Children and Adolescents Living with Mobility Impairment

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Abstract

Aim: This thesis aims to describe perceived overall well-being, coping strategies, experiences of intimacy and sexuality, and global and dimension-specific self-esteem among children and adolescents with mobility impairment.

Methods: The study included 141 children and adolescents aged 7–18 years with mobility impairment. Data was gathered by comprehensive semi-structured interviews and the self-report inventories “Children’s Coping Strategies Checklist” (CCSC) and “I Think I am”. Perceived overall well-being was measured by the nine-grade visual “Snoopy scale”. Motor function and pain were measured by the BL motor assessment, and independence or dependence by Katz Index of Independence in Activities of Daily Living.

Results: The majority reported a favourable level of perceived overall well-being and positive global and dimension-specific self-esteem. Lower global self-esteem was significantly related to: greater age, being a first-generation immigrant, having an acquired disease or injury and experience of pain, while lower level of perceived overall well-being was significantly related to all of these in addition to not living with both parents. Generally, children and adolescents identified themselves as sexual beings and most expressed future aspirations as living together with partner having children. However, many had limited or no experience of partner-related intimacy and sexual activities, and socio-demographic and disability characteristics had a marginal influence. A history of sexual abuse was reported by 7% in the age cohort 13–18 years. A four-dimensional model of coping strategies including “active coping”, “distraction”, “avoidance” and “support seeking” strategies provided an adequate fit to the CCSC data. Three of the four strategies, all except “avoidance”, were significantly related to several demographic and disability features. Well-being was not significantly related to coping strategies, although the higher the trust in the strategies, the higher the estimation of well-being.

Conclusion: The understanding of vulnerability factors as well as identification of coping strategies among children and adolescents with mobility impairment is essential for providing proper care, treatment and support during childhood and adolescence.

Keywords: adolescents, children, coping, disability, intimacy, mobility impairment, self-esteem, sexual abuse, sexuality, well-being

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Just remember in the winter
far beneath the bitter snow
lies the seed that with the sun’s love
in the spring becomes the rose

(Amanda McBroom)
This doctoral thesis is based on the following original papers which are referred to in the text by their Roman numerals:


The articles were reprinted with permission from Acta Paediatrica.
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Introduction

Above all, children and adolescents with mobility impairment are simply children and adolescents. They meet with and go through experiences in life just like their peers without mobility impairment. Childhood development and the transition to adult life are influenced by individual characteristics as well as social and cultural contexts. However, mobility impairment involves a variety of potential stressors that could influence the physical, cognitive, emotional and social development among children and adolescents.

An understanding of how children and adolescents experience their present life situation is essential for providing proper care and support during childhood and adolescence. How do children and adolescents with mobility impairment experience different situations in life? How do they cope with the consequences of their disability?

Mobility impairment

The underlying causes of mobility impairment can be congenital or acquired and encompass a number of conditions: cerebral palsy, spina bifida, muscular dystrophy and spinal muscular atrophy, brachial plexus injury, arthrogryposis multiplex congenita, juvenile rheumatoid arthritis, limb deficiencies and amputations, orthopaedic conditions, osteogenesis imperfecta, spinal conditions (scoliosis, kyphosis, lordosis), and spinal cord injuries and brain injuries (traumatic brain injuries, brain tumour) (1).

There is no general definition of mobility impairment, although the World Health Organisation (WHO) states that impairment *per se* is a problem in body function or structure, while disability is an umbrella term covering impairments, activity limitations and participation restrictions (2). In Sweden, a number of definitions of mobility impairment are applied by public authorities for the purpose of official statistics (3, 4) and regulation of social support, e.g. for transportation service or car-park permission. In the present thesis, mobility impairment is understood as a catchall term for the manifestation of a condition that affects locomotor function. The degree of impairment varies amongst children and adolescents and combinations of disorders are common.

Normative stressors in children and adolescents refer to the common, developmental stressors of daily life, while non-normative stressors arise
from unusual or traumatic experiences (5). Mobility impairment affects the lives of young people at different levels, and the need for support, care and treatment varies between individual children and adolescents during their development and throughout their lives. The condition per se has different direct effects on the development. Medical treatment including surgery, single or multiple hospital admissions, physiotherapy, occupational therapy, speech therapy, trying out orthopaedic and technical aids are examples of ordinary experiences for many children and adolescents with mobility impairment.

Children and adolescents with impaired mobility have to manage varying degrees of physical dependence on parents, siblings, friends, personal assistants, and other people in their social network.

Limited mobility and restricted accessibility in society such as physical obstacles and difficulties to use public communications, could influence participation in peer relations and hence the development of socialization skills (6-10). Making friends and communicating with them has been reported to be more problematic for adolescents with physical disabilities (11) and many are dependent on their parents or other grown-ups to take part in peer interaction that might open up for intimate and sexual experiences (12). Hirst (8) found that the quality of social life among teenagers with spina bifida and cerebral palsy was related to impairment and disability, due to dependency on others, restricted choices, physical barriers and the adverse reactions of others leading to extreme social isolation.

Indeed, young people with mobility impairment do face negative attitudes from the environment. Skär (10) demonstrated that adolescents with disabilities saw themselves as regular members of the peer group, whereas the peers without disabilities saw them as being different. van Daalen-Smith (13) demonstrated negative impacts of being excluded, marginalised and viewed as “other” among girls with spina bifida. There are reports (14-16) on experiences of having been bullied during schooldays among young people with mobility impairment in Sweden.

All of the above are common stressors for young people with mobility impairment. Evidently, not all children and adolescents meet all of these difficulties, and most find a way to manage these challenges.

Coping

As children and adolescents face the complexity of challenges during their development, they use a variety of coping strategies (17, 18). Research on coping in children is mainly based on theories and models developed for adults. The most commonly applied theory in research on coping in children is the transactional model developed by Lazarus and Folkman (19). The model of coping with disability presented by Moos and Schaefer (20) has
been used to describe coping with disability from a developmental perspective (21).

However, Ayers et al. (22, 23) developed a dispositional measure of children’s coping, the Children’s Coping Strategies Checklist (CCSC), partly based on content analysis of semi-structured interviews with children (24). The authors found that a four-dimensional model of coping in children that included “active coping”, “distraction”, “avoidance” and “support seeking” strategies provided the best fit to the data compared with both the problem-focused and emotion-focused coping approach described by Lazarus and Folkman (19), and the passive and active coping approach described by Billings and Moos (25).

The Lazarus-Folkman process approach is also the most frequently applied conceptualisation of coping and defines coping as: “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (19). In the present thesis, coping strategies refer to the specific ways in which children and adolescents cope with stressors; that is, how they usually cope when faced with a problem.

While there is a considerably body of literature on psychosocial adjustment among children and adolescents with mobility impairment, the theoretical and empirical knowledge of coping strategies is insufficient. Furthermore, Patterson and Geber (26) have discussed the importance of improvement of coping skills for the development of competence in children with chronic illness or disability and their families. Carlson et al. (21) have described the impact of disability or illness and the coping process from infancy to adolescence from a developmental psychological perspective.

Janelle (27) compared internal and external locus of control between children with congenital physical disabilities and a matched control group without, and found no differences between the groups. In agreement, Monsen (28) compared coping among adolescents with spina bifida and a matched control group without disabilities and found no differences in problem-focused coping.

Several studies on coping among children at large have focused on anxiety in relation to medical procedures and pain. A Swedish in-depth interview study on coping with pain among 22 children with juvenile chronic arthritis (aged 6–17 years) found one core category: “making me different”; and six subcategories who described coping with pain: “controlling strategies”, “avoidance strategies”, “cognitive strategies”, “compliance with the treatment”, “seeking social support”, and “recovering” (29).
Well-being

A key feature of the Lazarus-Folkman approach is that the basis for forming a judgement whether a given coping process is good or bad depends on the individual person, that person’s goals and beliefs, type of stressor, and the intended outcome; i.e. subjective well-being, social functioning or somatic health (30). According to Diener et al. (31) subjective well-being is defined as “a person’s cognitive and affective evaluations of his or her life. These evaluations include emotional reactions to events as well as cognitive judgements of satisfaction and fulfilment. Thus, subjective well-being is a broad concept that includes experiencing pleasant emotions, low levels of negative moods, and high life satisfaction”. For the purpose of this thesis, the concept perceived overall well-being described by Stensman (32) is applied:

Well-being is a general keynote in an individual’s life. Influenced by psychological and physical conditions, as well as by relations to other people and society, well-being is a highly subjective and complex aspect of life experience which an individual assesses in relation to his or her needs and expectations. The concept of well-being and overall life satisfaction are almost congruous.

Research on well-being among children and adolescents with mobility impairment embraces a variety of aspects, such as life satisfaction, and predominantly quality of life and health-related quality of life. There is an increase in the development of paediatric quality of life instruments, although only a few are based on an explicit theory (33). Moreover, quality of life per se is an ambiguous term (34) making more exact interpretation of findings difficult.

Livingston et al. (35) reviewed research on quality of life and health-related quality of life in adolescents with cerebral palsy and found lower well-being among those with cerebral palsy compared to normative data. However, functional status was not associated with psychosocial well-being. In the US, Watson and Keith (36) compared self-reported quality of life between 76 school-aged children with and 64 without disabilities, and found that those with disabilities scored significantly lower both on the total score for quality of life and on the subscales satisfaction, well-being and social belonging. In a European study including six countries, Dickinson et al. (37) found self-reported quality of life among 8-12-year-old children with cerebral palsy to be similar to children in general. Shelly et al. (38) examined the relation between self-reported domain-specific quality of life and functioning in children with cerebral palsy, and found no significant association between functioning and the domain of emotional well-being. Using an age-related disease-specific instrument, where the adolescents self-reported, Schoenmakers et al. (39) investigated self-reported health-related quality of life and functional abilities in children and adolescents with spina
bifida. These authors found being independent in mobility more important for quality of life than being independent in self-care or being wheelchair-dependent. Padua et al. (40) studied self-reported health-related quality of life in adolescents with spina bifida and found that those with greater disability reported good quality of life from an emotional point of view. The self-reported health-related quality of life in boys and young men with Duchenne muscular dystrophy has been found to be high and not correlated to the degree of physical or respiratory impairment (41). Other studies have demonstrated significantly lower self-reported quality of life for children with cerebral palsy experiencing pain (37, 42).

Studies on well-being that are based on interviews with children and adolescents are rare (43, 44). In a previous interview study including 22 children with mobility impairment and 24 without disability, I (45) used a global rating to measure perceived overall well-being and found no differences between the groups. A qualitative interview study (44) on boys and girls aged 12–19 years with long-term illness or disability found that the adolescents generally experienced well-being like everybody else. Sällfors et al. (46) found that global well-being in children with juvenile chronic arthritis was associated with pain and attendance in physical education lessons. Börjeson and Lagergren (47) described the living conditions of 26 adolescents with myelomeningocele based on interviews, and the majority reported positive feelings when asked to describe their general state of mind. Furthermore, “being believed in”, “believing in yourself” and “being accepted by others”, i.e. belonging, have been found to be three key psychosocial factors for being happy in life among adolescents with cerebral palsy (48).

Self-esteem

The development of self-esteem is fundamental for children and adolescents adaptive functioning and perceived well-being (49). Wallander and Varni (50) considered behavioural adjustment, self-esteem and social integration to be important dimensions of adjustment in children. Self-esteem enhancement and self-esteem protection has been described as a basic human need (51).

Self-concept and self-esteem are often used interchangeably. A review (52) over 20 years of ways of measuring self-concept/self-esteem with children and adolescents concludes that definitions of the concepts are still a subject of discussion although there is some agreement that “self-concept refers to an overarching view of the self, whilst self-esteem reflects a person’s evaluative assessment of themselves”. Self-concept has been approached with the question “Who am I?” and self-esteem with the question “Am I worthy?” (53).
In this thesis, in agreement with Suonpää et al. (54), self-esteem is defined as:

The cognitive and emotional concept of an individual about himself. It is an individual’s own idea of himself and it also contains his understanding and definition of what kind of a person he is and how much he respects himself. Self-respect is dependent on a person’s idea of his success in meeting the demands and reaching the goals which he has set for himself and of which he is more or less aware. It also depends on his idea of how he is valued by other people.

Research on self-esteem in children and adolescents with mobility impairment has been focused on the impact of the impairment or disability *per se*. Comparisons between children and adolescents with and without impairments has demonstrated both similarities and differences in global and domain-specific self-esteem. Physical disability has been associated with a lower sense of self-worth, greater anxiety and less integrated view of self (55). A greater risk of depressive mood, low self-worth and suicidal ideation has been described in young people with spina bifida (56). Whereas other studies (57, 58), have found contradictory results.

Most studies on self-esteem are based on small samples and selected groups (59). Arnold and Chapman (60) found no differences in the level of self-esteem between adolescents with and without physical disability, and actually pointed out positive aspects of physical disability. Mackelprang and Altshuler (61) found that the vast majority (90%) of young people with disabilities demonstrated a high degree of pride in themselves and living with their disability. Shields et al. (62) demonstrated that children with cerebral palsy did not have lower global self-concept, although they did feel less competent in some of the aspects of self-concept. In correspondence, Appleton et al. (63) explored self-concept in children and adolescents aged 7–18 years with spina bifida and a matched control group and found no group differences in global self-worth. Those with spina bifida did indicate less competence in six of the nine self-concept domains, yet they did not differ from their peers without disabilities in the valuation of the importance of the specific domains. Specht et al. (64) interviewed adolescents with physical disabilities and found global self-esteem equal to the norm score, even though the specific domains of self-esteem social acceptance and athletic and job competence were lower. Cartright et al. (65) analyzed the self-image profile of 50 adolescents aged 11–21 years with spina bifida and found no divergence from the norm scores on all the dimensions of self-image except for the subscale sexual attitudes where the mean was below the norm and the subscale family relationships where the mean was above the norm.

A study of self-esteem in 22 adolescents (mean age 16 years) with cerebral palsy and a matched control group found no difference in overall
self-esteem between the groups, although girls with cerebral palsy scored significantly lower on the physical and social personal subscales compared to boys with cerebral palsy (66). As adults, in a follow up study seven years later, there were still no difference in overall self-esteem between the groups, and the young women with cerebral palsy no longer differed from the young men with cerebral palsy (67).

Furthermore, a review (68) of six studies found that adolescent girls with cerebral palsy had a lower self-concept in the domains of physical appearance, social acceptance, athletic and scholastic competence compared with adolescent girls without disability.

Drotar (69) argues that studies on group differences in psychological research on child chronic illness sometimes assume that what is adaptive behaviour for a child with no illness is the same as for a child with an illness who actually faces quite different life circumstances. The author argues that chronic illness should not be viewed as the sole cause but a life stressor amongst other factors that could contribute to adjustment problems, and stresses the importance of research on factors that relate to successful adjustment within the group with chronic illness.

Several authors have described different factors influencing self-esteem among young people with physical disabilities. Varni et al (70) found that classmate, parent, teacher, and friend social support were all significant predictors of self-esteem in children with limb deficiencies. Cherry (71) studied self-esteem among adolescents with and without disability and found that physical disability in interaction with a smaller total social network was a predictor of low self-esteem. In a multivariate model, Manuel et al. (72) found that the only significant relationship was between a lower level of self-esteem and a greater impact of the perception of disability. Antle et al. (73) found “perceived social support from parents” to be a stronger predictor of self-worth than gender, age or onset of disability, i.e. congenital or acquired. In another study (74), parental permissiveness in social participation as well as age-appropriate parental treatment were factors most positively contributing to adolescents’ self-esteem. Factors negatively associated with self-esteem were school problems and being considered disabled by others.

In general, children and adolescents with various conditions leading to mobility impairment appear to be able to protect their global self-esteem, even though several studies indicate vulnerability in specific domains of self-esteem.
Intimacy and sexuality

The World Health Organization (WHO) (75) has provided a working definition that clearly illustrates the complex and dynamic nature of human sexuality:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

Sexuality is an integral part of development in childhood and adolescence. Generally speaking, development of a sense of self and body image, presence of role models, close and intimate relationships, experiences of role play, friendship, falling in love, romance, closeness, intimacy, sexual activities, having a boyfriend or girlfriend and possibilities of developing a sexual relationship and starting a family are fundamental components of the development process of sexuality from childhood to adulthood.

The sexual developmental needs for children and adolescents with mobility impairment are the same as those of their peers without impairment. Adolescents with disabilities express the same desires and aspirations of close and intimate relationships, sexual relationships, marriage and having children as their peers without impairment (11, 43, 76-82).

However, beyond basic developmental issues, mobility impairment involves further sexual challenges for children and adolescents (83-87). Medical problems related to the condition such as mobility limitation, impaired sensibility, pain and incontinence could interfere with and/or delay sexual development.

Lack of privacy and difficulties in exploring and learning about the body could negatively influence children and adolescents’ perception of their body and body functions. Experiences of touch can be affected by other experiences from being touched in relation to medical procedure or activities of daily living (83).

Furthermore, limited access to participation in social activities influences the development of socialization skills, and thereby sexuality. Several studies (8, 9, 11, 88) have reported that children with restricted mobility have more difficulties in developing peer relationships than their peers without disability. Adolescence is characterized by increased independence, but many adolescents with mobility impairment are dependent on their parents or other grown-ups to take part in peer interaction that might open up into intimate and sexual experiences (12). Parents as well as professionals
often avoid teaching young people with disabilities about sex, because they do not believe that they will ever have a sexual relationship and want to protect the child or adolescent from further unhappiness (7). Parents also have expressed fears that their children will be unable to establish a satisfactory relationship, or will be exploited or hurt if they actually do become involved in sexual activities (84).

Furthermore, young persons with disabilities are rarely described as sexual beings in the mass media, and several authors have pointed out that society by in large considers people with disabilities to be asexual, unattractive, emotionally immature, and incapable of and uninterested in sexual activities (12, 89, 90). Presuming that acceptance as a sexual being from the environment is by no means a matter of course, self-identification as other than heterosexual could be even more problematic (12, 91). In fact, several authors have found that young people with mobility impairment lack sexual knowledge owing to limited sex education in school and restricted access to information about sex from other sources, such as parents, peers and health care professionals (11, 76, 77, 79, 92-94).

Sexual abuse in children is a serious problem for society as well as for research, clinical practice, and bringing up and protecting children (95). Sexual abuse of children and young teenagers can be defined as: “any sexual contact between an adult and a sexually immature (sexual maturity is socially as well as physiologically defined) child for purposes of the adult’s sexual gratification; or any sexual contact to a child made by the use of force, threat, or deceit to secure the child’s participation; or sexual contact to which a child is incapable of consenting by virtue of age or power differentials and the nature of the relationship with the adult” (96). Sobsey (97) has described the additional vulnerability to being subjected to sexual abuse that obtains among children and adolescents with disabilities. Moreover, Crosse et al. (98) reported an overrepresentation of maltreatment including sexual abuse among children with disabilities, and found a 1.75 greater risk of sexual abuse in children with disabilities compared to children without.

First-hand reports of children and adolescents’ own thoughts about and experiences of intimacy and sexuality are rare. Stevens et al. (11) found that only one third of adolescents aged 13–16 years with physical disabilities had ever been on a date. Cromer et al. (79) reported that adolescents with myelomeningocele and cystic fibrosis had significantly less experience of having had sex than a control group without disabilities. By contrast, Suris et al. (99) found no differences regarding ever having had sex between groups of adolescents with and without chronic conditions. A UK interview study including 46 adolescents aged 13–19 years with spina bifida demonstrated frequent occurrence of concerns about sexual relations, sexual function and marriage (100). Several subsequent studies with similar findings have also
described concerns among young people with spina bifida regarding reproduction and genetic risks (47, 80, 101, 102).

Child and adolescent perspective

How can we as adults understand how children and adolescents with mobility impairment experience different situations in life? How can we understand how they cope with the consequences of their disability? How can they make themselves heard? One way of optimising the extent of participation in society for children and adolescents with mobility impairment is to bring out their personal experiences.

Yarrow (103) describes the interview as a research method that is particularly well adapted to exploring subjective definitions of experiences and conceptualisation of life experiences among children. The interview requires an interpersonal relationship between the interviewer and the child which could facilitate the communication process and promote the validity of the data. The interviewer can compensate for misunderstandings by explaining the meaning of a question if necessary. A permissive attitude from the interviewer makes it easier for a child to talk about difficult experiences and to express negative feelings and thoughts.

According to Biermann (104) the most natural way for the clinician to find out how children are thinking and feeling is to ask them:

If the clinician wishes to know how children are thinking and feeling about their problems, the logical way to find out is to ask them. Only they can say what they perceive their problems to be, and only they can describe their impressions, their hopes and their fears about themselves and their relationships.

However, to make the interview a valid and reliable method for exploring children’s thoughts and feelings, both the interviewer and the interview method must be adjusted to the child’s stage of development (104). Stone and Lemanek (105) have summarised the specific cognitive and social-cognitive developmental factors that form the basis of children’s ability to provide adequate self-reports. They conclude that from the age of 7 years, children have incorporated psychological characteristics and social comparisons in their self-descriptions, and they have an awareness of different components of self in different situations and can differentiate between physical and mental aspects of self. Furthermore, children aged 7 years and older have accurate recognition of negative emotions; they use mental cues to understand their own emotions and understand simultaneous experience of different emotions.
The quality of the communication between the child and the interviewer and the quantity of information from the child depend on how the interview is performed (104). Children often respond sparingly, indistinctly and in an unorganized manner in a traditional interview situation with open-ended questions. The interviewer can make it easier for the child by reducing the demands on the verbal ability to describe thoughts and feelings and limiting the task. The interviewer’s direct and often frightening focus on the child can be deflected from the child and to the task in a stimulating way, for instance with the use of pictures, dolls or a certain adjustment of the style in the interview or the language used. Non-verbal or less complicated verbal answering alternatives can make it easier for the child to communicate feelings that he or she would have difficulty describing in words.

Examples of non-verbal answering alternatives are pictures with different facial expressions to describe different feelings. Instead of answering verbally, the child can choose a picture to make his or her answer clear. There are several examples of faces scales. As early as 1944, Temple and Amen (106) used pictures with happy, sad and angry faces to facilitate for children to show how they felt in different situations. McGrath and Unruh (107) used a 9-grade faces scale to assess pain among children. This 9-grade scale was also used by Irgens (108) to measure subjective life satisfaction among school age children in Sweden. At the present time, a 6-grade computer faces scale is available for measuring paediatric pain (109).

Another research method to obtain information from children and adolescents is self-report questionnaires. Stone and Lemanek (105) state that one of the most important considerations for self-report instruments is that the language be adjusted to children’s vocabulary and reading abilities. In generally, they contend that younger children up to the age of 8 years require the self-report questionnaire to be read aloud, so the method will be more like a structured interview.

The introduction of this thesis covers some areas of importance for children and adolescents. Over the years in clinical practice as a paediatric physiotherapist I have met a large number of boys and girls with thoughts about well-being and self-esteem, including body image, and questions about sexuality. In fact, most questions about sexuality made me feel uncomfortably unskilled to such an extent that I felt it necessary take a course in clinical sexology.

Concerning coping strategies, I consider that an important task as a physiotherapist is to assist the individual child or adolescent in her or his coping process. As outlined here, both theoretical and empirical knowledge is limited regarding coping, well-being, self-esteem and sexuality with special regard to mobility impairment in childhood and adolescence. Hence, I believe that a deeper understanding of children’s and adolescents’
experience of their lives as well as coping with everyday stress and major life events ought to be obtained from the child or adolescent’s point of view.
Aim

The overall aim of this thesis is to explore how children and adolescents with mobility impairment experience their life situation, especially with regard to perceived overall well-being and coping strategies.

Specific aims

- To describe the well-being of children and adolescents with mobility impairment in relation to demographic data and disability characteristics.

- To evaluate the applicability of a four-dimensional model of coping strategies on children and adolescents with mobility impairment, and to describe coping strategies in relation to demographic data, disability characteristics and well-being.

- To describe experiences of intimacy and sexual activity and exposure to sexual abuse among children and adolescents with mobility impairment, and to relate these experiences to socio-demographic data, disability characteristics and well-being.

- To describe global and dimension-specific self-esteem in children and adolescents with mobility impairment in relation to demographic data and disability characteristics, and to identify the impact of five self-esteem dimensions on well-being and coping strategies.
Method

Design
The study is a cross-sectional survey with both a descriptive and a correlational design (110). The descriptive part is mostly quantitative and aims to yield an understanding of and to identify features of the experiences of school-aged children and adolescents with mobility impairment. The correlative part aims to analyse differences and associations between the described experiences and a number of variables, primarily demographic and disability characteristics.

Participants
Target population
Criteria for inclusion were age 7–18 years, mobility impairment and ability to communicate in Swedish. Diagnosis-related groups were cerebral palsy, spina bifida, muscle disease, other disease or injury in the central nervous system (CNS) (e.g. brain tumour sequelae, contusio cerebri sequelae), disease or injury in the peripheral nervous system (PNS) (e.g. plexus trauma sequelae, polio sequelae) and disease or injury in skeleton and/or joint/s (e.g. juvenile chronic arthritis, osteogenesis imperfecta).

Criteria for exclusion were mental retardation (IQ < 70), deafness or severe hearing impairment, blindness or severe visual impairment and neuropsychiatric diagnosis.

Sampling
There is no national Swedish register for children and adolescents with mobility impairment. However, in Sweden children and adolescents with mobility impairment in need of care and treatment are generally registered at a Child Development Centre (CDC). In addition to the CDC’s, there are schools with special classes for pupils with impaired mobility in Sweden. Therefore, CDC’s and schools with special classes were chosen to mediate contacts with families with children and adolescents with mobility impairment. The county of Uppsala included one county CDC with four
district CDC’s, and one regional CDC with a special school for pupils with impaired mobility. The county of Stockholm included 13 CDC’s, of which three were selected to represent large urban, small urban and suburban areas, and four nine-year compulsory schools with special classes and one national comprehensive upper secondary school for pupils with impaired mobility.

To begin with the author contacted the heads of the CDC’s and the schools by letter and telephone to inform them about the study and ask if they would like to assist in the sampling procedure. All the heads were positive towards the study and agreed to participate in the selection of children and adolescents and to mediate the contact between the author and the families. Then, the author visited each CDC to inform the head and the relevant staff about the study, in particular about the inclusion and exclusion criteria. The information was given both verbally and in writing. The staff had the opportunity to discuss matters of the study and was encouraged to contact the author if they had any further questions.

The staff at the CDC’s selected the children and adolescents according to the criteria for inclusion and exclusion. To preserve professional secrecy, the staff at the CDC’s asked the selected families for consent to be contacted by the author and receive information about the study. The CDC’s in the county of Uppsala and two out of three CDC’s in the county of Stockholm contacted the families personally. One CDC in the county of Stockholm contacted the families by post. When a family granted their permission, the author was provided with the necessary information for taking contact (name of the child/adolescent, telephone number and address). Two letters were sent to the family: one addressed to the parent/s and one to the child/adolescent, describing the aims of the study and practical matters. After approximately one week the family was contacted by telephone. The parent/s and the child/adolescent received repeated information about the study and had opportunities to ask questions directly to the author. First the parent/s and then the child/adolescent were asked if they would like to take part and both had to agree before participating in the study.

The contact procedure in the schools was different. The author visited the five nine-year compulsory schools with special classes and informed the teachers and the pupils in each class about the study. The pupils received a letter with a description of the study and practical matters including a reply form for their parent/parents to sign. The reply form was collected by the teachers. The pupils at the national comprehensive upper secondary school were asked by a similar letter personally distributed by the school staff.

**Study sample**

The study sample included all children and adolescents registered at the two CDC’s in the county of Uppsala, and three CDC’s and all the schools with special classes for pupils with impaired mobility in the county of Stockholm.
who matched the inclusion criteria. A total of 216 children and adolescents and their parents were contacted. Out of these, 141 children and adolescents accepted and 75 declined to participate in the study (response rate 65%) (see Figure 1). Among those who declined, 22 did not respond to the original inquiry from the CDC, 23 declined contact with the author when asked by the CDC, and 30 declined participation after contact by mail and phone with the author. The distribution on age cohorts, gender, diagnosis-related group and onset of disability among those who accepted to participate and the dropouts are given in Table 1.

Figure 1 Flowchart of the subjects and reasons for declining among the total sample of children and adolescents aged 7–18 with mobility impairment.
Table 1  Age cohorts, gender, diagnosis-related group and onset of disability among the participants in the study and the dropouts (n = 216)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Participants (n = 141)</th>
<th>Dropouts (n = 75)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Age cohort (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7–9 (girls/boys)</td>
<td>15</td>
<td>11/13</td>
</tr>
<tr>
<td>10–12 (girls/boys)</td>
<td>18</td>
<td>13/14</td>
</tr>
<tr>
<td>13–15 (girls/boys)</td>
<td>20</td>
<td>14/16</td>
</tr>
<tr>
<td>16–18 (girls/boys)</td>
<td>15</td>
<td>11/8</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Girls</td>
<td>68</td>
<td>48</td>
</tr>
<tr>
<td>Boys</td>
<td>73</td>
<td>52</td>
</tr>
<tr>
<td>Diagnosis-related group(^a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>79</td>
<td>56</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>25</td>
<td>18</td>
</tr>
<tr>
<td>Muscle disease</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Other disease/injury in CNS</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>Disease/injury in PNS</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Disease/injury in skeleton/joints</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>Disability onset(^a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital</td>
<td>130</td>
<td>92</td>
</tr>
<tr>
<td>Acquired</td>
<td>11</td>
<td>8</td>
</tr>
</tbody>
</table>

\(^a\)Medical data only available for 71 of the dropouts.
Percentages may not total 100 due to rounding.

Description of the participants

**Demographic data**

The study included 141 children and adolescents (68 girls and 73 boys) aged 7–18 years (mean age 12.3 years). The age distribution of girls and boys is presented in Figure 2. The majority of the children and adolescents lived with both biological parents (n = 98, 70%), while 32 (23%) lived with a single parent and 11 (8%) lived alternately with their mother and father. The vast majority had one or more sibling (n = 131, 93%), and most common was to have one (n = 55, 39%) or two (n = 53, 38%).

Most children and adolescents were born in Sweden (n = 130, 92%). Out of the 11 children and adolescents (8%) who were first-generation immigrants, eight (73%) immigrated together with their families and three (27%) were internationally adopted. The first-generation immigrants had lived in Sweden on average 7.6 years (range 2–16 years) at the time of the interview. More children and adolescents were second-generation immigrants as 16% of the mothers and 18% of the fathers were born in a
country other than Sweden. In all, 36 children and adolescents were first or second generation immigrants (26%).

A large number of the children and adolescents lived in a densely populated area (n = 122, 86%), while 19 (14%) lived in a sparsely populated area. Seventy-three (52%) lived in a private home or a row house, 55 (39%) in a flat and 13 (9%) on a farm in the countryside. Thirteen (9%) of the youngsters also lived at a school boarding house during semesters.

![Figure 2](image_url)  
**Figure 2** Age distribution in girls and boys with mobility impairment (n = 141).

**Disability characteristics**

The greater part of the children and adolescents had a congenital disease or injury (n = 130, 92%). The acquired diseases or injuries had occurred at the age of three or later, but at least three years prior to the interview.

Children and adolescents were grouped according to diagnosis of mobility impairment: cerebral palsy (n = 79, 56%), spina bifida (n = 25, 18%), muscle disease (n = 8, 6%), other disease or injury in the CNS (n = 14, 10%), disease or injury in the PNS (n = 4, 3%), and disease or injury in the skeleton and/or joints (n = 11, 8%) (see Figure 3).
In addition to the mobility impairment 87 (62%) of the children and adolescents had one or more disorder or disability. In the whole group the most frequent were urinary incontinence and scoliosis/kyphosis (n = 33 and n = 32, 23%, respectively). Additional disorders or disabilities occurred in all the diagnosis-related groups (Table 2). However, the only diagnosis-related group where all the additional disorders or disabilities were represented was the group of children and adolescents with cerebral palsy. The group with spina bifida had the most frequent occurrence of additional disorder or disability as 24 out of 25 children and adolescents (96%) had urinary incontinence and 20 out of 25 (80%) had hydrocephalus with shunt and/or faecal incontinence.

More than half of the children and adolescents reported presence of pain that affected their daily life (n = 80, 57%). As can be seen in Table 3, pain occurred in all the diagnosis-related groups: cerebral palsy (n = 41, 52%), spina bifida (n = 15, 62%), muscle disease (n = 3, 38%), other disease or injury in CNS (n = 9, 64%), disease or injury in PNS (n = 4, 100%) and disease or injury in skeleton/joint (n = 8, 73%). Pain was reported to prevail in different parts of the body, most frequent in the back.
Table 2 Additional disorder/disability by diagnosis-related group among children and adolescents with mobility impairment (n = 141)

<table>
<thead>
<tr>
<th>Additional disorder/disability</th>
<th>Cerebral palsy (n = 79)</th>
<th>Spina bifida (n = 25)</th>
<th>Muscle disease (n = 8)</th>
<th>CNS (other) (n = 14)(^a)</th>
<th>PNS (n = 4)(^b)</th>
<th>Skeleton/joint (n = 11)(^c)</th>
<th>Total (n = 141)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe speech impairment</td>
<td>23 (29)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>2 (14)</td>
<td>0 (0)</td>
<td>1 (9)</td>
<td>27 (19)</td>
</tr>
<tr>
<td>Chewing/drinking/swallowing difficulties</td>
<td>16 (20)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (7)</td>
<td>0 (0)</td>
<td>1 (9)</td>
<td>18 (13)</td>
</tr>
<tr>
<td>Moderate visual impairment</td>
<td>6 (8)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (18)</td>
<td>8 (6)</td>
</tr>
<tr>
<td>Moderate hearing impairment</td>
<td>4 (5)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>1 (7)</td>
<td>0 (0)</td>
<td>1 (9)</td>
<td>7 (5)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>10 (13)</td>
<td>2 (8)</td>
<td>0 (0)</td>
<td>1 (7)</td>
<td>0 (0)</td>
<td>1 (9)</td>
<td>14 (10)</td>
</tr>
<tr>
<td>Hydrocephalus with shunt</td>
<td>5 (6)</td>
<td>20 (80)</td>
<td>0 (0)</td>
<td>2 (14)</td>
<td>0 (0)</td>
<td>2 (18)</td>
<td>29 (21)</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>6 (8)</td>
<td>24 (96)</td>
<td>0 (0)</td>
<td>3 (21)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>33 (23)</td>
</tr>
<tr>
<td>Faecal incontinence</td>
<td>4 (5)</td>
<td>20 (80)</td>
<td>0 (0)</td>
<td>1 (7)</td>
<td>0 (0)</td>
<td>1 (9)</td>
<td>25 (18)</td>
</tr>
<tr>
<td>Scoliosis/kyphosis</td>
<td>12 (15)</td>
<td>12 (48)</td>
<td>3 (38)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>4 (36)</td>
<td>32 (23)</td>
</tr>
</tbody>
</table>

\(^a\)Acquired disease/injury: n = 9.
\(^b\)Acquired disease/injury: n = 1.
\(^c\)Acquired disease/injury: n = 1.
Table 3 Distribution of daily pain in different parts of the body by diagnosis-related group among children and adolescents with mobility impairment (n = 140, 1 missing)

<table>
<thead>
<tr>
<th>Pain</th>
<th>Cerebral palsy (n = 79)</th>
<th>Spina bifida (n = 24)</th>
<th>Muscle disease (n = 8)</th>
<th>CNS (other) (n = 14)</th>
<th>PNS (n = 4)</th>
<th>Skeleton/joint (n = 11)</th>
<th>Total (n = 140)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Presence of pain</td>
<td>41</td>
<td>52</td>
<td>15</td>
<td>62</td>
<td>3</td>
<td>38</td>
<td>9</td>
</tr>
<tr>
<td>Neck</td>
<td>6</td>
<td>8</td>
<td>3</td>
<td>12</td>
<td>1</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Back</td>
<td>17</td>
<td>22</td>
<td>10</td>
<td>42</td>
<td>2</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Shoulder</td>
<td>6</td>
<td>8</td>
<td>2</td>
<td>8</td>
<td>1</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Elbow</td>
<td>3</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Wrist</td>
<td>4</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Finger</td>
<td>3</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Hip</td>
<td>13</td>
<td>16</td>
<td>2</td>
<td>8</td>
<td>1</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Knee</td>
<td>12</td>
<td>15</td>
<td>3</td>
<td>12</td>
<td>2</td>
<td>25</td>
<td>2</td>
</tr>
<tr>
<td>Ankle</td>
<td>9</td>
<td>11</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>25</td>
<td>4</td>
</tr>
</tbody>
</table>
The level of motor function in the group of children and adolescents varied from considerably limited to less limited. The median motor capacity was 192.5 and the range 11–255 measured by the BL motor assessment (111, 112) were 258 equals normal capacity. The distribution of motor capacity by age is presented in Figure 4.

![Figure 4](image)

**Figure 4** Motor capacity by age among children and adolescents with mobility impairment (258 equals normal motor capacity) (n = 140, 1 missing).

According to the Katz Index of Independence in Activities of Daily Living (ADL) (113), 52 of the children and adolescents (37%) were independent and 89 (63%) were dependent with respect to personal ADL.

Motor capacity in relation to independence and dependence in personal ADL is presented in Figure 5. There was a significant difference in motor capacity, as children and adolescents who were independent had a higher level of motor capacity than those who were dependent in personal ADL ($p < 0.0001$).
Figure 5 Motor capacity by dependence in personal ADL among children and adolescents with mobility impairment (258 equals normal motor capacity) (n = 140, 1 missing).

Measurements

Semi-structured interview

The main instrument of gathering data for this thesis was a semi-structured interview. Semi-structured approaches have often been used in developmental research and allow the interviewer to match the task demands of the interview to the child’s developmental level (114). The intention of the interview was to explore children and adolescents’ thoughts and feelings about their life experiences, and the interview had to cover quite a number of spheres of importance in the lives of children and adolescents.

Planning and writing an interview schedule and interviewing children and adolescents require careful consideration of the purpose with the interview as well as knowledge of child social-cognitive and language development. The interpersonal relationship between the child and the interviewer requires experience of being together with and communicate with children and adolescents. Further, interviewing children and adolescents with impaired mobility requires knowledge and experience of the conditions as well as technical aids, primarily communication aids. The interviewer (i.e. the
author) had many years of experience of working together with children and adolescents with mobility impairment and their families as a clinical paediatric physiotherapist, and a degree in Basic Training in Psychotherapy. Further, the interviewer had previous experience of interviewing children and adolescents with mobility impairment and their parents (45).

The process of designing the interview schedule is described in Table 4. First, the areas of importance were identified (Step 1). Then questions were worded and responses defined (Step 2–3). Areas of importance and questions were based on the results from a pilot study of 22 children and adolescents aged 8–16 years with mobility impairment (45).

Table 4 Design of semi-structured interview schedule

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Identification of areas of importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 2</td>
<td>Wording of questions</td>
</tr>
<tr>
<td>Step 3</td>
<td>Definition of item responses</td>
</tr>
<tr>
<td>Step 4</td>
<td>Wording of instructions of how to use the Snoopy scale</td>
</tr>
<tr>
<td>Step 5</td>
<td>Analysis of interview schedule together with experienced clinicians and senior researchers</td>
</tr>
<tr>
<td>Step 6</td>
<td>Pre-test of interview schedule on boys and girls with mobility impairment in different ages for age-appropriateness and language understanding</td>
</tr>
<tr>
<td>Step 7</td>
<td>Analysis of interview schedule together with an adolescent with mobility impairment</td>
</tr>
<tr>
<td>Step 8</td>
<td>Rewording of questions</td>
</tr>
</tbody>
</table>

The interview included open-ended, fixed-alternative, and scale questions. Fixed-alternative and scale items were used to make it easier for the child or adolescents by reducing the demands on their verbal ability to describe thoughts and feelings and limiting the task. All fixed-alternative and scale items included a follow-up question or an opportunity to comment on the answer.

An example of a fixed-alternative item:

```
How do you want to live when you are a grown up?
Living alone
Partner relationship, not living together
Living together, no children
Living together, children
```
An example of a four-grade scale item:

Do you think that your body functions as you want on an everyday basis?
   Most of the time
   Often
   Sometimes
   Never

All questions about children’s and adolescents’ feelings in different situations as well as perceived overall well-being were scale items using a faces scale, the Snoopy scale, as response (see Figure 6). A faces scale allows the child or adolescent to estimate his or her feelings without the demand of putting them into words. Furthermore, the child or adolescent’s estimation yields a basis for further probing of the meaning and the significance of their feelings or emotional states.

There are faces scales with different layouts and number of faces. Many children and adolescents are in fact acquainted with some kind of faces scale as they often occur in assessments of e.g. books, movies and music in the media. The Snoopy scale is a nine-grade faces scale with nine different facial expressions that relate to different feelings or emotional states. Originally the Snoopy scale was developed to measure the liking for candy bars in younger children aged 5–7 years (115). The Snoopy scale was previously used to measure experiences of physiotherapy and quality of life in children with and without mobility impairment from the age of 7 years (45).

The Snoopy scale was chosen mostly for the attractive layout and the number of faces. Indeed, a study where different faces scales were compared indicated that children and parents preferred scales that they perceived to be happy and cartoon-like (116). In general, faces scales consist of simple drawings of faces with no ears or hair, and sometimes without noses. The Snoopy scale differs from other faces scales in that Snoopy is a genuine figure which could possibly make it easier for children and adolescents to identify with the different facial expressions. The presentation of the Snoopy scale as a response scale could help to divert some of the interviewer’s direct focus on the child or adolescent to the “task”, and thus perhaps reduce the strain on the child or adolescent during the interview.

Children and adolescents received an enlarged copy of the Snoopy scale coated with plastic. For validation purpose, the interview schedule included a standardised introduction of the Snoopy scale and how it worked (see Appendix 1) (Step 4). The instruction was followed by some check-up questions to ensure the child’s or adolescents’ understanding of the response scale. Furthermore, before the question about perceived overall well-being, the interviewer began with a conversation about the meaning of well-being and once more told the child or adolescent about the Snoopy scale and how it worked; that “A” corresponded to the worst possible well-being and “I”
with the best possible well-being. The child or adolescent was then requested to estimate his or her well-being over the last six months on the Snoopy scale.

![Snoopy scale](image)

**Figure 6** The Snoopy scale. The scale goes from A (representing the worst possible well-being) to I (the best possible well-being). (Reprinted from H. R. Moskowitz, 1985, with permission of the author and Food and Nutrition Press.).

The interview schedule was checked by several clinicians and senior researchers with knowledge and experience of interviewing children and adolescents and mobility impairment (Step 5). Further, the interview schedule was tested on boys and girls of different ages to make sure that the wording of the questions and the fixed-alternative and scale responses were age appropriate and adequate (Step 6). In addition to the pre-test, one adolescent with mobility impairment read and commented on the interview schedule (Step 7). The interview schedule was revised several times based on the input from children and adolescents with mobility impairment and professionals (Step 8). Finally, the semi-structured interview schedule included a total of 198 questions in the following 14 domains: demographic data, school, leisure, friends and relationships, existential matters, well-being, the mobility impairment, habilitation and physiotherapy, body image, gender issues, sexuality, coping, leaving home, and alcohol and drug use. The present thesis includes results based on the variables of demographic data, friends and relationships, well-being, the mobility impairment and sexuality.

**Questionnaires**

Coping strategies were measured by the Children’s Coping Strategies Checklist (CCSC) (22, 117, 118). This checklist, from the US, is a 52-item self-report inventory where children report their dispositional style in coping, which is how they usually cope with problems. The 52 items are classified into 11 conceptually distinct coping subscales (Appendix 2). According to Ayers et al. (22), the 11 subscales form four dimensions of
children’s coping: “active coping”, “distraction”, “avoidance” and “support seeking” strategies.

The CCSC states: “Sometimes kids have problems or feel upset about things. When this happens, they may do different things to solve the problem or to make themselves feel better. Below is a list of things kids may do when faced with a problem. For each item, select the response that best describes how often you usually do the behavior when you have a problem. There are no right or wrong answers, just indicate how often you usually do each thing in order to solve the problem or to make yourself feel better”. Children and adolescents are asked to report whether they use the strategies “never”, “sometimes”, “often” or “most of the time”.

In addition to the 52 items, the CCSC addresses how well the children and adolescents believe that their usual manner of handling a problem actually works with the two questions: “Sometimes things people do to handle their problems work really well to make the situation better, and sometimes they don’t work at all to make the situation better” and “Sometimes things people do to handle their problems work really well to make them feel better and sometimes they don’t work at all to make them feel better”. Children and adolescents report whether the things they usually do “do not work at all”, “work a little”, “work pretty well” or “work very well”.

The Children’s Coping Strategies Checklist was forward-backward-forward linguistically validated to Swedish. The Swedish version was then tested on children of varying ages to ensure that they understood the instructions and the items.

Self-esteem was measured using “I think I am”, a Swedish self-report inventory (119). The inventory is designed in a 32-item version for children aged 7–9 years, and a 72-item version for children and adolescents aged 10–18 years. “I think I am” includes five dimensions: “physical characteristics” (appearance, body image), “talents and skills”, “psychological well-being” (psychological stability, strength, anxiety, aggressiveness), “relationships with the family” (parents, siblings) and “relationships with others” (friends, teachers). The instrument allows measurement of global self-esteem as well as independent measurement of each dimension; thus, confounding of physical characteristics could be controlled. Children and adolescents report on whether they think that the different statements describe them. The answering alternative for the 32-item version is “yes” or “no” and for the 72-item version: “exactly”, “to a certain extent”, “not very well” or “not at all”. All points are summarised and the total score range from −32 to +32 for children aged 7–9 years and from −144 to +144 for children and adolescents aged 10–18 years.
Assessment of motor function, pain and dependency

The assessment of motor function and pain was carried out by the interviewer at the end of the last interview session. Level of motor function and occurrence of pain were measured by the BL motor assessment (111, 112), a modification of the instrument for evaluation of physical performance among adults who has suffered from a stroke, developed by Fugl-Meyer et al. (120). The BL motor assessment includes 7 parts: A. Capacity to perform active movements in upper and lower extremities, B. Movement rapidity, C. Mobility, D. Balance, E. Sensation, F. Pain and G. Passive range of motion. Active movements include 31 movements of the arms, wrists, hands and legs in supine, sitting and standing positions. Movement rapidity includes four rapid agonist-antagonist movements. Movements are scored on a 4-grade scale where 0 equals inability to perform movement and 3 equals normal function. Mobility includes eight items, of which seven is scored on a 4-grade scale where 0 equals cannot do it and 3 equals can do it independently, and one; walking, is scored on a 7-grade scale where 0 equals cannot walk and 6 equals can walk at a normal speed for her or his age. Balance includes seven items scored on a 4-grade scale. Motor capacity includes active movements, movement rapidity, mobility and balance. The scores are summarised, range 0–258, and high scores equal high motor capacity. Sensitivity and passive range of motion is scored on a 3-grade scale.

The occurrence of pain in different parts of the body (see Table 3) is assessed on a 3-grade scale where 0 implies pain at rest or strong pain in movement, 1 implies pain in movement or pain when joint/s are in outer position and 2 implies no pain at all. The pain scores are summarized, range 0–36, and low scores indicate higher frequency of pain. The occurrence of pain was dichotomized into “yes” (values 0–35) and “no” (value 36). The assessment of pain was completed with a question on whether the presence of pain affected the daily lives of the children and adolescents. The present thesis includes results based on motor capacity, i.e. active movements, movement rapidity, mobility and balance, and pain.

The BL motor assessment is easy and convenient to carry out in different places outside a clinical setting. The assessment required quite simple equipment: bed, chair, table, pen, paper and tennis ball, and could easily be carried out in the homes of the children and adolescents.

Functional independence or dependence was evaluated with the internationally well-established Katz Index of Independence in Activities of Daily Living (Katz Index of ADL) (113). The Katz Index of ADL evaluates functional independence or dependence in bathing, dressing, going to the toilet, transfer, continence and eating. Functioning was assessed on a 3-grade
scale as independent, partly independent and dependent and then dichotomised into independent or dependent.

Further medical information on the child or adolescent’s diagnosis of mobility impairment and any occurrence of additional disorder/s or disability/ies was reported on a questionnaire by a professional in the child development team. The measurements in the studies (I–IV) are summarized in Table 5 and the independent variables and classification of responses (I–V) in Table 6.

**Table 5** Summary of the measurements in study I–IV

<table>
<thead>
<tr>
<th>Measurements</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Semi-structured interview</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The Snoopy scale</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Children’s Coping Strategies Checklist</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>I think I am</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>BL motor assessment</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Katz Index of ADL</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Medical information</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Table 6 Independent variables and classification of responses in studies I–IV

<table>
<thead>
<tr>
<th>Variable</th>
<th>Scale</th>
<th>Response</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Nominal</td>
<td>Girls/boys</td>
<td>I–IV</td>
</tr>
<tr>
<td>Age</td>
<td>Numerical</td>
<td>7–18 years</td>
<td>I–III</td>
</tr>
<tr>
<td>Age cohorts</td>
<td>Ordinal</td>
<td>7–9/10–12/13–15/16–18 years</td>
<td>I–IV</td>
</tr>
<tr>
<td>Living with</td>
<td>Nominal</td>
<td>Two parents/single parent/alternately mother/father</td>
<td>I–IV</td>
</tr>
<tr>
<td>Number of siblings</td>
<td>Ordinal/numerical</td>
<td>0–6</td>
<td>I–IV</td>
</tr>
<tr>
<td>First-generation immigrant</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>I–IV</td>
</tr>
<tr>
<td>Living area</td>
<td>Nominal</td>
<td>Densely/sparsely populated</td>
<td>I–IV</td>
</tr>
<tr>
<td>Housing</td>
<td>Nominal</td>
<td>Flat/private home or row house/farm in the countryside</td>
<td>I–IV</td>
</tr>
<tr>
<td>Having a caring grown up to turn to Close friend</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Several friends</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Feelings of loneliness</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Future aspirations</td>
<td>Nominal</td>
<td>Living alone/partner relationship not living together/living together no children/living together children</td>
<td>III</td>
</tr>
<tr>
<td>Disability onset</td>
<td>Nominal</td>
<td>Congenital/acquired</td>
<td>I–IV</td>
</tr>
<tr>
<td>Diagnosis-related group</td>
<td>Nominal</td>
<td>Cerebral palsy/spina bifida/muscle disease/CNS (other)/PNS/skeleton joint</td>
<td>I–IV</td>
</tr>
<tr>
<td>Additional disorder/disability</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>I–IV</td>
</tr>
<tr>
<td>Severe speech impairment</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Hydrocephalus with shunt</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Faecal incontinence</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Scoliosis/kyphosis</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>III</td>
</tr>
<tr>
<td>Pain (daily)</td>
<td>Nominal</td>
<td>Yes/no</td>
<td>I–IV</td>
</tr>
<tr>
<td>ADL</td>
<td>Nominal</td>
<td>Independent/dependent</td>
<td>I–IV</td>
</tr>
<tr>
<td>Motor capacity</td>
<td>Numerical</td>
<td>0–258</td>
<td>I–IV</td>
</tr>
</tbody>
</table>
Procedure

The timing and location of the interviews were adjusted to children and adolescents’ special requirements. Children and adolescents and their parents were allowed to choose when and where the interview should take place. Forty percent of the children and adolescents were interviewed at home, 21% at the CDC, and 39% at another place, e.g. at school, school boarding house or a café. The duration of each interview session was also adjusted to the individual child or adolescent. The interviewer had to be sensitive to any sign of lack of attention or fatigue in the child or adolescent. The length of the interview and the number of interview sessions varied from a total of 50–315 minutes (mean 105 minutes) and 1–6 separate occasions. Most participants (n = 114, 81%) completed the interview in two sessions.

In the beginning of the interview, the interviewer introduced herself and explained that she was a physiotherapist working with young people with mobility impairment. The interviewer explained the purpose with the study and told the child or adolescent about the reasons for undertaking the study. Then, the interviewer asked if the child or adolescent had any questions, and also told them that they could ask any question or comment on anything they wanted throughout the interview. After that, the interviewer explained the matter of confidentiality and ensured the child or adolescent that all information was going to be treated confidentially. Further, the interviewer told the child or adolescent that they did not have to answer questions if they did not want to and that they could stop the interview at any time, and if they did, that they did not have to explain themselves. At last, the interviewer told the child or adolescent that there were no right answers and that the interviewer was interested in their particular opinions and ideas and thoughts and feelings about things.

During the interview, the interviewer wrote down the answers verbatim, which gave the child or adolescent time to consider the answer and the opportunity to check that the answer was correctly recorded. The questionnaires were introduced after approximately half of the interview, most common at the end of the first interview session. To provide the best possible opportunities of accurately answering the questions in the questionnaires, children and adolescents were allowed to choose how they wanted to complete the questionnaires.

At the end of the interview, the interviewer asked the child or adolescent if they could think of any question of importance for them that the interview did not include. Further, the interviewer expressed her thanks to children and adolescents in the study. All children and adolescents that participated received a small gift, a pencil and a cinema ticket, afterwards.
Statistical methods

Statistical analyses were carried out using Statistica 6.1 and SPSS 10.1 (I), SAS/STAT® software version 9.1.3 (II, IV) and LogXact® 7 (III). Results were considered statistically significant if the \( p \)-value was less than 0.05.

Different regression analysis methods were used based on the type of dependent variable: simple and multiple ordinal regression analyses (I, IV) (121), simple and multiple linear regression analyses (II, IV) (122, 123) and simple and multiple exact logistic regression analyses (III) (124). The simple regression is used to predict the expected value of one dependent variable from the value of an independent variable. In multiple regression analysis more than one independent variable is included in the prediction equation. In the present thesis, all final multiple regression models were based on the significant variables in the univariate analyses. The different explanatory variables were then included and excluded in a stepwise procedure. To avoid overfitting, the principle of parsimony was used (125).

Evaluation of the applicability of a four-dimensional model of coping strategies on children and adolescents with mobility impairment (II) followed the procedure described by Ayers et al. (22). First, the 11 coping subscales were evaluated. Mean scale scores for each item were created by summing the item scores within each of the 11 coping subscales. The item totals were then divided by the number of items within that subscale. Coefficient alpha (\( \alpha \)) and the fit of confirmatory factor analysis (CFA) models were used to evaluate the psychometric characteristics of each of the 11 individual coping subscales (123). In the CFA models, it was hypothesised that all items representing a specific coping subscale load on a single latent factor. Bivariate correlations and coefficient alphas were calculated using the CORR procedure in SAS. CFA utilised the CALIS procedure, which is based on the maximum likelihood method. Second, the four-dimensional coping model was evaluated. Based on the correlations between the 11 coping subscales, maximum likelihood CFA was used to evaluate the four-dimensional coping model including the factors: “active coping”, “distraction”, “avoidance” and “support seeking”. Bentler’s confirmatory fit index (CFI) (126) was used to measure the goodness of fit of the model. A score was then created for each of the four factors by calculating the mean scores of the coping subscales contributing to each of the four factors (see Figure 8). In the calculation, the coping subscales were scored: never = 1, sometimes = 2, often = 3 and most of the time = 4. Consequently, the mean score ranged from 1–4, where higher scores correspond to strategies used more often.
Ethics

Children and adolescents with mobility impairment represent a vulnerable group in the society and need to be treated with respect and preserved integrity. Some of the questions in the interview could involve violation of integrity or arouse negative feelings and thoughts within the child or adolescent. Ethical concerns were taken into careful consideration and precautions were made to avoid harm. As a matter of routine, low estimation of well-being, report on sexual problems and report on exposure to sexual abuse were followed up by the interviewer. As a precaution, the interviewer had an established contact with a psychologist or a social worker at each CDC and could help the child or adolescent to get in contact if necessary.

On the other hand there were also possible benefits with the study. Children and adolescents had the opportunity to express their thoughts and feelings and opinions and thus make themselves heard. The opportunity of introspection and interaction with the interviewer could possibly enhance children and adolescents knowledge of themselves and self-esteem. In fact several children and adolescents said that their reason for participating in the study was that they wanted to contribute to knowledge of the life situation for young people with impairment that could help others in the future.

The study was approved in 1998 by the Research Ethics Committee at the Faculty of Medicine at Uppsala University (registration number 98384).
Results

Well-being (I)

This study describes perceived overall well-being among children and adolescents with mobility impairment in relation to demographic data and disability characteristics. Generally children and adolescents in the study indicated a favourable level of well-being (median 8, range 1–9). A majority of the children and adolescents (n = 107, 76%) estimated their well-being equal to the happy faces G–I on the Snoopy scale. However, 10 children or adolescents (7%) indicated an evidently low level of well-being (A–C on the Snoopy scale) (see Figure 7).

![Figure 7](image-url)

**Figure 7** Perceived overall well-being estimated on the Snoopy scale among children and adolescents with mobility impairment (n = 140, 1 missing) (A representing the worst possible well-being and I the best possible well-being).
Multiple ordinal regression was used to analyse the relationship between well-being and the independent variables, seven on demographic data and six on disability characteristics (Table 6). There were no significant differences in well-being between girls and boys or between those with and without siblings. Housing area (densely or sparsely populated) or housing condition (private home or row house, flat, or farm in the countryside) did not influence well-being significantly. Further, there were no significant differences in well-being with regard to diagnosis-related group, the presence of one or more additional disorder or disability, the level of motor capacity or independence or dependence in ADL. In the final multiple ordinal regression model, a lower level of well-being was significantly related to: greater age ($p < 0.001$), not living with both parents ($p = 0.015$), being a first-generation immigrant ($p = 0.009$), having an acquired disease or injury ($p = 0.002$), and experience of pain ($p = 0.036$).

Following the question on well-being, children and adolescents were asked if anything could increase their well-being and 84 (60%) answered in the affirmative. Some of the answers are listed below:

"If I could just start attending an ordinary class" (9-year-old boy, Snoopy = A)

“If I could walk, it would probably be more fun then. I could climb trees and all” (11-year-old girl, Snoopy = H)

"If I didn’t have to have those medical examinations” (12-year-old boy, Snoopy = E)

“To have friends and a girlfriend and feel secure and stuff. To be happy” (13-year-old boy, Snoopy = A)

“I don’t know. I’m happy with my life, but I want to talk better, I want to walk better, I don’t want to stagger like a drunk when I walk” (13-year-old boy, Snoopy = H)

“If I could get rid of that cerebral infarction. If I got healthy all of the sudden. Then I would appreciate life more. Than before” (14-year-old girl, Snoopy = D)

“It would be to have a boyfriend” (15-year-old girl, Snoopy = G)

"If I could do what I want in my spare time, not be excluded because I sit in chair. Since I turned 15 years and wanted to start to go out I have been really sad that I can’t go out like my friends” (17-year-old girl, Snoopy = C)
Coping (II)

The first part of this study deals with the evaluation of the applicability of a four-dimensional model of coping strategies for children, which encompasses “active coping”, “distraction”, “avoidance” and “support seeking” strategies, on children and adolescents with mobility impairment. Coping strategies were measured by Children’s Coping Strategies Checklist (CCSC) (22, 117, 118). 52 items classified into 11 subscales form the basis for the four-dimensional model of coping strategies (see Statistical methods).

Psychometric characteristics of the 11 coping subscales were evaluated by coefficient alphas and the fit of confirmatory factor analysis (CFA) models (Table 7). Coefficient alphas ranged from 0.45 to 0.78 and acceptable fits ranged from 0.88 to 1.00, using Bentler’s CFI. The most frequently used were, in order, “direct problem solving”, “cognitive avoidance” and “avoidant actions”; and the least frequently used were, in order, “physical release of emotions”, “expressing feelings” and “problem-focused support”.

Table 7 Means, standard deviations, coefficient alphas and fit of the single-factor models for the coping subscales of the Children’s Coping Strategies Checklist (CCSC) among children and adolescents with mobility impairment (n = 133). High mean values correspond to strategies used more often

<table>
<thead>
<tr>
<th>Coping subscale</th>
<th>Mean</th>
<th>SD</th>
<th>Alpha</th>
<th>CFI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Decision Making</td>
<td>2.26</td>
<td>0.79</td>
<td>0.78</td>
<td>0.98</td>
</tr>
<tr>
<td>Direct Problem Solving</td>
<td>2.50</td>
<td>0.67</td>
<td>0.64</td>
<td>1.00</td>
</tr>
<tr>
<td>Seeking Understanding</td>
<td>2.08</td>
<td>0.63</td>
<td>0.66</td>
<td>0.92</td>
</tr>
<tr>
<td>Positive Cognitive Restructuring</td>
<td>2.12</td>
<td>0.65</td>
<td>0.67</td>
<td>0.99</td>
</tr>
<tr>
<td>Distracting Actions</td>
<td>2.19</td>
<td>0.64</td>
<td>0.61</td>
<td>0.92</td>
</tr>
<tr>
<td>Physical Release of Emotions</td>
<td>1.57</td>
<td>0.62</td>
<td>0.65</td>
<td>0.88</td>
</tr>
<tr>
<td>Expressing Feelings</td>
<td>1.77</td>
<td>0.67</td>
<td>0.64</td>
<td>1.00</td>
</tr>
<tr>
<td>Cognitive Avoidance</td>
<td>2.50</td>
<td>0.61</td>
<td>0.45</td>
<td>1.00</td>
</tr>
<tr>
<td>Avoidant Actions</td>
<td>2.48</td>
<td>0.65</td>
<td>0.48</td>
<td>1.00</td>
</tr>
<tr>
<td>Problem-focused Support</td>
<td>2.00</td>
<td>0.61</td>
<td>0.65</td>
<td>0.88</td>
</tr>
<tr>
<td>Emotion-focused Support</td>
<td>2.03</td>
<td>0.55</td>
<td>0.50</td>
<td>0.89</td>
</tr>
</tbody>
</table>

When fitting the four-dimensional coping model, one of the estimated error variances was negative. This was related to the “distraction strategies” factor, containing the subscales “distracting actions” and “physical release of emotions”. Various modifications of the four-factor model were evaluated and the best fit was achieved by replacing the latter subscale with the subscale “expressing feelings”, while the rest of the model remained unchanged (Bentler’s CFI = 0.95). The proposed model is presented in Figure 8.
**Figure 8** Graphical portrayal of the proposed four-dimensional model of coping strategies of children and adolescents with mobility impairment (n = 133). The results displayed are the standardised solution from a confirmatory factor analysis. Causal relationships are depicted by straight arrows, with the arrow emanating from the predictor variable and the arrowhead towards the dependent variable. Curved arrows represent correlations between constructs where no causation is implied. The error terms are displayed to the left in the figure.

The second part of the study was based on this model with the purpose of analysing the relationship between coping strategies and demographic data, disability characteristics and well-being.

“Active coping” was used significantly more often by older (in cohorts) children and adolescents, those who lived in a private home or row house,
those with no or more than one sibling, and first-generation immigrants. Children and adolescents with cerebral palsy used “active coping” more often than those with other disease or injury in CNS or with spina bifida. Further those who reported that they “almost always” had a grown-up who cared for them and to whom they could turn to used “active coping” more frequently. “Distraction strategies” was used significantly more often by older (in years) children and adolescents, girls and first-generation immigrants. “Support seeking strategies” was used significantly more often by older (in years) children and adolescents. Children and adolescents with cerebral palsy used “support seeking” more often than those with other disease or injury in CNS or with spina bifida. Those who reported that they “almost always” or “often” had a grown-up who cared for them and to whom they could turn to used “support seeking” to a greater extent than those who did not. There were no significant relationships between “avoidance strategies” and the evaluated variables.

The majority (n = 91, 70%) estimated that their usual manner of handling a problem worked at least pretty well, both with regard to making the situation better and making them feel better.

Perceived overall well-being was not significantly associated with frequency of use of the four coping strategies. However, those who perceived that their strategies helped to make the situation better and to make them feel better reported a significantly higher level of well-being (p < 0.0001 and p = 0.0011, respectively).

Intimacy and sexuality (III)

This study deals with children’s and adolescents’ experience of intimacy and adolescents’ experiences of sexual activity, sexual problems and exposure to sexual abuse. Questions about intimacy and sexuality were adjusted to the respondents age and for that reason the sample was divided into the age-cohorts 7–12 years (n = 72) and 13–18 years (n = 69).

Age cohort 7–12 years

The part of the interview about intimacy for children aged 7–12 years began with an open question: “How does one know that one is in love?” Some answers were:

"You feel it inside” (7-year-old girl)

“That you like somebody so much that you want to kiss that person” (7-year-old girl)
“I am in love so I should know. It tingles a little and you feel it in your ear lobe” (9-year-old boy)

“It can tingle in the body when you look at a boy or a girl. And then you can get really warm when you think about him or her” (12-year-old girl)

At the time of the interview 13 children (18%) had a boyfriend or girlfriend (“going steady”), and in all 33 (46%) had experience of such a relationship (Table 8). Among these, about half had experience of holding hands, kissing and hugging, while fewer had experience of caressing. Out of those with no present relationship, about a third reported that they would like to have a relationship.

Multiple logistic regressions were used to analyse the relationships between the intimacy variables and the independent demographics, disability characteristics and social relationships variables (see Table 6). Experience of playing doctor/house was significantly more likely among girls than boys, and among those without than in those with severe speech impairment. Occurrence of urinary incontinence and pain was significantly related to greater likelihood of having been in a relationship. Those who suffered from faecal incontinence had an ongoing relationship significantly more often. There were no significant likelihoods between a wish to have a relationship or intimate experiences and any of the independent variables.
Table 8 Experiences of intimacy, sexual activities, sexual problems and exposure to sexual abuse among children and adolescents with mobility impairment by age cohorts

<table>
<thead>
<tr>
<th>Experience of playa</th>
<th>Age cohort 7–12 years (n = 72)</th>
<th>%</th>
<th>Age cohort 13–18 years (n = 69)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of playing doctor/housea</td>
<td>42</td>
<td>59</td>
<td>39</td>
<td>57</td>
</tr>
<tr>
<td>Experience of having a relationship</td>
<td>33</td>
<td>46</td>
<td>38</td>
<td>55</td>
</tr>
<tr>
<td>Present relationship</td>
<td>13</td>
<td>18</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Desire to have a relationshipb</td>
<td>18</td>
<td>32</td>
<td>28</td>
<td>51</td>
</tr>
</tbody>
</table>

Experience of:

| Holding hands | 17 | 52 | 29 | 91 |
| Kissing | 16 | 48 | 30 | 94 |
| Hugging | 16 | 48 | 31 | 97 |
| Caressing | 10 | 30 | 23 | 72 |
| Sexual intercourse/caressing | - | - | 7 | 22 |

Experience of sexual relationshipd | 10 | 15 |
Sexual problemsd | 10 | 15 |
Sexual abused | 5 | 7 |

aChildren 7–12 years (n = 71, 1 missing), adolescents 13–18 years (n = 68, 1 missing).
bAmong children 7–12 years (n = 57, 2 missing) and adolescents 13–18 years (n = 55) with no present relationship.
cAmong children 7–12 years (n = 33) and adolescents 13–18 years (n = 32, 6 missing) with experience of having a relationship.
dAdolescents 13–18 years (n = 68, 1 missing).

Age cohort 13–18 years

Teenagers aged 13–18 years were asked about what qualities they considered important in the person they wanted to have a relationship with. Some answers were:

“She should be pretty for starters, and then nice and all” (13-year-old boy)

“That person should be like me, I mean mobility impaired and so. Kind and so” (13-year-old girl)

“They should absolutely not have prejudices. I like guys with a good sense of humour. They should not be nursing; they should be a little bit cocky. It would be an advantage if the guy in any way has had sex with another girl in a wheelchair” (15-year-old girl)

“That you can rely on the person. That the person has the same opinions as oneself about the issues of most importance” (16-year-old boy)

“That he has a sense of humour. That we can talk and be open toward each other” (18-year-old girl)
At the time of the interview 14 teenagers (20%) had a boyfriend or girlfriend and in all 38 (55%) had some experience of being in a relationship (Table 8). Among these teenagers, a majority reported experiences of different intimate acts such as holding hands, kissing, hugging and caressing, while experience of sexual caressing and sexual intercourse were less common. In all, 10 (15%) had some experience of a sexual relationship. Among those with no present relationship, half reported that they would like to have one.

The adolescents were asked if they had any difficulties regarding their sexuality and possible problems were exemplified by the interviewer. No sexual dysfunction was reported. However, some (n = 10, 15%) expressed worries about future sexual activities; i.e. physical appearance, pain in connection with sexual intercourse, their personal assistant would get too much insight in their sexual life, questions on reproduction (“Could I have a child?”), being questioned as a parent, realization of sexual intercourse (“How is it done?”) and concerns regarding a future partner (“Will I get an understanding girlfriend?”). About half of these, who reported such worries, had no one or nowhere to turn to with their problems and expressed a wish to discuss their sexuality with a skilled professional, and answered in the affirmative to the follow-up question as to whether they would like the interviewer to help them get in contact with a sexologist.

Five adolescents (7%) reported having been involuntarily involved in sexual acts. Two of these also reported having been forced into a sexual act.

Multiple logistic regressions were used to analyse the relationships between the intimacy and sexual variables shown in Table 8 and the independent demographics, disability characteristics and social relationships variables (see Table 6). Having a current relationship was significantly more likely among those with urinary incontinence. Expressing a wish to have a relationship was significantly more likely to prevail among those with scoliosis/kyphosis and those with a lower level of perceived overall well-being. The experience of holding hands was significantly more common among those with relatively higher motor capacity. Those who expressed future aspirations of living together with a partner and eventually having children were 26 times more likely to have had experiences of caressing than those with future aspirations of living together with a partner, but without children. Experiences of sexual intercourse/caressing increased significantly with a higher age. There were no significant associations between the remaining intimate and sexual variables and the independent variables.

Self-esteem (IV)

This study describes dimension-specific and global self-esteem measured by the “I think I am” inventory (119) in children and adolescents with mobility impairment, in relation to demographic data and disability characteristics,
and identifies the impact of five self-esteem dimensions on well-being and coping strategies.

Generally the children and adolescents reported a positive dimension-specific and global self-esteem (as shown in Table 9). Estimations ranged from a low on the dimension “talents and skills” to a high on “relationships with family”.

Table 9 Means, standard deviations and minimum and maximum values for the five dimensions of self-esteem and global self-esteem of “I think I am” (119) (n = 138)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical characteristics</td>
<td>0.59</td>
<td>0.32</td>
<td>-0.36</td>
<td>1.00</td>
</tr>
<tr>
<td>Talents and skills</td>
<td>0.48</td>
<td>0.36</td>
<td>-1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>0.50</td>
<td>0.36</td>
<td>-0.50</td>
<td>1.00</td>
</tr>
<tr>
<td>Relationships with family</td>
<td>0.66</td>
<td>0.32</td>
<td>-0.89</td>
<td>1.00</td>
</tr>
<tr>
<td>Relationships with others</td>
<td>0.62</td>
<td>0.29</td>
<td>-0.21</td>
<td>1.00</td>
</tr>
<tr>
<td>Global self-esteem</td>
<td>0.57</td>
<td>0.26</td>
<td>-0.38</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Multiple regressions were used to analyse the relationships between dimension-specific and global self-esteem and the independent variables on demographics and disability characteristics (Table 6). Six regression models were constructed; one for global self-esteem and one for each of the five dimensions (see Table 10). Significantly lower estimation of “physical characteristics” was reported by older (in cohorts) children and adolescents, first-generation immigrants, those who reported pain and those with a higher level of motor function. The dimension “psychological well-being” was reported to be significantly lower by older (in cohorts) children and adolescents, those with an acquired disease or injury, those who experienced pain and those who were dependent in Activities of Daily Living (ADL). Significantly lower estimation of “relationships with others” was reported by older (in cohorts) children and adolescents and those with an acquired disease or injury. The sole significant association between the dimension “talents and skills” and independent variables was that the older (in cohorts) estimated this dimension significantly lower than the younger ones. The dimension “relationships with family” was not significantly related to any of the evaluated variables. Finally, global self-esteem was reported to be significantly lower in older (in cohorts) children and adolescents, first-generation immigrants, those with an acquired disease or injury and those with experience of pain.

Three of the five self-esteem dimensions were positively associated (multiple ordinal regression) with perceived overall well-being: “physical characteristics”, “psychological well-being” and “relationships with others” ($p = 0.0229$, $p = 0.0185$ and $p = 0.0161$, respectively).
The impact of the five self-esteem dimensions on coping strategies was also analysed in multiple regression models, one for each of the four coping strategies, i.e. “active coping”, “distraction”, “avoidance” and “support seeking” strategies. The only significant relationship found was that children and adolescents who estimated low “physical characteristics” used “distraction strategies” to a greater extent ($p < 0.0001$).
Table 10 Relationships between the dimensions of self-esteem and global self-esteem of “I think I am” (119) and the different background variables in the final multiple regression models (n = 138)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Physical characteristics</th>
<th>Talents and skills</th>
<th>Psychological well-being</th>
<th>Relationships with family</th>
<th>Relationships with others</th>
<th>Global self-esteem</th>
</tr>
</thead>
<tbody>
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In this general discussion I shall first address the aspects of well-being and self-esteem, followed by intimacy and sexuality, and subsequently the subject of coping.

On well-being and self-esteem

It is encouraging that the majority of the children and adolescents in the study indicated a relatively high level of well-being and positive self-esteem. These findings support those of others (41, 61).

Final multiple regression models of perceived overall well-being and global self-esteem were almost identical with regard to the background variables included. This being so, one could argue that these measures assess the same aspects of children’s and adolescents’ perception of well-being. However, perceived overall well-being was defined as a judgement of life as a whole, while global self-esteem referred to a summary evaluation of five self-esteem dimensions. Further multivariate analysis actually identified that three out of the five self-esteem dimensions were significantly related to perceived overall well-being, namely “physical characteristics”, “psychological well-being” and “relationships with others”. These results indicate that assessment of perceived overall well-being as well as global self-esteem could contribute to the understanding of the subjective well-being of children and adolescents with mobility impairment. Moreover, Huebner et al. (127) investigated the discriminant validity of global self-esteem and global life satisfaction in children without disabilities, and found that children differentiated between these two constructs.

The findings that lower level of perceived overall well-being and lower level of global and dimension-specific self-esteem were significantly related to greater age appear to reflect relevant psychological developmental changes (128). Young children, on average, have relatively high self-esteem that gradually declines during adolescence (129). Adolescence is a period characterised by physical and psychological changes and an intense emotional life. The adolescent has to confront her or his “new” body and growing sexuality. Youths with mobility impairments face the same challenges as their peers, at the same time as they have to handle personal
and environmental barriers. Hayden Bellin et al. (130) described experiences of stress related to daily living and incontinence and catheterization, as well as mobility, among adolescent girls and young women with spina bifida. Stewart et al. (131) identified a bad fit between young persons with disabilities and the adult world they were entering.

Based on interviews with young adults with physical disabilities, Barron (132) argues that gender is an important aspect of autonomy for these young people as boys and girls are subject to different expectations and given different opportunities for autonomy in their everyday life. Thus even though there were no gender differences in perceived overall well-being or global and dimension-specific self-esteem in the present study, being met as a boy or a girl is incorporated in child and adolescent psychosocial development.

Living area or housing did not influence perceived overall well-being or self-esteem significantly. However, those who lived with both their parents estimated their well-being significantly higher. This finding corresponds to the results of Amato and Keith (133) who in a meta-analysis of 92 studies deducted that parental divorce or factors associated with it appeared to lower the well-being of children. Furthermore, a population-based study of the effects of single parenthood on health problems and psychosocial disturbances in Swedish children, adolescents and young adults, demonstrated an increased risk of psychiatric disease, suicide or suicide attempts, injury and addiction (134). Mobility impairment could add to difficulties in connection with parent separation. Indeed, in the interviews, some of those who most of the time lived with one of their parents reported major obstacles to spending time with or staying at the other parent’s home due to insufficient or lack of technical aids and home adjustments.

Culture and ethnicity affect many aspects of child and adolescent development (135). Being a first-generation immigrant involves specific challenges for children and adolescents with mobility impairment. This appears reflected by the present findings that first-generation immigrants estimated lower level of perceived overall well-being, as well as their lower level of the self-esteem dimension “physical characteristics” and global self-esteem. Separation, bereavement and changing family patterns are all stressors that affect children (136). In the interviews, adolescents who were refugees expressed grief for relatives lost in war and a longing for the life they had lived earlier in their native country. Another example from the interviews is an adolescent girl who said that she had a triple whammy since she was a woman, had a disability and was an immigrant. First-generation immigrants used both “active coping” and “distraction” strategies more often than children and adolescents born in Sweden. Certainly, these children and adolescents meet further challenges while adapting to their changed life situation. Duncombe (137) asserts that the culture, i.e. the context in which one grows and develops, has an impact on self-esteem that becomes compounded when the culture into which one is born is different from the
culture in which one lives. Research regarding development of children and adolescents who are of minority status due both to ethnicity and disability is insufficient (135). Increased knowledge regarding possible socio-cultural differences, e.g. gender and ethnicity, in children and adolescents with mobility impairment is required for a better understanding. I would also like to emphasize the importance of identifying children and adolescents with traumatic experiences related to war and political violence in order to provide opportunities to adequate support.

The findings in this study indicate that the impairment per se does not influence overall well-being or global self-esteem negatively, as no significant relationships could be attributed to diagnosis-related group, occurrence of one or more additional disorder/disability, the level of motor function or dependence in ADL. Even though the assessment of perceived overall well-being could be interpreted quite differently from assessments of quality of life, these findings are partly comparable to those in such studies. Thus, neither Livingstone et al. (35), nor Shelly et al. (38) found evidence for a relationship between the level of motor function and psychosocial quality of life in children with cerebral palsy.

However, in the analyses of domain-specific self-esteem, a higher level of motor function was significantly related to a lower estimate of “physical characteristics”. This finding corresponds to a meta-analysis that concluded that minor physical disabilities had a large effect on the self-esteem of physical competence (138). Minchom et al. (139) found that among young people with spina bifida greater severity of disability was associated with increased self-esteem in physical appearance and global self-worth. In contrast, using the same self-esteem measure, Antle (73) found no relationships between the severity of disability and the perceptions of physical appearance or global self-worth in children and adolescents with spina bifida and spinal cord injuries. These contradictory findings could partly be explained by disparities in the definitions of severity of disability. In the present study, degree of impairment was assessed by motor function, a fairly specific measure of mobility impairment. There are several possible explanations for the finding that those with a higher motor function estimated their “physical characteristics” lower. One could be that young people with minor functional limitations identify with their peers without disabilities and therefore meet with larger demands from the environment. Another aspect is that children and adolescents with major visible physical disabilities to a larger extent receive other people’s empathy and attention and consequently get greater opportunities to receive social support (138).

Furthermore, independence in activities of daily living, which presumably extends the freedom and autonomy of the child or adolescent, was positively associated with estimated “psychological well-being”. This finding is partly supported by King et al. (53) who found a positive relationship between
increased independence and social self-efficacy among adolescents with physical disabilities.

With regard to disability characteristics, the most outstanding finding was the increased vulnerability in children and adolescents with acquired disease or injury and those with occurrence of pain, indicated by the significant relationship to lower level of perceived overall well-being as well as global and dimension-specific self-esteem. In the interview, children and adolescents with acquired disease or injury expressed grief for their losses, loss of physical and psychological functions and abilities as well as loss of their identity. Cohen and Napolitano (140) have described the dealing with multiple losses and adjustment after acquired spinal cord injury and maintain that readjustment involves relearning and understanding one’s new persona.

It is noteworthy that more than half of the children and adolescents in the study reported occurrence of lingering pain that affected their daily lives. This finding has been reinforced by others (37, 42, 141). Dickinson et al. (37) found pain to be associated with a lower level of self-reported quality of life in 8–12-year-old children with cerebral palsy. And Russo et al. (42) found pain to be common and related to both lower quality of life and lower self-concept in children with hemiplegic cerebral palsy. The variety of possible underlying causes of pain related to the disability (142) and the potential of over-sensitivity (143) place children and adolescents with mobility impairment at great risk for chronic pain. In clinical practice interventions often focus on the functional level, and pain as a separate disorder has been disregarded. These findings acknowledge the importance of providing opportunities for psychological evaluation and support for children and adolescents with mobility impairment. Further, the significant associations between having an acquired disease or injury and occurrence of pain and well-being and self-esteem clearly demonstrate a need for specialized management.

On intimacy and sexuality

Self-reported experience of intimacy and sexual activities among young people with mobility impairment is a largely unexplored field of research, especially in the younger individuals. Both the younger children and the teenagers clearly identified themselves as sexual beings and a majority expressed their future aspirations of living together with a partner and having children. Experiences of holding hands, kissing, hugging and caressing were reported both by younger children aged 7–12 years and older aged 13–18 years. However, more than half of the children had no experiences of different intimate acts, and as few as seven of the adolescents reported experiences of sexual caressing and intercourse within a partner relationship, and only 10 out of 68 reported experience of at least one sexual relationship.
Adolescents with scoliosis/kyphosis were more likely to express a wish for a relationship. A close relationship is important for well-being, which could explain the finding that those adolescents who estimated a lower level of well-being were more likely to express a longing for a relationship.

In the younger age cohort, experience of role playing with peers such as playing house and doctor were less common among boys and those with severe speech impairment. These groups would certainly benefit from adult encouragement and support in peer activities.

Incontinence or pain did not interfere with making intimate contact with others. Younger children with urinary incontinence and pain reported more experiences of having had a relationship and both children with faecal incontinence and adolescents with urinary incontinence were more often in a present relationship. This finding corresponds well with Castree and Walker (78) who found no evidence that those with a urinary appliance were any more isolated than those without one. Several authors have reported that young people with spina bifida have serious concerns about urinary incontinence and sexuality (78, 92).

That adolescents with a higher motor capacity were more likely to have experienced holding hands, may partly be explained by these adolescents having the motor ability. Naturally, experiences of sexual intercourse and sexual caressing increased significantly with a higher age.

The limited experiences of intimacy among children and adolescents in this study are in agreement with others (47, 77, 80). The restricted intimate and sexual experience is further emphasised by the adolescents’ reported concerns regarding their future sexuality, a majority of which were disability-related. These findings are in accordance with others that have described insignificant experiences of intimate relationships (101) and major concerns about relationship matters among teenagers with disabilities (82, 100, 101).

Many of the children and adolescents expressed a wish to have a relationship. Their hopes and expectations of love and affection and a close relationship reflect an age-appropriate development. At the same time, children and adolescents reports disclose the hardship they have to face. Remarkably, prior to the interview none of the teenagers reported that they had expressly been asked questions on sexuality, and several of them spontaneously reported being excluded from sex education in school. As an example, one girl reported that before a theme day devoted to sex education in her school her teacher suggested that she should book time at her physiotherapist or orthopaedic clinic to make use of the time, since the theme day did not concern her. Furthermore, none of the adolescents who reported sexual concerns had received any kind of support to approach their problems and most were in need of professional care. Reluctance to provide sexuality counselling and education to young adult with disabilities has been
described (144). Evans (145) found a discrepancy between occupational therapists’ positive attitudes toward sexual habilitation of children with disabilities and what they practised, although therapists who had received information on sexual habilitation also performed more of these tasks. This underlines a need for specific education in sexual medicine for professionals working within this field of habilitation.

An even more complicated issue concerning sexuality among young people with mobility impairment is that of sexual abuse. Earlier studies support the finding that children with disabilities are at a higher risk of exposure to sexual abuse than children without disabilities (98, 146). Sawyer and Roberts (94) reported that 10 out of 27 females and one out of 24 males with spina bifida had had experiences of unwanted sexual touching or having something done to them sexually. Quite similar figures for the exposure of sexual abuse among young people with disabilities, 10% and 7%, were reported by Blackburn et al. (147) and by us in the present study. In a previous study of sexual abuse among Swedish women aged 18–74 years, 12% had a history of some kind of sexual abuse and for nearly 60% of these women the (first) abuse had taken place during childhood or adolescence (148), and in the same sample, 3% of the men reported sexual abuse (149).

Even though there is a general risk of sexual abuse in children and adolescents, it is an absolute necessity to recognize the extra vulnerability associated with having impaired mobility (150). Much further work needs to be done about sexual abuse in children and adolescents in order to develop prevention programs as well as support programs for victims. For the group of children and adolescents who are growing up with mobility impairment, there is an urgent need to bring out these issues. To illustrate, the majority of the existing prevention programs focus on teaching children how to protect themselves (97). This being so, how do children and adolescents with impaired mobility learn how to protect themselves and with whose help? To protect these children and adolescents from potentially harmful situations appropriate sex education is an absolute necessity; hopefully leading to enhancing positive attitudes to the joy and strength of a satisfying sexual life.

On coping

Whereas the body of literature on the relationships between quality of life and self-esteem and demographic and disability features is growing, the interaction with coping strategies remains largely unexplored. A major clinical implication of this study is that the Swedish version of the Children’s Coping Strategies Checklist (22) is applicable as a measure of coping strategies even among children and adolescents with mobility impairment. Furthermore, a four-dimensional model of coping strategies has
been identified in Swedish children and adolescents with mobility impairment. Although the model is not exactly to the same as the original one (22) the proposed four-factor model of coping strategies enables us to identify coping strategies among the children and adolescents with mobility impairment and furthermore relate these to pertinent demographic and disability characteristics variables.

The finding that older children and adolescents used “active coping”, “distraction” and “support seeking” strategies to a larger extent than the younger ones, appear to reflect relevant psychological developmental changes (128). Increased use of coping strategies with greater age has been described by others. During the period of changes in adolescence young people examine coping behaviour and acquire new coping responses (151). The findings in this study are principally congruent with those of others. Thus, Ryan (152) found that older children listed more coping strategies. Brown et al. (153) investigated catastrophising and coping cognitions in response to imagined stressors among children and adolescents and found that coping cognitions in particular increased with age and older children used more varied types of strategies.

Whereas children and adolescents with brothers and sisters did not significantly differ in perceived overall well-being or self-esteem compared to those without siblings, those with no siblings or more than one used “active coping” strategies more often than those with one sibling. This may be speculatively explained by a probability that children and adolescents with one sibling are more dependent on the brother or sister and therefore less (psychologically) apt to seek their own solutions.

The fact that those who lived in a private home or row house used “active coping” more often than those who lived in a flat or on a farm may tentatively be explained by the possibility that the former group have greater physical and social freedom of action in their home setting than the latter group.

Analyses of the relationship between coping strategies and disability characteristics revealed only one significant finding: children and adolescents with cerebral palsy used both “active coping” and “support seeking” strategies more frequently than those with spina bifida and other disease or injury in the CNS. Further knowledge of possible variation of individual characteristics such as psychological and social maturity in these diagnosis-related groups is necessary to be able to understand these differences.

Marriage and Cummins (154) found that self-esteem predicted subjective quality of life in children without disabilities, whereas primary and secondary control in coping did not predict either self-esteem or subjective
quality of life. In the present study, perceived sense of overall well-being and self-esteem were connected, as three out of five dimensions of self-esteem were positively associated with perceived overall well-being: “physical characteristics”, “psychological well-being” and “relationships with others”.

Studies (155, 156) have suggested that lower self-esteem is related to more avoidance coping strategies while higher self-esteem is related to more problem-focused strategies in adolescents without disabilities. Meijer et al. (157) demonstrated that the coping style “confrontation”, i.e. active and purposeful problem-solving, was an important determinant of social self-esteem. In children and adolescents with idiopathic scoliosis, Beka et al. (158) found that lower general self-esteem was associated with increased use of emotion-focused coping strategies. In this study, coping strategies distinguish as not related to perceived overall well-being and with only one significant relationship to self-esteem; those who estimated their “physical characteristics” lower used “distraction” strategies more often.

Nevertheless, the more children and adolescents believed that their manner of handling problems worked, the higher their estimation of their own well-being. This indicates that a suitable coping strategy, irrespective of which, has an influence on well-being and may serve to prevent mental health problems among children and adolescents with mobility impairment.

Methodological considerations

The present study has a cross-sectional design as data were collected at one point in time. The thoughts and feelings and experiences of children and adolescents in the study are obtained as they manifest themselves at the time of the interview. In other words, the study provides a “snapshot in time” of the variables studied. Hence this study is focused on describing, ad hoc, experiences and the relationships between these experiences and a number of background variables, but not causalities. Nevertheless, when causalities are indicated (I, IV) they are based on clinical and theoretical arguments.

Children and adolescents with mobility impairment are a heterogeneous group with regard to onset of disability, conditions, additional disorders or disabilities, level of motor function and dependence in personal ADL. Therefore, children and adolescents with varying severity of mobility impairment were included in the study. To depict developmental differences the study included children and adolescents aged 7–18 years.

The sample studied here can probably best be characterised as convenience samples recruited from two counties (Uppsala and Stockholm) in the east of Sweden. Against this background efforts were made to secure a sufficiently large number of participants to catch the range of socio-
demographic variation in the group. All the children and adolescents with mobility impairment in the county of Uppsala were targeted in the study. In the county of Stockholm, three CDC’s were selected to represent large urban, small urban and suburban areas, and all the schools with special classes for pupils with impaired mobility were included.

Whereas the present sample is not epidemiologically anchored in the Swedish population, a recent report (159), including 470 pupils aged 6–16 years with mobility impairment, provides at least partial support for socio-demographic generalisability of the findings concerning distribution of the study sample on gender, living with two parents, being a first generation immigrant and living in a densely or sparsely populated area.

However, the sampling procedure involved possible non-response bias. The response rate for participating was 65%. The reasons for not responding to the inquiry from the CDC or declining participation in the study are unknown in 45 of the 75 non-responders. Indeed the study involved an interpersonal contact with an unfamiliar person and a time-consuming interview, and it is feasible that children or adolescents and/or parents who experienced a high level of strain in their everyday life to a relatively great extent declined participation. As a group, the 75 non-responders may differ from the participants in interest and motivation, and it is also possible that they had other characteristics under-represented in the sample.

Children’s self-report measurements are subject to all of the methodological limitations that concern adult self-report measurements, as well as those that are particularly child related such as developmental change (160). Assessment of reliability and validity depends on the type of measurement and what kind of consistency one is interested in (110).

The main instrument for gathering data for this thesis was the semi-structured interview. Several steps were taken to strengthen the reliability with regard to quality and adequacy, as well as optimising the content validity of the interview schedule and the interview. In the interview, the child or adolescent could talk about her or his thoughts and feelings and experiences in confidence. The interviewer could verify that he or she did understand the questions, explain and clear up any misunderstandings, and was able follow-up on the answers to obtain a deepened understanding.

The Snoopy scale was used as response scale in all questions about feelings and emotional states. The faces scale is a well-known, simple method of asking young children to express their own feelings (161). In clinical practise as well as research, faces scales are commonly used in assessment of self-reported pain in children (162). There is support for test-retest reliability and construct and discriminant validity for faces scales to measure procedural pain intensity in children from the age of 3 years (163). Hicks et al. (164) found a 6-grade faces scale to be a valid instrument for the assessment of intensity of acute pain in children from the age 4 or 5 onward.
Likewise, a Swedish study on postoperative pain in children found that a 6-grade faces pain scale was a useful and valid instrument for measuring pain in children from the age of 4 years (165). Further, Maldonado et al (166) described that children aged 4–7 years could use a faces scale to indicate sleepiness.

Temporal consistency estimated as test-retest reliability of the Snoopy scale would imply that well-being is stable over time in children. Developmental changes could reduce the stability estimates and the test-retest intervals highly influence the reliability coefficient. Thus lower coefficients would not necessarily indicate an unreliable measure (160); reliability estimates of temporal consistency or stability of the Snoopy scale in the measurement of well-being was not assessed. However, the significant relationship between estimated perceived overall well-being and “psychological well-being” indicates content validity, since these variables are very likely to correlate.

Children and adolescents’ experiences of the Snoopy scale were mainly positive as many of the respondents enjoyed using the scale and spontaneously used it to express their feelings even when it was not required. Moreover, one girl with severe speech impairment wanted a copy of the scale and affixed it on her wheelchair table and used it to express her feelings about things.

The measurement of coping strategies was evaluated by the same criteria as originally described by Ayers et al. (22). Inter-item reliability was assessed by internal consistency to establish whether the items tapped the same underlying construct. Coefficient alphas (α) were comparable to those of Ayers et al. (22) and other coping instruments for children with similar numbers of items per subscale (151, 167). Furthermore, the internal structure of the coping subscales was assessed by the fit of confirmatory factor analysis (CFA) models. Acceptable fits on the subscales ranged from 0.88 to 1.00, using Bentler’s Confirmatory Fit Index (CFI) (126).

The Swedish “I think I am” inventory has been used in both non-clinical (54) and clinical (168-175) groups of children measuring dimension-specific and global self-esteem (119). This instrument has been standardized on a Swedish sample of 3,465 children and adolescents (176). The internal consistency and stability over time is adequate, and validity studies, mainly concerning construct validity, have indicated that the inventory measures the aspect intended (119).

Level of motor function was measured by the BL motor assessment (111, 112). This instrument was developed for adults who had suffered stroke/brain damage and not for children with impaired mobility. However, there is no reason to assume that the physiotherapists’ assessment of the ability to perform movements and mobility and balance in children and adolescents would be less adequate with this instrument. The instrument has successfully been used to measure motor function among young people.
(from the age of 7 years) with mobility impairment (45, 177, 178). The author has experience in using the instrument in clinical practice before and after referring young people with mobility impairment to physiotherapy at adult habilitation services. However, the reliability of the instrument has not been assessed in children and adolescents with mobility impairment.

Conclusions
To sum up, the findings in this study acknowledge areas of importance for health care professionals as well as parents and other people close to children and adolescents to consider. In short, there are some main conclusions:

The Swedish version of the Children’s Coping Strategies Checklist is an applicable measure of coping strategies in children and adolescents with mobility impairment.

The four-factor model of coping strategies including “active coping”, “distraction”, “avoidance” and “support seeking” strategies enables identification and analysis of coping strategies in children and adolescents with mobility impairment.

Children and adolescents who are growing up with mobility impairment in general experience a favourable level of perceived overall well-being and a positive self-esteem.

There are vulnerability factors for lower perceived overall well-being: greater age, not living with both parents, being a first-generation immigrant, having an acquired disease or injury and occurrence of pain.

There are vulnerability factors for lower global self-esteem: greater age, being a first-generation immigrant, having an acquired disease or injury and occurrence of pain.

Young people with mobility impairment clearly identify themselves as sexual beings, even though many have limited or no experiences of intimacy and sexual activities.

Several aspects of sexual health are not fulfilled for children and adolescents with impaired mobility, and there is a need for specialized sexual health care services to protect the sexual rights of this group.
Some reflections on the future

My hope is that the new knowledge provided here will promote changes of attitudes and opinions in the minds of parents, personal assistants and teachers as well as health care professionals and other people in society, and thus enhancing dialogues with children and adolescents.

Altogether, based on findings in this study and my impressions from the interviews, children and adolescents with mobility impairment should be given greater opportunities to receive psychosocial support from skilled professionals. This is particularly evident with regard to issues on close relationships and sexuality. Confiding with an important other, discussion groups for teenagers and contact with adults with disabilities are important sources of support for children and adolescents (179). Group psychotherapy has been found to have a significant positive effect on sense of intimacy in close friendship and self-esteem in children (180). Nowadays, there are various ways of providing support. As one example, Valkenburg et al. (181) demonstrated that positive feedback on the profiles on friend networking sites increased adolescents’ social self-esteem and well-being. Furthermore, psychotherapy, individually or in group, with a special emphasis on coping strategies, should help and support children and adolescents in their adjustment process. Future studies on the implementation and evaluation of preventive interventions to enhance well-being and self-esteem are required.

This thesis has focused on the experiences of children and adolescents exclusively. Naturally, parents and siblings are major sources of support for children and adolescents during their development. Lagerheim (182) described that children with disabilities could work through adolescent stress by talking to adults close to them, and emphasised the importance of professional support to enable parents to help their children. In agreement, I believe that parents would benefit from expanded opportunities for counselling and support, especially during the challenging period of transition from young adolescence to adulthood.

Finally, the entire study is based on children and adolescents’ own reports. Beyond figures and significant relationships, the main message this thesis offers is the importance of asking children and adolescents about everything that matters in their lives.
Barn och ungdomar med rörelsehinder är i första hand just barn och ungdomar. De har samma behov av trygghet, stöd, vägledning och uppföstran som sina kamrater utan rörelsehinder. Att växa upp med ett rörelsehinder påverkar hela livssituationen och barnen och ungdomarna möter olika svårigheter under uppväxtåren. För att vi ska kunna ge ett bra stöd och omhändertagande behöver vi kunskap om hur de själva ser på sin tillvaro och hur de handskas med de svårigheter de möter.

Det övergripande syftet med denna avhandling var att beskriva hur barn och ungdomar med rörelsehinder upplever sin tillvaro, särskilt med avseende på trivsel med livet, coping strategier, nära relationer och sexualitet samt självvärdering.

Studien omfattar 141 barn och ungdomar i åldern 7–18 år med rörelsehinder och förmåga att kommunicera på svenska språket. Exklusionskriterier var mental retardation eller andra svåra kognitiva störningar, dövhet eller svår hörselnedsättning, blindhet eller svår synnedsättning samt neuropsykiatrisk diagnos.


En övervägande del av barnen och ungdomarna med rörelsehinder rapporterade en god trivsel med livet. Det var ingen signifikant skillnad i trivsel med livet med avseende på diagnos, förekomst av ett eller flera
ytterligare funktionshinder eller grad av motorisk funktionsnedsättning. Däremot fanns signifikant samband mellan lägre trivsel med livet och att ha ett förvärvat funktionshinder, att ha smärta som påverkar det dagliga livet, högre ålder, att inte bo tillsammans med båda föräldrarna samt att vara första generations immigrant.

Resultaten visade att den svenska versionen av ”Children’s Coping Strategies Checklist” kan användas för att mäta coping strategier hos barn och ungdomar med rörelsehinder samt att en fyrdimensionell modell för coping omfattande strategierna ”aktiv”, ”distrarherande”, ”undvikande” och ”stödsökande” kan användas för att beskriva och analysera coping. Ett flertal signifikanta samband visades mellan tre av de fyra coping strategierna: ”aktiv”, ”distrarherande” och ”att söka stöd” och såväl demografska som funktionshinderrelaterade variabler. Det fanns dock inget signifikant samband mellan trivsel med livet och hur ofta barnen och ungdomar använde de fyra olika coping strategierna. Däremot framkom att ju bättre barnen och ungdomarna tyckte att de strategier de använde sig av fungerade för att få dem att känna sig bättre till mods och för att lösa problem, desto högre skattade de sin trivsel med livet.

Ungefär hälften av barnen och ungdomarna rapporterade att de någon gång hade haft en flickvän eller pojkvän, och en femtedel att de hade ett förhållande vid tidpunkten för intervjun. Trots att många hade begränsad eller helt saknade erfarenhet av intim och sexuell aktivitet identifierade de sig som sexuella varelser och majoriteten förväntade sig en framtid med partner och barn. Bland tonåringarna hade endast 15 % någon erfarenhet av en sexuell relation. Ingen av dem rapporterade någon sexuell dysfunktion, men 15 % uttryckte en oro över framtida sexuell aktivitet relaterad till rörelsehindret. I åldersgruppen 13–18 år, rapporterade 7 % att de varit utsatta för sexuella övergrepp.

De flesta av barnen och ungdomarna med rörelsehinder hade en positiv självvärdering. Multivariat analys visade signifikant samband mellan lägre global självvärdering och högre ålder, att vara första generations immigrant, att ha ett förvärvat funktionshinder och att ha smärta som påverkar det dagliga livet. Endast ett signifikant samband mellan självvärdering och coping strategier visades: barn och ungdomar som skattade sina ”fysiska egenskaper” lägre använde ”distrarherande” strategier i en större utsträckning. Trivsel med livet samvarierade signifikant med tre av de fem dimensionerna av självvärdering: ”fysiska egenskaper”, psykologiskt välbehinnande” och ”relationer till andra”.

Sammanfattningsvis visar studien på komplexiteten i de utmaningar som barn och ungdomar med rörelsehinder möter under uppväxten. Resultaten kan bidra till förståelse av barnen och ungdomarnas livssituation och hur de möter svårigheter i livet. Denna kunskap är av stor betydelse för att kunna individualisera vård, behandling och stöd under uppväxtåren.
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References

13. van Daalen-Smith C. "My mom was my left arm": The lived experience of ableism for girls with spina bifida. Contemporary Nurse 2006-2007;23(2):262-273.
15. Brodin J, Fasth Å. Vi vill bara vara som andra. En rapport från projektet Att fånga dagen och framtid (We just want to be like everybody else. A report
from the project To seize the day and the future) (Swedish). Stockholm: Unga RBU:are; 2001.


45. Jemtå L. Barn med rörelsehinder - deras upplevelse av sjukgymnastik samt värdering av faktorer i livet och trivsel med tillvaron i jämförelse med barn utan rörelsehinder (Children with mobility impairment - their experiences of physiotherapy and evaluation of factors in life and well-being compared to children without mobility impairment) (In Swedish, English summary). Uppsala: Centrum för omvårdnadsvetenskap, Uppsala Universitet; 1996.


118. Program for Prevention Research. Manual for the Children's Coping Strategies Checklist and the How I Coped Under Pressure Scale (Available from Arizona State University, P.O. Box 876005, Tempe, AZ 85287-6005); 1999.


159. Paulsson K, Stenberg L. Särskild, särskiljd eller avskiljd? Om skolsituationen för elever med rörelsehinder i grundskolan (Special, separated or isolated? About school situation for pupils with mobility impairment in nine-year compulsory school) (Swedish) In print; 2008.


Appendix 1

**Instruction before the first question with Snoopy scale as response:**

A good way for me to find out about your opinion is for me to ask a question and you to answer by choosing one of these Snoopy pictures.

When Snoopy thinks that something is best or cannot be better he looks like this: I
worst or cannot get worse he looks like this: A
Those Snoopy pictures that are between I and A show in different ways how Snoopy can feel when he thinks that something is not best or worst but somewhere in between.
## Appendix 2

The 11 coping subscales and their definitions from the Manual for the Children’s Coping Strategies Checklist and the How I Coped Under Pressure Scale (118)

<table>
<thead>
<tr>
<th>Coping subscale</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Decision Making (CDM)</td>
<td>This refers to all planning or thinking about ways to solve the problem. It includes thinking about choices, thinking about future consequences, and thinking of ways to solve the problem. It is not simply thinking about the problem—but thinking about how to solve it. It involves the planning and not the execution of actions to solve the problem.</td>
</tr>
<tr>
<td>Direct Problem Solving (DPS)</td>
<td>This refers to efforts to change the problem situation by changing the self or by changing the environment. It involves what one does, not what one thinks.</td>
</tr>
<tr>
<td>Seeking Understanding (SU)</td>
<td>This includes cognitive efforts to find meaning in a stressful situation or to understand it better. It involves seeking understanding of the situation and not seeking to put a positive interpretation on the situation.</td>
</tr>
<tr>
<td>Positive Cognitive Restructuring (PCR)</td>
<td>This refers to thinking about the situation in a more positive way. It includes thoughts that minimize the problem or the consequences of the problem, acceptance that one can live with the situation the way it is an optimistic thinking.</td>
</tr>
<tr>
<td>Expressing Feelings (EF)</td>
<td>This involves the overt expression of feelings either by an action to express feelings, or a verbal expression of feelings or simply an overt release of emotion. It is a solitary activity and does not include discussing feelings with another person. It also does not include inappropriately acting out feelings by threatening or hurting another person.</td>
</tr>
<tr>
<td>Physical Release of Emotions (PRE)</td>
<td>This includes efforts to physically work off feelings with physical exercise, play or efforts to physically relax. There needs to be at least moderate amount of physical exertion involved, so that very light physical activity for a child (e.g. walking) would not be included here.</td>
</tr>
<tr>
<td>Distracting Actions (DA)</td>
<td>This includes efforts to avoid thinking about the problem situation by using distracting stimuli, entertainment or some distracting activity. If the distracting activity involves more than moderate physical exertion it should not be included here.</td>
</tr>
<tr>
<td>Avoidant Actions (AVA)</td>
<td>This includes behavioral efforts to avoid the stressful situation by staying away from it or leaving it.</td>
</tr>
<tr>
<td>Cognitive Avoidance (CA)</td>
<td>This includes efforts to avoid thinking about the problem or avoiding thinking about it. It includes the use of fantasy or wishful thinking, or imagining that it was better. It refers to cognitive activity and not behaviors one does to avoid thinking about it.</td>
</tr>
<tr>
<td>Problem Focused Support (PFS)</td>
<td>The use of other people as resources to assist in seeking solutions to the problem situation. This includes seeking advice or information or direct task assistance and not emotional support.</td>
</tr>
<tr>
<td>Emotion Focused Support (EFS)</td>
<td>The involvement of other people in listening to feelings or providing understanding to help the person be less upset.</td>
</tr>
</tbody>
</table>
A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine”.)