)	20 children 6-11y	Asthma	"to assess the support and education needs and preferred interventions of allergic children with asthma and/or severe allergies […]" (p 68)	Mothers perceived as major education and support source; Wish for more peer support, older role models	Medium

[a] Quality ratings based on quality assessment tool (Appendix 4): high =15-17 points, medium = 12-14, low = 0-11.

Appendix 6

Perceived support providers and life areas of support

Study	Perceived support provider				Life area of support
	Family	Peers	Profess-ionals	Spiritual power	
Battles and Wiener (2002)		X[a] Peers (friends)			- Everyday life - Coping with illness
Einberg et al. (2016)		X Close friends			- Everyday life - School
Eiser et al. (2004)	X				- Coping with illness - School
Kamper et al. (2010)	X Parents	X Faith affiliate		X God/ greater power	- Everyday life - Coping with illness
Kiernan et al. (2005)		X Friends (summer camp)			- Summer camp
Mac-Donald & Greggans (2010)		X Befrienders			- Everyday life
Martin et al. (2010)	X Parents	X Community	X School		- Coping with illness - school
Mitchell et al. (2006)	X Parents	X Peers (support groups)	X Health & school staff		- Everyday life - School - Coping with illness/ Hospital
Pendleton et al. (2002)		X Faith community		X God	- Coping with illness
Pendley et al. (2002)	X Parents	X Peers (friends)			- Everyday life
Steward et al. (2011)	X Mothers	X Peers (support group)	X doctors		- Coping with illness

[a] X indicates articles mentioning a support provider. Specific social support providers are described in words.

Appendix 7

Types of perceived social support

Study	Emotional		Instrumental		Informational		Appraisal	
	Social support	Evaluation	Social support	Evaluation	Social support	Evaluation	Social support	Evaluation
Battles and Wiener (2002)							- disclosing to others personally about illness→ perceiving more social support	
Einberg et al. (2016)	- equal and mutual commitments	Ratings of what makes friend-ships supportive	- Providing help - Mutual empathic actions				- Saying positive things (respect)	
Eiser et al. (2004)	- talking to others about emotions/ illness - social and family	"nice" Happy with support			- Seeking advice or social support	Not major coping style	- Making social comparison	Not major coping style
Kamper et al. (2010)	- seeing family - knowing others care - relational social support - spending time with family/ friends/ pets - praying	Praying helps (82%)	- Mediation to a higher (praying) being by others				- Believing in an afterlife - Praying for normalcy	
Kiernan et al. (2005)	- Being with other children - Having friends (loyal)	Better for coping					- Learning social skills - Being more confident (not being alone with illness, illness doesn't stop them)	

Mac-Donald & Greggans (2010)	- having friends - distraction - doing things together	Doing things is most important			- Talking about important issues with older peers (advice)		- Daring to do more things with friends
Martin et al. (2010)			- Parents help with medications (supervise)	Feel comfor-table with it			
Mitchell et al. (2006)	- family support (socially and emotionally) - being there in hospital - school staff is understanding	Generally satisfied	- Parents care for them (in hospital) - Hospital staff helps to become independent - Help with medication - School support	Very impor-tant; satisfied	- Receiving information about illness and advice - Understandable language - Directly talking to child - Taking time - Advice from peers	Highly valued by chil-dren	
Pendle-ton et al. (2002)	- god looks out for child - others pray - god makes me feel better	God is very important; other's prayers help	- God makes you feel better mentally and physically - God acts on their requests - Rituals and activities of faith group - Food, clothes,		- God provides guidance		- Using spiritual meaning to reappraise something negative into something positive/ with meaning

		presents from faith group	
Pendley et al. (2002)	- makes them feel good - companionships	- Tangible support	- Information support only by family
Steward et al. (2011)	- acknowledge child's fears and concerns - supportive concerns from mothers & doctors		- Mothers educate children about disease & management - Talking to other children