

Psychosocial Development and Social Support among Adolescents with Visual Impairment



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Psychosocial Development and Social Support among Adolescents with Visual Impairment

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ACADEMIC DISSERTATION

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ACADEMIC DISSERTATION

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the Faculty of Medicine of the University of Tampere,
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on June 16th, 2000, at 12 o'clock.

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Tampere 2000*

To Tommi-Petteri

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1 LIST OF ORIGINAL PUBLICATIONS

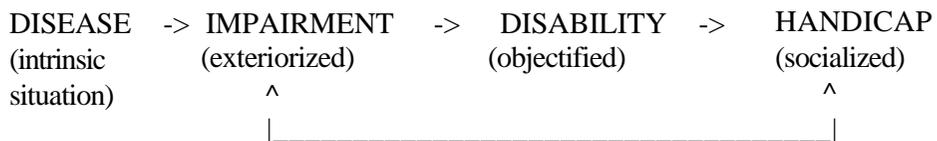
This thesis is based on the following original publications, which are referred to in the text by their Roman numerals I - V.

- I Huurre T, Komulainen E, Aro H. Näkövammaisten nuorten sosiaaliset verkostot ja sosiaalinen tuki. *Sosiaalilääketieteellinen Aikakauslehti* 1996, 33, 17-24. Supplementti.
- II Huurre TM, Aro HM. Psychosocial development among adolescents with visual impairment. *Eur Child Adolesc Psychiatry*, 1998, 7, 73-78.
- III Huurre TM, Komulainen EJ, Aro HM. Social support and self-esteem among adolescents with visual impairments. *Journal of Visual Impairment & Blindness*, 1999, 93, 26-37.
- IV Huurre T, Komulainen E, Aro H. Relationships with parents and friends, self-esteem and depression among adolescents with visual impairment. (Submitted)
- V Huurre T, Aro H. Psychosocial wellbeing among adolescents with visual impairment compared with that of adolescents with chronic conditions. (Accepted for publication by the *Journal of Visual Impairment & Blindness*).

2 THEORETICAL BACKGROUND AND LITERATURE REVIEW

2.1 Characteristics and prevalence of visual impairment

The International Classification of Impairments, Disabilities and Handicaps (ICIDH), developed in the 1970s, was issued by the World Health Organization in 1980 as a tool for the classification of the consequences of disease and of their implications for the lives of individuals (World Health Organization 1980). This classification has provided definitions of the concepts disease, impairment, disability and handicap, which can be linked in the following manner:



An **impairment**, resulting from a **disease** (such as diabetes, glaucoma, or cataracts), is defined as any loss or abnormality of psychological, physiological, or anatomical structure or function (World Health Organization 1980). This concept refers to residual defects in an organ or body parts that may remain after the active phase of a pathology (Kirchner 1989). Examples of vision impairments include impairment of visual acuity, field of vision, or contrast sensitivity. A **disability** is defined as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (World Health Organization 1980). The concept refers to limitations in functioning in relation to specific tasks and involves the whole person. Reading and mobility are defined types of tasks which may be affected by various types of visual impairment (Kirchner 1989). A **handicap** is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors). Handicap therefore results from the interaction between the person and the social environment (World Health Organization 1980). It depends on the transactions and interactions among a range of social, cultural and behavioural variables. An actual or perceived inability to meet role expectations held by oneself or others in domestic, professional, or civil life are examples of the social or psychological disadvantages an individual may experience as a result of visual impairment or disability (Peterson et al. 1988).

The classification of the ICIDH (World Health Organization 1980) has been criticized to view disability as a personal problem, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals (“medical model” to understand and explain disability and functioning). Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy (World Health Organization 1999).

The World Health Organization (1999) developed a new classification of the International Classification of Functioning and Disability (ICIDH-2, Figure 1) in which medical aspects and social aspects are integrated. Disability is viewed not only an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment (“social model”). The ICIDH-2 attempts to achieve a synthesis providing a coherent view of different dimensions of health at biological, individual and social levels. ICIDH-2 organizes information according to three dimensions: (1) body level, (2) individual level and (3) society level. These dimensions are named: Body functions and structure, Activities and Participation. Dimensions are conceived as having two poles: At one end they can be used to indicate problems (e.g. impairment, activity limitation or participation restriction); at the other end they can be indicated as nonproblematic (i.e. neutral and positive) aspects of functional states. “Functioning” is used as an umbrella term for the positive or neutral aspects of dimensions at body, individual and society level and “disability” is the term used for the problems in these dimensions. Functioning and disability are conceived of as a dynamic interaction between health conditions and contextual factors (personal and environmental factors). The ICIDH-2 classification is undergoing systematic field trials and is subject to further consultation. It is planned to publish final version in 2001.

A person is considered to be visually handicapped if he or she has considerable difficulties in daily functioning because of lowered sight (Ojamo 1999). Visual impairment may result in various degrees of visual loss existing along a continuum from total blindness to nearly normal sight. There are several areas in visual functioning, such as visual acuity, visual field, contrast sensitivity, colour vision, adaptation, visual sphere and the influence of light. The official classification of visual impairment is based on the measurement of visual acuity using optotypes (e.g. E-test) and the measurement of visual field recommended by the World Health Organization. According to this definition, a person is considered visually handicapped if the corrected visual acuity is permanently less than 0.3 (normal visual acuity 1.0-2.0) in the better eye of the patient, or if the person should for some other reason be considered comparable with a person with permanent visual impairment as described above (Ojamo 1999). The classification of visual impairments according to the World Health

Organization (WHO) is presented in Table 1.

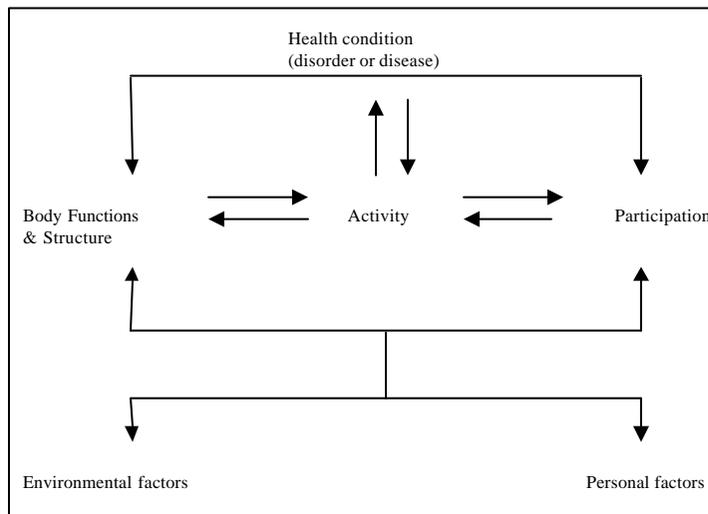


Figure 1. Interactions between the dimensions of ICDH-2

Table 1. WHO recommendation for the classification of visual impairments (Ojamo 1999).

Classification	Visual acuity	The diameter of visual field	Functional description
1 Moderate low vision	$0.3 > v \geq 0.1$		Nearly normal visual function using low vision optical aids.
2 Severe low vision	$0.1 > v \geq 0.05$		Able to see with low vision aids, but the efficiency is not normal (reading velocity, reading difficulties).
3 Profound low vision	$0.05 > v \geq 0.02$	$\varnothing \leq 20^\circ$	Not capable of reading. Mobility difficulties. The use of other senses.
4 Near-total blindness	$0.02 > v - 1/\infty$	$\varnothing \leq 10^\circ$	Eyesight unreliable. The main function with the aid of other senses.
5 Total blindness	$v=0$, no light perception		Totally blind. Totally dependent on other senses.

Visually impaired persons are classified into subcategories by the severity of their visual impairments. There are two main categories: low vision (WHO categories 1 and 2) and blind (WHO categories 3-5, Ojamo 1999). In school life, the group of blind pupils includes those who use braille in their studies.

The total number of visually impaired people in Finland is estimated to be about 80,000 out of a population of 5.2 million (Ojamo 1999). About 580 visually impaired pupils study in regular classrooms in Finnish comprehensive and upper secondary schools. In addition, about 60 pupils study in special schools (School for the Visually Impaired in Jyväskylä 1999). About 60 % of children and adolescents (under 18 years) with visual impairment have additional handicapping conditions, such as hearing or physical impairments, mental retardation or cerebral palsy. The main diagnoses of visual impairments of children and adolescents are non-congenital disorders of the optic nerve and visual pathways, congenital anomalies of the eye, hereditary retinal dystrophies and retinopathy of prematurity (Ojamo 1999).

In Finland, in the 1970s, the idea of integration, or mainstreaming, became generally accepted in education and since then the principle has been to educate all children in regular classrooms. Over 90 % (School for the Visually Impaired in Jyväskylä 1998) of the pupils with visual impairments in Finland study in regular classrooms. Those visually impaired pupils who are mainly severely and multiply handicapped attend special schools for the visually impaired. Special schools in Finland serve as resource centres for learning and development of visually impaired pupils. The schools offer children rehabilitation and education from pre-school to the end of secondary education. They also provide supportive consultation for pupils in local comprehensive schools and upper secondary schools, offering regional tutoring and special courses for pupils, teachers and key workers.

2.2 Psychosocial development during adolescence

2.2.1 Adolescent development

Adolescence, the transition from childhood to adulthood, is characterized by unique, multiple physical and psychological changes and social demands (Vondra and Garbarino 1988). Three phases have been distinguished within adolescence: early, middle and late adolescence. The early stage of adolescence begins at approximately the age 12 or 13 and ends around 15. The middle stage of adolescence begins approximately at age 15 and ends around 18, and the late stage begins around the age of 18 and ends around 20 - 25.

The set of biological changes that mark the beginning of adolescence is called puberty (Clarke-Stewart et al. 1988). During puberty, the young person comes to have the appearance and size of an adult and to have the potential for mature reproduction, together with all the underlying processes. Puberty occurs almost two years earlier in girls than in boys, and there are great individual variations in the time and sequence with which changes

are experienced (Petersen and Hamburg 1986).

Adolescence is the stage not only of physical changes but also of cognitive changes. During adolescence, persons become more mature in their reasoning and problem-solving capabilities (Sroufe and Cooper 1988). Piaget (1977) called this level of thinking formal operational. Formal operations are new kinds of mental transformations that teenagers are able to perform. They allow youngsters to reason more logically about abstract concepts and to think more systematically (Sroufe and Cooper 1988).

During adolescence, youngsters attain a qualitatively new level of self-development. The self becomes more cohesive, unified and integrated. Adolescents are able to tie together their past behaviours and their anticipated future roles, they acquire the important capacity of self-reflection (Sroufe and Cooper 1988). Erikson (1968) introduced the term identity formation to describe the new way of thinking about self in adolescence. In this theory, the difficulties that adolescents encounter when trying to establish their personal identities is referred to as an identity crisis. Blos (1979) described adolescence as the second individuation process.

Self-concept and self-esteem take an important place in adolescence. Self-esteem is based on the conception of one's own worthiness, which is determined not only by self-perceptions but also by interpretations of feedback from significant others (Rosenberg 1979). The self-esteem of oneself is an affective judgement, and varies from high to low. Self-concept refers to the cognitive schemata people have about themselves (Nurmi 1997).

Grow and development occur in interaction with other people that are important to the adolescent, such as parents, siblings, relatives, friends, and school personnel. During adolescence, youngsters change in the way they interact and relate to family and peers. Functional changes occur in family interactions because the young adolescent begins to demand greater autonomy and an altered relationship with parents. Peers play an important role in adolescents' emergence from family towards independence (Kirchler et al. 1991). Adolescents increase their involvement with peers and increase intimacy, and shared thoughts and feelings as a basis of friendship (Hartup 1983). The relationship with members of the opposite sex also assumes a new importance. Girls especially have been claimed to be concerned with communicating and relating to other people and deriving intensive emotional support from their friends. Boys have been found to be more interested in sharing things and activities (Frey and Röthlisberger 1996). Although peer influence increases during adolescence, parents still remain strong socializing agents throughout the period (Youniss and Haynie 1992). In most cases, adolescents have positive and constructive relationships with their parents, and peers' values appear to be consistent with parents rather than in conflict with them (Coleman 1989).

2.2.2 Psychosocial development among adolescents with visual impairment

The period of adolescence may cause a great deal of anxiety for the person with a physical handicap, who faces not only the usual developmental challenges but also the added strain of his or her physical handicap.

Tuttle (1987) has claimed that persons with visual impairments have four major problems with which to contend. First, in order to feel competent, they must develop good coping skills and adaptive behaviours. Second, they deal with the task of maintaining a sense of self-esteem in the face of predominantly negative reflections. The third problem centres on visually impaired persons' abilities to maintain control over situations, to perceive alternative courses of action, and to make decisions or choices regarding events in their lives. The fourth problem has to do with the negative impact on self-esteem that results from the fact that a visually impaired person, even with the best of coping skills and adaptive behaviours, is still dependent on others to accomplish certain daily tasks and consequently does not appear to be exercising an internal locus of control.

There are individual variations in psychosocial development among adolescents with visual impairments as there are among those without impairments. Some sources of variation in the growth and development can be attributed to visual impairment, such as onset and severity of impairment (Scholl 1986, Warren 1989).

It has been claimed that congenitally impaired persons have more developmental difficulties than those who have been impaired later in life (Suokas 1992). The study by Suokas showed that the congenitally impaired and those impaired in infancy have more problems in the development of identity and that the scope of their experiences is narrower than that of those impaired at a later age. Congenitally impaired persons have few hobbies and their contacts with other people are limited to family members and professional helpers. On the other hand, Määttä (1981) has stated that particularly those who have been impaired at a later age may suffer difficulties in their physical and psychological development. These persons have lost the self-identity of an able-bodied and well-functioning person, whereas those who have been impaired since birth perceive their impairment as one of their physical characteristics, thus being disabled is a normal condition for them.

Persons with low vision have been claimed to have more difficulties in psychosocial development than have the blind. They may be misdiagnosed, misunderstood, undereducated, and socially ostracised (Jan et al. 1977). Parents, teachers, and the community tend to expect more from them, thus placing more stress and pressure on them to perform as sighted and blind persons. Persons with low vision may view themselves as belonging to neither the sighted nor the visually handicapped world, which may result in a reduced self-concept or emotional problems (Scholl 1986). They may also hide or "mask" their visual impairment, rather than disclose their needs to others, because they attach negative attributes to their visual impairments. This may lead to feelings of social isolation and difficulties in establishing a positive sense of self (Sacks and Corn 1996).

In addition to factors related to visual impairment, variations in the growth and

development of visually impaired persons consist of environmental circumstances in which visually handicapped persons are brought up and educated. These factors include the nature of the physical environment, the sensory and learning environment, and particularly the social setting, including patterns of family interaction (Warren 1989).

Many empirical studies have shown that visual handicap may be a risk factor in psychosocial development. Although there is some evidence that a handicap may put adolescents at psychosocial risk, it may not necessarily cause problems in functioning. Summarizes the methods and main findings of studies of psychosocial development among adolescents with visual impairments are presented in Table 1 in Appendix 1.

Some studies (Meighan 1971, Beaty 1992) have found that visual impairments may cause adolescents to feel inadequate and inferior - feelings that are thought to reflect their lack of social acceptance, academic underachievement, physical incapability, and social maladjustment (Obiakor and Stile 1989). However, other studies (Beaty 1994, Pierce and Wardle 1996) have suggested that visually impaired persons are not at higher risk of developing lower self-esteem than their sighted counterparts. In a recent study by Kef (1999), a significantly higher level of self-esteem was reported among visually impaired adolescents compared to sighted adolescents.

There is some evidence that adolescents with visual impairment may be at increased risk for depression and psychological problems (Jan et al. 1977, Schnittjer and Hirshoren 1981, Van Hasselt et al. 1986, Abolfotouh and Telmesani 1993). Abolfotouh and Telmesani (1993) found that depression was more prevalent among the blind (14%) than among the deaf students (6.5%). The results of the study of Schnittjer and Hirshoren (1981) suggested that visually impaired children do not differ markedly in their problem behaviour patterns from other children. Van Hasselt et al. (1986) found differences in symptomatology between visually impaired and sighted adolescents showing visually impaired males attending residential and publicly funded school to be more disturbed than the controls. In the study of Jan et al. (1977) forty-five per cent of the visually impaired children and adolescents were rated as having moderate or severe psychiatric disorders. A "normal" diagnosis was given for to 32 percent of the blind and 49 percent of those with partial vision. Central nervous system disorder, multiple impairments, maternal mental illness and marital breakdown were all important aetiological factors. Severity of visual impairment was also related to psychiatric disorder with blind children being more likely to show psychopathology than were the partially sighted.

Many studies have shown increased vulnerability and difficulties during the social development of adolescents with visual impairment. Visually impaired adolescents have been reported especially to have problems in their relationships with friends, such as social isolation, being rejected or taunted by their peers, having fewer friends and dating experiences, lower sociometric status and smaller social networks than fully sighted adolescents (Havill 1970, Jones et al. 1972, Eaglestein 1975, Jan et al. 1977, Hoben and Lindstrom 1980, Van Hasselt 1983, Freeman et al. 1991). Many of them have reported that their impairment interferes with their social relationships with friends and social activities (Nemshick et al. 1986, Urponen 1989). They have also been found to spend more time

alone in passive activities than normally sighted adolescents and those students who have friendships had to work harder to maintain them. Especially the adolescents with low vision have been found to be involved in the fewest activities and to be the least in social situations with many other people (Wolffe and Sacks 1997, Sacks and Wolffe 1998, Sacks et al. 1998). It has also been claimed that girls with visual impairment are, in particular, at a disadvantage and may be isolated from the peer group (Scholl 1986). In addition, many children with visual impairments lack the social skills that are important for social development and acceptance by their peers (Kekelis 1992).

There are fewer studies in which no or only few differences between visually handicapped and nonhandicapped adolescents have been found in the area of adjustment, social coping and social relationships (Cowen et al. 1961, Schindele 1974, Urponen 1989, Rosenblum 1997, Rosenblum 1998).

Disability often causes added demands in family life and problems in family relationships (Patterson and Blum 1996). Most visually impaired adolescents have, however, reported that their relationships with parents are close and their family members are important sources of social support (Kent 1983, Nemshick et al. 1986, Suokas 1992, Loijas 1994, Wolffe and Sacks 1997, Kef 1999). It has been claimed that the extra attention which adolescents with disabilities need from their parents may lead to very close parent-adolescent relationships (McAndrew 1979).

Several hypotheses have been presented to explain why persons with visual impairment and other physical handicaps have fewer social experiences: people's attitudes toward individuals with handicaps may be negative, especially towards those who have deviations in physique. Visually impaired persons may have deviations in physique because of eye pressing or motor mannerisms or a lack of social skills (Van Hasselt 1983). According to Loijas (1994) negative attitudes and prejudices towards individuals with a handicap are often results of earlier experiences and inadequate or lack of knowledge about the nature of the visual impairment.

Visual impairment may also cause functional restrictions, especially relating to mobility and orientation. Visually impaired persons find it therefore more difficult to participate in social events and maintain relationships with other people. These limitations may be more pronounced in adolescence, which is a period when social contacts, friends and dating are very important.

One central issue during adolescence is personal independence. Many disabled adolescents may find it difficult to become independent of their families, because of their physical incapacity or psychological dependence, and others may not be allowed by their families to develop distance (McAnarney 1985).

The quality of social interactions between those with and without handicaps may be also poor. Van Hasselt (1983) in his review of social adaptation of visually impaired persons, states that non-handicapped individuals tend to offer the handicapped less variability in opinions, greater distortion of opinion, and shorter replies in comparison to their encounters with other nonhandicapped persons.

2.2.3 Differences and similarities in the psychosocial development of adolescents with different types of chronic conditions or disabilities

Many studies in which different chronic illnesses and disabilities are studied together have found that adolescents with chronic illnesses and disability are at increased risk for the development of psychosocial problems (Cadman et al. 1987, Gortmaker et al. 1990, Seigel et al. 1990, Stevens et al 1996; Wolman et al.1994).

The risk of developmental problems may, however, vary across chronic condition and disability groups, although the degree to which this occurs is still uncertain. In the meta-analysis of studies on the psychological adjustment of children with chronic physical disorders, Lavigne and Faier-Routman (1992) reported a trend for sensory and neurological disorders to show the greatest risk for psychological adjustment problems, whereas Pless et al. (1993) found that those with cardiac and respiratory disorders were at greatest risk for psychological problems. Rutter (1970) found in an epidemiological study of the Isle of Wight the highest number of psychological problems among subject with disabilities due to organic brain diseases and in those with visual and hearing impairments. In the study by Urponen (1989), the neurologically ill and mentally retarded, those with sensory impairments and with muscular-skeletal impairment or disability reported most frequently numerous difficulties in school, choice of occupation, employment, and, on the job, in social integration, with family and hobbies. Kokkonen and Kokkonen (1993, 1995) reported most severe mental problems and psychological and somatic symptoms among those with motor handicaps.

It has also been claimed that the nature of the person's disorder is not important in determining its psychosocial consequences. Regardless of the idiosyncratic characteristics of each condition, different conditions share common attributes affecting people's lives and thus children and adolescents with different chronic conditions and disabilities encounter similar problems in their psychosocial development (Wolman et al. 1994). This approach represents a noncategorical orientation toward a chronic illness or disability and in this method subjects with a chronic illness or disability are grouped in a single study. In the study by Gortmaker et al. (1990), no differences were found in behaviour problems by individual chronic condition. The results of the studies by Suris et al. (1996), Wolman et al. (1994) and Meijer et al. (2000) were similar: no differences were found in the prevalence of emotional distress and suicidal ideation (Suris et al. 1996), emotional well-being, worries and body image (Wolman et al. 1994) and social consequences (Meijer et al. 2000) between different categories of condition or disability.

There is also considerable intradisorder variation in psychological outcomes. Thus, factors resulting in variations across diseases or disabilities are not completely clear, nor are the factors resulting in similarities in outcomes across disease groups.

The information of whether or not different chronic conditions and disabilities differ from one another in their effects on psychosocial development is important for the development of intervention strategies. If there are few differences across disabilities and

chronic conditions, then the rationale for developing common approaches is strengthened; if such differences exist, the intervention approaches must take account such differences (Lavigne and Faier-Routman 1992).

2.3 Social support

2.3.1 Definition of social support

Social support is a multidimensional concept and it has been conceptualized in many different ways. Definitions vary in their degree of specificity, breadth of transactions encompassed, and the importance attributed to the stability of interpersonal relationships (Wolchik et al. 1989).

In order to clarify the concepts of social support, House and Kahn (1985) have distinguished different aspects of social relationships that the term social support refers to. Social support is sometimes defined conceptually or operationally in terms of the existence or quantity of social relationships in general, or of a particular type such as marriage, friendship, or organizational membership. Terms such as social integration or isolation are most often used to refer to the existence or quantity of relationships. Social support has also sometimes been defined in the terms of the structure of a person's social relationships. The term social networks is most often used to refer to the structures existing among a set of relationships. Social networks analysis broadens the range of social relationships, encourages attention to multiple aspects and effects of these relationships and provides a method for describing the structural pattern of ties and for analyzing the effects of different patterns. The most commonly studied properties of social networks are size and density of networks.

Social support can be defined in terms of functional content of relationships (House and Kahn 1985). Functional measures of social support assess the functions that a relationship or network serve. The functional content of social support varies greatly from situation to situation (Tardy 1985). House (1981) distinguishes among four types of support: emotional (refers to the provision of trust, empathy, and love), instrumental (helping behaviours such as loaning money or giving one's time and skill), informational support (refers to advice) and appraisal support (refers to evaluative feedback). This category system accounts for most types of support content, alternative category systems have also been presented (e.g. Barrera 1981).

Many measures generally ask persons about their perceptions of the availability or adequacy of resources provided by other persons (Cohen and Syme 1985). These measures differ from measures of social embeddedness in that they do not quantify the number of supporters or the amount of social contact. They attempt to gain individuals' confidence that adequate support would be available if needed or to characterize an environment as helpful of cohesive or focus more exclusively on the perceived adequacy

of satisfaction with support (Barrera 1986). These subjective-functional measurements help to tap individuals' psychological representations of their support systems (Cohen and Syme 1985), such as the degree to which relationships involve flows of affect or emotional concern, instrumental or tangible aid, information and the like.

According to House and Kahn (1985) it is necessary to consider at least two of these three aspects of social relationships within a single study. The potential connections among these different aspects of social relations are presented in Figure 2.

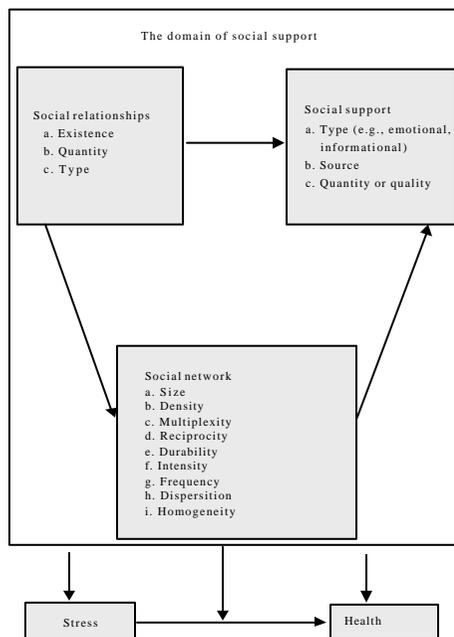


Figure 2. Connections among different aspects of social relations (House & Kahn, 1985)

House et al. (1988) state that in addition to social support, which refers to the positive aspects of relationships, two other aspects of relationships can be distinguished: **relational demands** and **conflicts** and **social regulation** or **control**. Relational demands and conflicts refers to the negative or conflictive aspects of relationships that may be deleterious to health. Social regulation or control refers to the controlling or regulating quality of social relationships which, depending on the behaviours controlled or regulated, may be either health promoting or health damaging.

Sarason et al. (1990, 1994) have suggested that because perceived support remains quite stable over time, even during periods of developmental transitions, it functions like a personality variable (a sense of social acceptance). According to them the sense of acceptance is characterized by good interpersonal skills, a strong sense of self-efficacy leading to adaptive behaviour under stress, low levels of anxiety, positive self-image, positive expectation of interactions with other, and a positive view of other's adjustment.

Social support can be divided into primary, secondary and tertiary levels on the basis of the intimacy of social relationships. The primary level support structure includes one's own family and closest friends. The secondary level includes friends, relatives, workmates and neighbours and the tertiary level the authorities and other distant support structures. Social support may be given by professionals or non-professionals. The primary and secondary levels include mainly non-professionals and tertiary level professionals, such as social and health care personnel (Cassel 1976).

2.3.2 Social support and health

Since the 1970s, after seminal works by Caplan (1974), Cassel (1976), and Cobb (1976), there has been a increase of interest in the concept of social support as it affects health and well-being.

Two different processes through which social support has a beneficial effect on wellbeing have been presented. One model proposes that support is related to wellbeing only (or primarily) for persons under stress. This is termed the **buffering model** because it posits that support buffers (protects) persons against the potentially pathogenic influence of stressful events. Support may play a role at two different points in the causal chain linking stress to illness. First, support may intervene between a stressful event and a stress reaction by attenuating or preventing a stress appraisal response. Second, adequate support may intervene between the experience of stress and the onset of the pathological outcome by reducing or eliminating the stress reaction or by directly influencing physiological processes (Cohen and Wills 1985).

The alternative model, the **main-effect model**, proposes that social resources have a beneficial effect irrespective of whether persons are under stress. A generalized beneficial effect of social support could occur because large social networks provide persons with regular positive experiences and a set of stable, socially rewarded roles in the community. This kind of support could be related to overall wellbeing because it provides

positive affect, and a recognition of self-worth. Integration in a social network may also help one to avoid negative experiences. This view of support has been conceptualized from a sociological perspective as "regularized social integration" or "embeddedness" in social roles and from a psychological perspective as social interaction, social integration, relational reward, or status support (Cohen and Wills 1985).

The majority of research examining the health effects and consequences of social relations have operationalized the concept in terms of support provided in social interaction. Several indicators of network structure, especially small-sized networks, strong ties, high density, high homogeneity and low dispersion have been seen advantageous for maintaining identity and, indirectly, for wellbeing and health (Schwarzer and Leppin 1991). Although social integration and network structure are used as indicators of social support, these give only a rough estimate of the support actually provided or perceived in the social relations. Not all relationships are supportive, and social networks may also be a source of pressure and conflict (House et al. 1988).

It has been claimed that the most important aspect of social support that is related to health outcomes is perceived social support, or the belief that help would be available if needed (Sarason et al. 1990). Health and wellbeing are claimed to be dependent on what the person sees and believes, be it accurate or not. On the other hand, it has been questioned whether measures of perceived social support truly reflect the actual availability of support. However, there is evidence that self-reports of the validity of the perceived social support measures are rather accurate (Schwarzer and Leppin 1991).

2.3.3 Social support and wellbeing among adolescents

Social factors and relations may be of special significance during developmental or social transition points, periods when an individual may often experience some degree of psychological strain or distress. Adolescence is a developmental stage that is often marked by considerable uncertainty and occasional stress. Multiple and simultaneous changes in physical and cognitive development, as well as in social roles and cultural attributions, converge at this time to create a period of marked transition and demands for adjustment (Vondra and Garbarino 1988).

During adolescence, parents and friends are the most important relations and sources of social support. Parents have great influence in future-oriented domains such as choice of school, education, career plans, and work. Peers are an important source of support in current events and activities such as spending leisure time, using alcohol and smoking. Both parents and friends are important sources of social support in questions concerning relationships, personal problems, and friendships (Bois-Reymond and Ravesloot 1994). In addition to parents and friends, also siblings, relatives and teachers are important sources of social support during adolescence (Furman and Buhrmester 1985). Girls have been found to be more concerned with communicating with and relating to other people than boys (Frey & Röthlisberger 1996). They have also been found to have larger social

networks than boys (Blyth et al. 1982, Coates 1987).

Social support from parents and friends has been found to play a significant role in the development of psychological wellbeing in adolescence (Greenberg et al. 1983, Faust et al. 1985, Walker and Greene 1986, Hoffman et al. 1988, Harter 1990, 1993, Papini and Roggman 1992, Välimaa et al. 1994, Robinson 1995, Sheerber et al. 1997, Välimaa 2000). Social support may be protective and improve wellbeing through the psychological effects of the mere presence of others, preventing isolation, through being a valued part of a network, receiving signs of love and understanding, and being sure of help when it is needed. This can foster self-esteem and self-assurance, and feelings of worth, but also of security and control over oneself and the environment (Nestmann and Hurrelmann 1994).

2.3.4 Social support and wellbeing among visually impaired adolescents

Studies on the social relationships, networks and support of visually impaired adolescents have indicated that many adolescents with visual impairments have fewer friends, social contacts and smaller social networks than those without impairments (Loijas 1994). Visually impaired adolescents have also been found to be more often lonely and isolated than normally sighted adolescents (Jan et al. 1977). Their social networks have been reported to consist mainly of family members and relatives (Loijas 1994, Kef 1999). Compared with sighted adolescents, visually impaired adolescents have been found to list a smaller number of extended family members, neighbours and friends (Kef 1999).

Most visually impaired adolescents have reported that their relationships with parents are close and that they receive social support in questions related to impairment mainly from their family members and professionals (Nemshick et al. 1986, Suokas 1992). Parents have been named as important sources of social support in daily functioning and in assistance related to homework (Kent 1983, Wolffe and Sacks 1997). Many visually impaired adolescents have reported also receiving social support from friends (Kef 1999), some of them have reported that although their close friend knows of their impairment, they cannot actually talk to their close friend about visual impairment (Nemshick et al. 1986). Material support such as adequate supplies and equipment have been found to be among important factors in successful mainstreaming (Bishop 1986).

The majority of adolescents with visual impairment have reported that they are satisfied with support, however, some studies have reported that adolescents with disabilities may receive inadequate social support (Anderson et al. 1982, Nemshick et al. 1986, Chang and Schaller 2000) or the “wrong kind” of support (their families overprotect them, do not understand their condition or deny the existence of the problem) (Nemshick et al. 1986).

Blind adolescents have been reported to experience more parental support compared with those with low vision. It has also been found that girls with visual impairment report more peer support than boys (Kef 1999).

There are only few studies concerning the relations between social support and

wellbeing among adolescents with visual impairment or adolescents with other handicapping conditions. These studies have shown the positive effect of social support, especially from peers, on the wellbeing and adjustment of impaired adolescents.

Kef (1999) studied social network factors, adjustment factors and wellbeing among visually impaired adolescents in the Netherlands. She found that functional network aspects especially (social support and satisfaction with support) were significant for the adjustment and wellbeing of visually impaired adolescents. The results also showed that social support from peers was a stronger predictor for wellbeing than parental support.

Varni et al. (1992) studied perceptions of social support in children with congenital or acquired limb deficiencies, and the effects of support on adjustment to disease. The results showed that perceived peer support was a more powerful predictor of adjustment (measured in terms of depression, anxiety and self-esteem) compared with parents' or teachers' support. Wallander and Varni (1989) also investigated the relationship between social support and adjustment in a sample of children being treated for a range of chronic conditions (diabetes, arthritis, obesity, spina bifida and cerebral palsy). Those children described by their mothers as having high social support from both family and friends were rated as better adjusted than children described as having plenty of support in only one of these areas. Children with little support from any source were rated as least adjusted.

Van Beek (1988) concluded that the behaviour problems, especially social problems, of visually impaired young people were related to low self-esteem, negative self-concept and poor social skills. Improving social skills led to increased wellbeing (Kef 1999).

2.4 Summary of the literature review and implications for the present study

The results of empirical studies of the psychosocial development among adolescents with visual impairment are somewhat contradictory. Some studies have reported that adolescents with visual impairment have problems in their psychosocial development, while other studies have suggested that these adolescents are not at higher risk for psychopathology than adolescents without visual impairment or those with chronic conditions (section 2.2.2, Appendix 1: Table 1, section 2.2.3). Studies on the social relationships, networks and support of visually impaired adolescents (section 2.3.4) have indicated that many adolescents with visual impairment have fewer friends and smaller social networks than those without impairments. Most visually impaired adolescents have reported that their relationships with parents are close and they receive social support from them. Few studies on the relations between social support and wellbeing among adolescents with visual have shown the positive effect of social support, especially from peers, on wellbeing of impaired adolescents.

Methodological differences may account for some of the reported differences between studies. Different perspectives have been utilized in measuring the social relations and social support, for example parental reports, self-reports, observations and autobiographical accounts have been used. The instruments of these studies have been very

different and often the psychometric properties have not been mentioned or tested. The samples have often been quite small and limited to a relatively small geographical area. There are also cultural differences between the countries, for example in relationships between parents and children. In addition, the wide age range of subjects has led to failure to take into account developmental differences in study subjects. There have also been great differences in the severity of handicaps, types of handicaps and the placements (integrated, residential) of subjects have been different. Lastly, the majority of available studies does not employ control groups. Without data on nonhandicapped adolescents, it is difficult to interpret the difficulties that emerge particularly in visually handicapped and handicapped adolescents.

No nationwide scientific research dealing with the psychosocial development and social support of visually impaired adolescents existed in Finland. Studies on these subjects in any other country are also rare. There exist, however, the need to obtain information on these areas for the development of health care interventions, social support initiatives, and school programs intended for visually impaired adolescents to facilitate their psychosocial adaptation to handicap and their successful integration into society.

3 AIMS OF THE STUDY

The aims of the study was to investigate psychosocial development and social support among adolescents with visual impairment. The main points of emphasis in the original publications were as follows:

- I To study the social networks and social support among adolescents with visual and without visual impairment (Study I).
- II To investigate the psychosocial development of adolescents with visual impairment and differences between them and their peers without visual impairment in psychological wellbeing (Study II).
- III To study social support from parents and friends, self-esteem and associations between them among adolescents with and without visual impairments (Study III).
- IV To investigate the prevalence of depression, relationships with parents and friends as protective factors against depression and the role of self-esteem in mediating the impact of relationships with parents and friends leading to depressive symptoms (Study IV).
- V To study whether adolescents with visual impairment and those with chronic conditions differ in psychosocial development (Study V).

4 SUBJECTS AND METHODS

4.1 Subjects and collection of data

Subjects in Studies I and II

The study population included all Finnish-speaking adolescents with visual impairment integrated in Grades 7 - 9 in regular comprehensive schools throughout Finland in the period 1993-1994. The subjects were obtained from the National Register of the School for the Visually Impaired in Jyväskylä. The data of the Register are based on information supplied by parents, teachers, regional secretaries of the Finnish Federation of the Visually Impaired, rehabilitation counsellors of hospitals and school nurses regarding adolescents with visual impairment. All adolescents were free of additional handicapping conditions. There were altogether 40 boys and 14 girls either with low vision (boys $n=36$, girls $n=9$) or blind (=Braille users; boys $n=4$, girls $n=5$). The mean age was 14.0 (SD 0.87).

The control group consisted of normally sighted adolescents from the same grades ($N=410$, boys 186, girls 224). In Study II, the 25 normally sighted classmates who reported that they had chronic conditions that interfered with their daily lives (such as asthma and diabetes mellitus) were excluded from the control group. Thus, the total number of pupils in the control group was 385 (172 boys and 213 girls). The mean age of the control group was 13.9 (SD 0.86).

Subjects in Studies III and IV

The study population comprised two age cohorts, one studied in the period 1993-1994 and the other in the period 1996-1997, of Finnish-speaking adolescents with visual impairment who were integrated in Grades 7-9 in regular comprehensive schools throughout Finland. The participants with visual impairment were obtained from the National Register of the School for the Visually Impaired in Jyväskylä; they had no additional handicapping conditions. Cohort 1 consisted of 40 boys and 14 girls and cohort 2 of 36 boys and 25 girls. The total number of adolescents with visual impairment was thus 115 (boys 76, girls 39), 94 (67 boys and 27 girls) with low vision and 21 (9 boys and 12 girls) who were blind and were braille readers. These 115 adolescents ranged in age from 13 to 16 (mean age 14.1 years, SD 0.87); 38% of the boys and 55% of the girls had been visually impaired since birth.

The control group consisted of the normally sighted classmates of the 66 visually impaired adolescents (cohort 1: $n=410$; cohort 2: $n=241$) in comprehensive schools throughout Finland. The 44 classmates without visual impairment reporting that they had

chronic conditions (such as asthma, and diabetes mellitus) interfering with their daily lives were excluded from the control group. Thus, the total number of participants in the control group was 607 (275 boys and 332 girls). These participants ranged in age from 12 to 17 (mean age 14.0 years (SD=0.88)).

Subjects in Study V

The study population of adolescents with visual impairment was identical with that in Studies III and IV. The controls consisted of the fully sighted classmates of the 66 visually impaired adolescents throughout Finland (N=651). Based on a question “Do you have any chronic condition or disability which interferes with your daily life?” two comparison groups were constructed: (1) adolescents with chronic conditions, consisting of 44 fully sighted participants (cohort 1: n=25; cohort 2: n=19); and (2) nondisabled controls, consisting of 607 fully sighted adolescents without any chronic conditions (cohort 1: n=385; cohort 2: n=222).

Of the group of nondisabled controls, 275 were boys and 332 were girls. The participants ranged in age from 12 to 17 years (mean age 14.0 years, SD=0.88). The group of participants with chronic conditions had the following conditions: asthma (n=16), allergy (n=9), diabetes mellitus (n=5), hearing impairment or cerebral palsy (n=3), epilepsy (n=2), heart problems (n=2), psoriasis (n=2), and others (n=5). Four adolescents had both asthma and allergy and one had diabetes mellitus and asthma. There were 19 boys and 25 girls. The mean age of the group was 14.1 years (SD=0.87, age range 13-16 years).

Data collection

The data were collected using a self-report questionnaire (Appendix 2). The questionnaire was transcribed into braille for the participants who were blind and into large print for those with low vision. The blind participants used computers as aids in responding to the questionnaires. Adolescents without visual impairment were given similar questionnaires in regular print except that all the questions directly related to visual impairment were excluded.

The data were collected in collaboration with school principals and teachers. The questionnaires were completed in the classroom during school hours. Teachers introduced the purpose of the study, following the researchers’ detailed instructions, and distributed the questionnaires to the participants. The pupils answered confidentially and returned the questionnaires in sealed envelopes to their teachers. It took the majority of participants about 45 minutes to complete the questionnaires; the blind participants needed more time.

The response rate was 100% in cohort 1 and 88.9 % in cohort 2 among participants with visual impairment, and 98.3% in cohort 1 and 94.9 % in cohort 2 among the normally sighted subjects. Of the visually impaired participants, 26 filled in the questionnaires during their support period in the School for the Visually Impaired in Jyväskylä, 78 completed them during school hours under the supervision of itinerant (N=12) or other teachers (N=66), and 11 completed them at home and mailed them back to the researchers in stamped,

addressed envelopes. Of the normally sighted participants, 604 completed the questionnaires during school hours at the same time as their 66 classmates with visual impairments, and 3 completed the questionnaires at home.

4.2 Measures

The questionnaire consisted of questions related to personal characteristics (gender, social skills) and school performance, visual impairment (severity and onset), family background (socio-economic status, family structure), social relationships, networks and support (relationship with the mother, the father and siblings, family climate, existence of many friends, difficulties in making friends, feelings of loneliness, fitting in easily with other young people, social interaction with friends during leisure time, number of important school friends, meeting friends at home and during hobbies, dating experiences, effects of visual impairment on social relationships with other people, size and composition of social networks and perceived available and adequacy of social support) as well as psychological wellbeing (self-esteem, distress symptoms, depression).

Measures of psychological wellbeing

Psychological wellbeing was measured using a self-esteem instrument, checklist of distress symptoms and a depression screening instrument.

Self-esteem was measured using a 5-point scale developed for Finnish students (Helenius and Lyttinen 1974, Aro 1988) The scale consisted of seven statements of self-worth resembling those used in Rosenberg's measure (1965): "I believe in myself and my possibilities," "I wish I were different from what I am," "I suffer from feelings of inferiority," "I think I have many good qualities," "I feel I lack self-confidence," "I am capable of doing the same as others," and "I am often dissatisfied with myself". The theoretical range of the scale scores was 7 to 35. The internal reliability rate of the scores (using Cronbach's alpha coefficient) was 0.76 for adolescents with visual impairment, 0.82 for adolescents with chronic conditions and 0.81 for control group adolescents.

Distress symptoms were assessed using a checklist of 17 physical and psychological symptoms. The same list has been used earlier with Finnish adolescents (Aro and Taipale 1987) and in an adult Finnish population (Aro 1981). The subjects answered the question "Have any of the following symptoms bothered you and, if so, how often during the last six months?" The symptom score was construed by summing up the following ratings of the separate items: 0 = Never, 1 = Sometimes, 2 = Quite often, 3 = Often or continuously. The Cronbach's alpha reliability rate for the scale of distress symptoms was 0.85 for adolescents with visual impairment, 0.80 for adolescents with chronic conditions, and 0.85 for control group adolescents.

The short, the 13-item Beck's Depression Inventory (S-BDI), modified for Finnish

population studies by the inclusion of introductory questions and an additional positive choice of answer for each item, which does not affect the rating of depression, was used as a screening instrument for depression (Beck and Beck 1972, Mattlar et al. 1987). The sum score of depressive symptoms ranges from 0 to 39. The Cronbach's alpha reliability rate for the scale was 0.83 for adolescents with visual impairment, 0.76 for the scale for adolescents with chronic conditions, and 0.84 for controls. Subjects with an S-BDI score of five or higher were classified as depressed (Beck and Beck 1972).

Measures of social relations, networks and support

The subject's relationships with the mother, the father and the siblings, family climate, existence of many friends, difficulties in making friends, feelings of loneliness and fitting in easily with other young people were measured on a 5-point scale, and dichotomized into positive and negative choices in Studies I and V. The negative and positive effects of visual impairment on social relationships with other people were measured with an open-ended question, in which visually impaired adolescents were asked to describe in their own words the effect of visual impairment on social relations (Study V).

In Studies III and IV, relations with friends was measured on the basis of three statements: "I have many friends", "I fit in easily with other young people" and "It is easy for me to make friends", using a 5-point scale. The statements related to number of friends, easiness of making friends and being together with friends have previously been used in a Finnish study of adolescents' social support, loneliness and self-esteem (Välilä et al. 1994). The measurement of relations with friends was focused to describe the degree of social integration with friends. The theoretical range of the scale scores was 3 to 15. The Cronbach's alpha reliability rate for the scale was 0.75 for adolescents with visual impairment and 0.74 for those without visual impairment.

The quality of relationship with parents was assessed in Studies III and IV with three questions relating to family climate, relationship with mother and father using a 5-point scale. The questions were "How do you describe the relationship with your mother"; "How do you describe the relationship with your father"; "How do you describe the family climate". The questions related to relationships with parents were previously used in a Finnish follow-up study of young adults (Palosaari et al. 1996, Tulisalo and Aro 2000). The theoretical range of the scale scores was 3 to 15. The Cronbach's alpha reliability rate for the scale was 0.74 for adolescents with visual impairment and 0.71 for adolescents without visual impairment.

The Social Network Inventory used was a self-report inventory based on earlier studies (Blyth et al. 1982, Coates 1987) in which the adolescents listed any important persons in the categories of family, relatives, other important adults, and friends at school. The size of the social network was constructed as a sum of these four categories. The Social Network Inventory included questions about the structural and relational properties of the social networks. The subjects were asked to list three important persons outside their home with a series of questions about each of the important persons, such as the composition of

the network (e.g. friends and relatives), frequency of contacts and specific social settings of meetings with network members (e.g. home, school, hobbies). The network properties related to meeting friends at each other's homes and in hobbies were investigated in Study V.

The measurement of perceived availability and adequacy of social support was based on a modified version of Barrera's Arizona Social Support Interview Schedule (ASSIS, Barrera 1981). ASSIS identifies persons who provide social support, and measures the following areas: the network of people serving supportive functions, the subjects' satisfaction with and need for support, and identification of those people who were sources of interpersonal conflict. The schedule includes the following six functions of social support: intimate interaction (interacting in a nondirective manner such that feelings and personal concerns are expressed), material aid (providing material aid in the form of money and other physical objects), physical assistance (sharing tasks), guidance (offering advice and guidance), feedback (providing individuals with information about themselves) and social participation (engaging in social interactions for fun, relaxation, and diversion from demanding conditions). These six categories appeared to cover the range of activities that a number of social support researchers had described. Example questions of ASSIS were "If you want to talk to someone about things that are very personal and private, who would you talk to?" (intimate interaction, private feelings) and "Who would you go to if a situation came up when you needed some advice, for example with homework?" (guidance, advice).

In Study III, the focus was to investigate the extent to which parents and friends serve different supportive functions. For that purpose, the score for perceived available support was constructed separately for parents and friends by the summation of these six functions of social support of ASSIS. A dichotomized scale was used with categories from 1=named no father/mother or friends as a source of support 2=named father/mother or friends as a source of support. The perceived available support from parents was constructed by the summation of variables relating to the father and mother. The theoretical range of the parents' scale scores was 12 to 24 and of the friends' scale scores 6 to 12. The Cronbach's alpha reliability rate for the scale of perceived available support from parents was 0.77 for adolescents with visual impairment and 0.76 for adolescents without visual impairment, and the scale of friends 0.69 for adolescents with visual impairment and 0.68 for adolescents without visual impairment.

Personal characteristics, school performance, the visual impairment and family background

Social skills were measured using a modified, shortened version of the Matson Evaluation of Social Skills with Youngsters (Matson et al. 1983). The pupil's self-reported average of grades on the school report was used as a measure of school performance.

The severity of visual impairment was divided into blind (=braille users) and low vision, and the age of onset of visual impairment was divided into onset at birth (under age 1) or after birth (age 1 or older; Kuotola 1976, Jan et al. 1977).

The subjects were grouped into two social classes - blue and white collar - on the basis

of a standard classification of occupations (Central Statistical Office of Finland 1989), primarily using the father's occupation, or if not available, then that of the mother. Family structure was divided into intact families, with two original parents, and others, which included one-parent families, stepfamilies and also some children in institutional care.

4.3 Statistical methods

Statistical methods included the chi-square test, logistic regression and one-way analysis of variance, including post hoc tests using the Scheffé procedure for estimates of means.

In Study III, Pearson's product-moment correlations and multiple linear regression analyses were carried out. In addition, in Study IV, structural equation methodology (SEM) was used to assess the latent trait recursive causal model. Variable diagnostics were carried out to estimate the fit of the data with binary logistic regression and SEM. The chi-square test, the normed (NFI) and the adjusted goodness of fit index (AGFI), and the root mean squared residual (RMSR) were the primary criteria for accepting the model in LISREL analysis. The GFI indices had to be above 0.9 and RMSR as close as possible to 0.0 in an acceptable model.

Boys and girls were mainly analysed separately. Data analyses were done using SAS software and the SPSS program.

5 RESULTS

5.1 Social networks and support among adolescents with visual impairment

The average size and composition of social networks among adolescents with and without visual impairment (VI) were quite similar. However, the average size of social networks of adolescents with visual impairment was smaller than control group adolescents (boys with VI mean=11.7 versus boys without VI mean=14.5, $p<.05$; girls with VI mean=14.5 versus girls without VI mean=15.2). The size of social networks of the girls was larger than that of the boys in both groups of adolescents, but especially among the visually impaired adolescents. There were no differences between adolescents with and without visual impairment in proportions of important family members and relatives.

Adolescents with and without visual impairment turned to their parents (especially to mother) mainly for intimate interaction, material aid, physical assistance, guidance and feedback. Friends were an important source of social support in intimate and social interactions. However, adolescents without visual impairment (especially the girls) listed support from friends more frequently than adolescents with visual impairment.

In coping with visual impairment, most adolescents reported that they turned to their parents and to professionals. The most frequently named professionals were ophthalmologists and school personnel (I Table 2). Only 7 % of boys and girls reported turning their friends in questions concerning of visual impairment. The same proportion of visually impaired adolescents reported that they did not have anybody with whom they could talk about visual impairment.

A number of adolescents with visual impairment reported that they would like to have more social support. In questions concerning visual impairment, about 30 % of adolescents with visual impairment reported that they would like to have more support. Some of the adolescents reported that they got too much support, especially in intimate interaction.

5.2 Visually impaired adolescents' psychosocial development

The results of Study II showed that adolescents with visual impairment were similar to their peer group in psychological wellbeing: no significant differences were found in depression or distress symptoms. Unexpectedly, boys with visual impairment scored less often in the depressed range (8%) than boys without visual impairment (15%). Self-esteem tended to be lower among girls with visual impairment than among girls in the control group. No such difference was seen among boys (II Table 1).

Most adolescents reported that they had close relations with their parents and siblings, and they also described their family climate as good. Those with visual impairment tended to describe their family relations as slightly better than those without visual impairment. Adolescents with visual impairment, especially girls, had many friends less often than adolescents without visual impairment (boys: 75% versus 92%; girls: 57% versus 95%; $p < 0.001$). In addition, dating experiences had been fewer among boys and girls with visual impairment than among those with normal vision ($p < 0.01$). Of girls with visual impairment, 57% reported feelings of loneliness compared with 33% of girls without visual impairment. Among boys there were almost equal numbers in both groups of those reporting loneliness. In addition, more adolescents of both sexes with visual impairment reported difficulty in making friends (20% of boys with visual impairment versus 14% of boys without visual impairment; 21% versus 10% of girls, respectively, II Table 2).

The study showed differences among girls in school performance and social skills: Girls with visual impairment had lower school performance (Mean=7.6 versus Mean=8.3, $p < 0.05$) and poorer social skills than those without impairment (Mean=19.3 versus 15.1, $p < 0.05$).

5.3 Social support and self-esteem among visually impaired adolescents

The results showed that adolescents with visual impairment did not differ statistically significantly from the control group in self-esteem. However, the self-esteem of girls with visual impairment tended to be lower than that of girls without visual impairment. In addition, girls with visual impairment reported statistically significantly lower scores of relations with friends ($p < 0.05$) and less perceived available support from friends than normally sighted girls ($p < 0.05$, III Table 1). No significant differences were found in the severity and onset of visual impairment in adolescents with visual impairment.

The results of correlational analyses showed that, for boys and girls with visual impairment, higher scores of relations with friends were associated statistically significantly with higher scores of self-esteem (boys $p < 0.01$; girls $p < 0.001$). In addition, there was a trend that higher social class was related to higher self-esteem among girls (III Table 2). For boys with low vision, higher scores of support from friends were related to higher self-

esteem, whereas for blind boys, quality of relationship with parents was related to higher self-esteem. For girls, both those with low vision and blind girls, higher scores of relations with friends were related to higher self-esteem. There was a trend that support from friends was related to higher self-esteem among those boys who had been visually impaired since birth. For boys who had been visually impaired after birth, associations with social support and self-esteem were very low. For girls of both subgroups' relations with friends were highly related to self-esteem.

Among adolescents without visual impairment, the results showed that for boys and girls both support from parents and higher scores of relations with friends were related to higher self-esteem. In addition, higher social class of the family among boys and intact family structure among girls were associated with higher self-esteem (III Table 2).

The predictors of self-esteem among adolescents with visual impairment are presented in III Table 3. The main predictor of higher self-esteem was higher scores of relations with friends. The severity and onset of visual impairment were not significant predictors of self-esteem.

For boys without visual impairment higher scores of relations with friends, close relationship with parents, white collar family background, and, unexpectedly, lower perceived available support from friends predicted higher scores of self-esteem. For girls without with visual impairment, higher scores of relations with friends and close relationship with parents predicted higher self-esteem (III Table 4).

5.4 Relationship with parents and friends, self-esteem and depression among adolescents with visual impairment

Depressive symptoms and the prevalence of depression were higher among girls than boys whether they were visually impaired or not. The female-to-male ratio was (5:1) among adolescents with visual impairment and (2:1) in those without visual impairment. No statistically significant differences were found in depressive symptoms and the prevalence of depression between visually impaired adolescents and the control group. However, there was a trend toward an excessive risk of depression among girls with visual impairment (31%) compared to girls without visual impairment (23%). In addition, of depressed girls with visual impairment, 21% reported moderate or severe depression compared to 12% of girls in the control group. Among boys, visually impaired boys tended to score less often in the depressed range (7%) than boys without visual impairment (12%, IV Table 1).

The results also showed that, in addition to male gender, higher scores of relationships with friends was an important protective factor against depression among adolescents with visual impairment and those without it (IV Table 2,3). Among adolescents without visual impairment relationship with parents was also an explanatory factor of depression (IV Table 3). Factors related to visual impairment and family were not significant predictors of depression.

Structural equation methodology was utilized to investigate the role of self-esteem as a mediating factor between relationships with parents and friends and depressive symptoms among adolescents with visual impairment and those without. The main structure of associations are summarized in Figure 3 (IV Figure 1, Table 4). The results showed that the effect of relationships with friends on depressive symptoms was mediated via self-esteem among adolescents with visual impairment and those without it. A direct effect of relationship with parents and indirect effect through self-esteem with depressive symptoms was present only among adolescents without visual impairment. In addition, self-esteem was a moderating factor between gender and depressive symptoms.

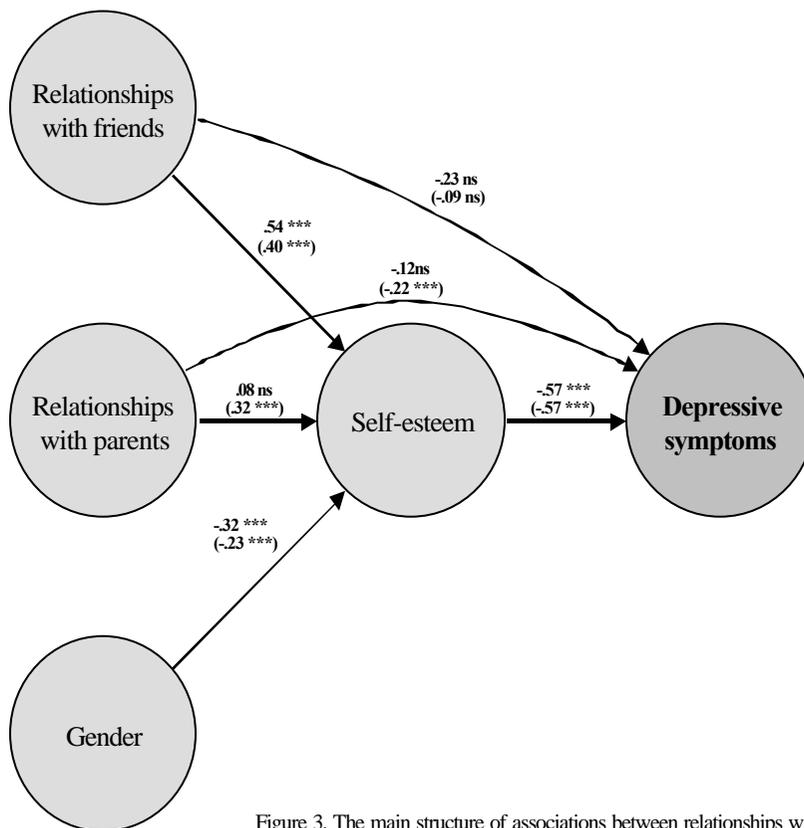


Figure 3. The main structure of associations between relationships with parents and friends, self-esteem and depressive symptoms among adolescents with and without visual impairment (VI) (NOTE: Adolescents without VI=in parenthesis)

5.5 Differences and similarities in the psychosocial development of adolescents with visual impairment and those with chronic conditions

Visually impaired adolescents had more difficulties in their relationships with friends than those with chronic conditions and non-disabled controls (Table 2, V Table 2). Boys with visual impairment reported having many friends less often than non-disabled controls (78% versus 92%, $p < .001$). More of them compared to non-disabled controls had never dated (71% versus 45%, $p < .001$). There was also a tendency that more of them had never dated compared to boys with chronic conditions (71% versus 58%). Fewer of them spent leisure time with friends compared to non-disabled controls (79% versus 90%, $p < .01$). In addition, boys with visual impairment met their friends less often in hobbies than non-disabled boys (16% versus 26%, $p < .05$) and boys with chronic conditions (16% versus 30%, $p = .07$).

Of girls with visual impairment, 67% reported many friends compared with 88% of girls with chronic conditions ($p = .05$) and with 92% of non-disabled controls ($p < .001$). They also had fewer dating experiences than girls with chronic conditions: 72% of them had never dated compared to 44% of girls with chronic conditions ($p < .05$) and 43% of non-disabled girls ($p < .001$). Fewer of them spent leisure time with friends compared to non-disabled girls (74% versus 94%, $p < .001$). Visually impaired girls described their relationship with father as better than girls with chronic conditions (74% versus 48%, $p < .05$). In addition, girls with visual impairment met friends less often in each other's homes than girls with chronic conditions ($p < .001$) and non-disabled girls ($p < .05$).

Social relations studied by the severity and onset of visual impairment showed that blind adolescents and those who had been visually impaired since birth reported more problems in social relations than those with low vision and those who had been visually impaired after birth.

The majority (62%) of visually impaired adolescents (boys 56%, girls 71%) reported that visual impairment interfered with their social relations. Blind adolescents compared to those with low vision (84% versus 56%, $p < .05$) and adolescents who had been visually impaired since birth compared to those who had been visually impaired after birth (76% versus 54%, $p < .05$) more often reported that visual impairment interfered with their social relations. About 40% of adolescents reported that other people's attitudes are often negative towards those with visual impairment. Twenty-three percent of adolescents with visual impairment reported that visual impairment interfered with their social activities, such as hobbies and going out with other young people. Some adolescents also reported problems in mobility and orientation, inability to use visual cues in social situations, problems in social skills, difficulties in career decisions and dependence of other people's help.

Most adolescents with visual impairment stressed the importance of social support from other people in coping with visual impairment. Some adolescents also mentioned the importance of social support from other visually impaired people. Eighteen percent of adolescents said that visual impairment did not interfere with their social relations.

The results concerning psychological wellbeing (Table 2, V Table 3) showed that visually impaired adolescents had fewer problems in their psychological wellbeing than

adolescents with chronic conditions. Boys with chronic conditions reported statistically significantly higher scores of distress symptoms than boys with visual impairment and the non-disabled controls. They also tended to report lower self-esteem, higher depression scores and higher prevalence of depression. Boys with visual impairment had statistically significantly lower scores regarding distress symptoms than boys with chronic conditions ($p < .001$) and non-disabled boys ($p < .01$). They also tended to have the lowest rates of depression and highest scores of self-esteem compared with boys with chronic conditions and non-disabled boys.

The same tendency as in the boys was partly seen among the girls. The mean distress scores, depression scores and prevalence of depression were highest among girls with chronic conditions. Unlike boys, girls with visual impairment tended to report lower self-esteem and a higher prevalence of depression than non-disabled girls. They also reported lower school performance than non-disabled girls ($p < .05$).

When the results were analysed by the severity and onset of visual impairment, blind girls were found to have higher school performance than girls with low vision (mean 8.4 versus 7.6, $p < .001$).

Table 2. Relationships with friends and psychological wellbeing among adolescents with visual impairment (VI), with chronic conditions (CC) and nondisabled controls (NC) by gender.

		Boys with VI (n=76)	Boys with CC (n=19)	Boys NC (n=275)	Girls with VI (n=39)	Girls with CC (n=25)	Girls NC (n=332)
Many friends %		78.0	78.9	92.4	66.7	88.0	92.4
Never dated %		71.1	57.9	45.1	71.8	44.0	42.8
Social interaction with friends %		78.7	89.5	90.1	74.4	84.0	93.7
Depression %	Depressed	6.6	21.1	11.7	30.8	41.7	23.3
	Non-depressed	93.4	78.9	88.3	69.2	58.3	76.7
Depression score	Mean (SD)	1.2 (2.4)	2.9 (3.1)	1.7 (3.0)	3.3 (4.0)	4.4 (4.2)	3.1 (3.9)
Distress symptoms	Mean (SD)	5.0 (3.9)	9.7 (5.8)	7.0 (4.4)	9.3 (6.3)	12.6 (5.4)	9.9 (5.3)
Self-esteem	Mean (SD)	27.1 (4.1)	25.2 (6.3)	26.8 (4.5)	22.7 (5.6)	23.7 (5.1)	24.1 (5.1)

p=.05, * p<.05, ** p<.01, *** p<.001

6. DISCUSSION

6.1 Study design and methods

To enhance external validity of this study the participants of the visual impaired group were obtained from the National Register of the School for the Visually Impaired in Jyväskylä. The data of the Register are based on information supplied by parents, teachers, regional secretaries of the Finnish Federation of the Visually Impaired, rehabilitation counsellors of hospitals and school nurses regarding adolescents with visual impairment. The data of visually impaired pupils are more complete in the Register of the School for the Visually impaired in Jyväskylä than that of the Finnish Register of Visual Impairment (Ojamo, 1998). The nationwide study population comprised either one or two age cohorts of Finnish-speaking adolescents with visual impairment integrated in grades 7-9 in regular comprehensive schools throughout Finland, and the participation rate was high, making the study non-selective and highly representative. However, the number of visually impaired adolescents was relatively small, especially that of girls. The number of blind adolescents was also small and caused difficulties in statistical analyses by the severity of visual impairment, which may weaken the generalizability of the results.

The comparison of our results of visually impaired adolescents with fully sighted adolescents was the main part of the study. An important question was, whether the results of the study were specific for adolescents with visual impairment by comparing them to the control group, which consisted of the fully sighted classmates of the visually impaired adolescents. The control group adolescents had the same background characteristics as the visually impaired adolescents' group. In Study V, the results were compared with adolescents with chronic conditions. The number of adolescents with chronic conditions was small, the group was heterogeneous and constructing the group of those with chronic condition was based on self-report including a definition of interference with their daily life. No independent verification was made of the chronic condition diagnoses. Thus, the results related to adolescents with chronic conditions should be considered as only indicative.

As the interest of the study was in subjective matters, the data were based on self-reporting. No complementary data from other sources, such as from parents and teachers, were available. The data were collected using a questionnaire and thus the study shares the general problems related to questionnaire studies, such as standard answer categories. Ninety-eight percent of questionnaires were completed in classrooms, where the situation was controlled and less open to bias compared to postal questionnaires. This also ensured a very high response rate. Possible interviewer bias was also avoided. The pupils answered confidentially and returned the questionnaires in sealed envelopes to their teachers.

Several limitation on the internal validity of the study should also be considered. This study was cross-sectional, which limits the interpretation of the association of social support and psychological wellbeing. The associations found in this study between social support and psychological wellbeing, need further investigation through longitudinal studies.

Some problems regarding the measures used should be considered. Many of our measures were based on standard scales with satisfactory reliability and validity. However, some of our measures were relatively crude, developed or modified for this study and thus the results may serve as hypotheses for further research with more sophisticated measures. Measurement poses particular problems in social support, which is a multidimensional concept and refers to different aspects of social relationships, thus operationalization and measuring of social support is complex. In this study, the quality of relationships, social integration, social networks and perceived availability and adequacy of social support were measured. The measurement of perceived availability and adequacy of social support was based on a modified version in Barrera's Arizona Social Support Interview Schedule (ASSIS, Barrera 1981). The data collection of original form of ASSIS is based on interview method, more detailed answering instructions should have been given for questionnaire study. Operationalization of the psychological construct of self-esteem is also complicated and difficult to measure in a survey.

Depression was measured by a modified 13-item Beck's Depression Inventory (S-BDI), which is a self-report screening instrument and does not necessarily refer to depression of clinical severity. The scale, however, is widely used and it has been shown to be a valid measure for screening depression (Beck and Beck 1972; Beck et al. 1974, Kaltiala-Heino et al. 1999).

6.2 Social networks and support among adolescents with visual impairment

This study showed that the average size and composition of social networks of adolescents with and without visual impairment were quite similar. However, the size of social networks, especially among boys group, were slightly smaller among adolescents with visual impairment. In view of previous research, this finding was expected (Kef 1999). The results also showed that girls had larger networks than boys in both groups of adolescents, which is consistent with the earlier findings of Blyth et al. (1982) and Coates (1987). In contrast to the study by Loijas (1994), there were no differences between these two groups in proportions of important family members and relatives. Parents and friends are the main sources of social support for adolescents (e.g. Hartup 1983, van Beest and Baerveldt 1999, Kef 1999). This was evident in the present study too. However, adolescents with visual impairment (especially the girls) listed support from friends less often than normally sighted adolescents. Fewer friends

as a source of social support might be connected to obstacles in relationships with friends, such as negative attitudes, functional restrictions caused by visual impairment or overprotection by parents (Van Hasselt 1983, Nemschick et al. 1986).

Adolescence is a phase of life when persons want to fit into a group and do not want to be special or different, for example due to their visual impairment (Kef 1999). Avoid being labelled as different, might be one reason why only few visually impaired adolescents reported turning to their friends in questions concerning visual impairment.

The results of the study showed that more boys than girls reported that they had nobody to whom they could turn to for social support. Gender differences in receiving social support have been explained by the fact that girls are more concerned with communicating with and relating to other people, whereas boys are more interested in sharing things and activities. This may also be attributed to the earlier maturation in girls (Frey and R othlisberger 1996). A number of adolescents with visual impairment reported that they would like to have more support, and interestingly, some of them reported that they got too much support, especially in intimate interaction. Adolescents might feel that some things and their thoughts were so private and personal that they did not want to share them with other people. There might be discrepancies between provided support and the need for support.

6.3 Visually impaired adolescents' psychosocial development

This study showed that, on average, the psychological development of the visually impaired adolescents seemed to be reasonably good, showing only a few differences in depression and self-esteem when compared with normally sighted adolescents. This finding is similar to a recent study by Kef (1999), but different from the findings of Rutter et al. (1970), Cadman et al. (1987), Gortmaker et al. (1990) and Wolman et al. (1994), who found that children and adolescents with a disability or chronic conditions showed poorer psychological adjustment than healthy controls.

In the area of relations with friends, adolescents with visual impairment, especially the girls, showed more problems than adolescents without visual impairment, as stated in earlier studies (Eaglestein 1975, Jan et al. 1977, Van Hasselt 1983). The increased vulnerability of girls in psychosocial development and feelings of wellbeing has also been found in the study of Kef (1999).

Several hypotheses have been evinced to explain why persons with visual impairment and other physical handicaps have fewer social experiences: people's attitudes toward individuals with handicaps may be negative, especially towards those who have deviations in physique. Visually impaired persons may have deviations in physique because of eye pressing or motor mannerisms or a lack of social skills (Van Hasselt 1983). A person who feels different and has fewer social contacts may consequently be unable to maintain peer activities (McAnarney 1985).

Visual impairment may also cause functional restrictions, especially relating to

mobility and orientation. Visually impaired persons find it therefore more difficult to participate in social events and to maintain relationships with other people. These limitations may be more pronounced in adolescence, which is a period when social contacts, friends and dating are very important.

One central issue during adolescence is personal independence. Many disabled adolescents may find it difficult to become independent of their families because of their physical incapacity or psychological dependence, and others may not be allowed by their families to develop distance (McAnarney 1985).

6.4 Relationships with friends significantly contributing to the enhancement of the self-esteem of visually impaired adolescents

The results of this study showed that adolescents with visual impairment did not differ significantly from the control group in self-esteem. This result is consistent with those of Beaty (1994) and Pierce and Wardle (1996). However, the self-esteem of girls with visual impairment tended to be lower than that of girls without visual impairment. For example, visually impaired girls reported more often than sighted girls that they wished to be different from what they were and that they lacked self-confidence.

This study showed that relations with friends was a more powerful predictor of self-esteem compared to the quality of relationship with parents in adolescents with visual impairment. Kef (1999) and Varni et al. (1992) found similar results. In the comparison group, both relations with friends and quality of relationship with parents (close relationship with mother and father and good family climate) were important predictors of self-esteem.

Having friends and being an accepted member of the peer group are among the most important concerns of adolescents. Interactions with friends are a source of ego support, helping adolescents develop an image of themselves as competent and worthy individuals (Furman and Buhrmester 1985). For adolescents with visual impairment, social isolation (e.g. Wolffe and Sacks 1997) and lack of adequate social support may lead to lowered self-esteem.

On the other hand, the adolescents' self-esteem could affect their ability to form close and supportive friendships rather than vice versa. Loss or lack of vision may cause adolescents to feel inadequacy and inferior, which has a debilitating effect on their self-esteem (Beaty 1992). Adolescents with low self-esteem may be reticent about approaching others for companionship and support because they are afraid of being criticized, embarrassed, or rejected. Although social interaction is an important source of feedback about self, persons with low self-esteem may isolate themselves from others to protect fragile feelings of self-worth (East 1989).

It has been reported that friends are especially important for adolescent girls' self-esteem (e.g. Walker and Greene 1986). The findings of this study support this view: The association between relations with friends and self-esteem was stronger among

girls than boys in both reference groups, but even stronger in the group of adolescents with visual impairment.

The results also showed that although relations with friends was highly correlated to self-esteem, this was not the case with perceived available social support from friends (friends listed as a source of different types of support, e.g. guidance and intimate interaction). The entire data set showed a clear curvilinear (inversed U form) relationship between self-esteem and available support from friends. In all four subgroups, the form of relationship remained the same, although no longer significant, as the power of the test decreased within the subsets of the data. The finding is interesting, but the mechanism is unclear and it deserves closer examination in future studies.

6.5 Relationship with parents and friends, self-esteem and depression among adolescents with visual impairment

Several studies have identified a gender difference in prevalence of depression in adolescence showing a higher prevalence among girls than boys (e.g. Larsson and Melin 1990, Connelly et al. 1993, Olsson and von Knorring 1997). Our study is in agreement with these studies. The prevalence of depression was higher among the girls than the boys, whether they were visually impaired or not. However, among adolescents with visual impairment the female-to-male ratio was higher (5:1) than among controls (2:1) or in earlier adolescent samples (Bebbington 1998).

The mediating role of self-esteem between gender and depression was further investigated. The results showed that an excessive risk of depression was mediated via low self-esteem. This mediating role of self-esteem may be connected to gender differences in self-esteem and strong relations between self-esteem and depression, as has been found in earlier studies (Harter and Jackson 1993, Bolognini et al. 1996, Chubb et al. 1997). The directionality of self-esteem and depression cannot be assessed in a cross-sectional study. The possibility remains that low self-esteem is secondary to depression. The associations found, however, remain interesting and deserve closer investigation in future follow-up studies.

Family and peer relations contribute significantly in multiple ways to psychosocial development in adolescence (e.g. Hunter 1985). They serve as complementary rather than competitive influences on young people. In this study, relationships with parents and friends had an effect on depression among adolescents with visual impairment different from that among adolescents without visual impairment. In both groups, higher scores of relationships with friends, indicating higher degree of social integration with friends, reflected resilience against depression via self-esteem, but a direct effect of relationship with parents and an indirect effect of relationship with parents through self-esteem with depressive symptoms was present only among adolescents without visual

impairment. The accentuated role of friends in the psychological development of visually impaired adolescents may be linked to their difficulties in relationships with friends, as reported in many studies ((Eaglestein 1975, Jan et al. 1977, Van Hasselt 1983). The limitations caused by visual impairment may be more pronounced in adolescence, when social contacts, friends and dating become very important.

6.6 Differences and similarities in psychosocial development of adolescents with visual impairment and those with chronic conditions

It has been presented that especially those with visual and sensory impairments are, at greatest risk for developing psychological problems (Rutter 1970, Lavigne and Faier-Routman 1992) and problems in social integration (Urponen 1989) compared with subjects with other chronic illnesses. This study supported partly these findings: the results showed that visually impaired adolescents had more difficulties in their relationships with friends, but fewer problems of psychological wellbeing than adolescents with chronic conditions.

Increased problems in social relations among persons with visual impairment may be linked to the strong role of vision in socialization, negative attitudes toward individuals with handicaps and functional restrictions caused by visual impairment.

Visual information plays an important role in the acquisition and refinement of skills that are critical for positive social interaction. Facial expressions, eye contact and responses to other people are some facets of social interaction that may be affected by the ability to see. Visually impaired persons who lack these skills may often be ignored or rejected by their peers (Kekelis 1992).

A disability is often viewed negatively by peers and places the disabled person at risk of being perceived as unpopular or being left out (Rosenblum 1998). Over 40% of the visually impaired adolescents in this study reported experiences of other people's negative attitudes toward them. Visual impairment causes problems, especially in mobility and orientation. The lack of accessibility and dependence on other people's help may make it difficult to contact friends.

This study showed gender differences in psychological wellbeing among adolescents with visual impairment and those with chronic conditions. The results indicated that boys with visual impairment especially seemed to be psychologically well-adjusted. Gender differences in the psychological wellbeing may be linked to different coping mechanisms, which may be more effective among the boys. On the other hand, it is possible that boys may repress or deny those problems related to disability or they may be reluctant to report them to other people. It has been claimed that girls are more concerned with communicating with and relating to other people, especially with friends, whereas boys are more interested in sharing things and activities (Frey and

Röthlisberger 1996). Thus, reported problems in relations with friends might be more stressful for the psychological wellbeing of girls than boys. In addition, differences between boys and girls may be result from different ways of expressing ill-health. In this study, depression and distress symptoms were measured, and these may be more typical ways for girls to express their ill-health.

6.7 Implications and recommendations for health care, rehabilitation and future research

Visually impaired adolescent populations have relatively rarely been studied in Finland and elsewhere. This study was planned to obtain information on the psychosocial development and social support of visually impaired adolescents for the development of health care interventions, social support initiatives, and school programme targeted at them to facilitate their psychosocial adaptation to their handicap and successful integration in society.

The results showed that most adolescents with visual impairment traverse this period of life without any significant psychological difficulties. However, based on our findings and earlier studies, it seems likely that in adolescence, visual impairment causes stress, especially in girls. The key role within adolescent health care is to pay more attention to visually impaired girls and support them in their psychological development.

This study showed that relationships with friends had significant associations with the psychological wellbeing of adolescents with visual impairment. While many visually impaired adolescents, especially the blind and those who have been visually impaired since birth, reported problems in relationships with friends, it is important to pay more attention to enhance interaction between visually impaired and sighted adolescents in the rehabilitation of visually impaired adolescents. Opportunities for visually impaired adolescents to join leisure and other activities with friends are especially important.

Not only sighted friends, but also visually impaired friends are important in coping with visual impairment. The presence of visually impaired friends makes it possible to exchange experiences and to identify with the group of impaired adolescents. This should be taken into account when rehabilitation arrangements are planned and carried out.

Visually impaired children and adolescents are often at a disadvantage in acquiring the same level of social competence as their sighted peers because they lack the visual input that is critical to develop relationships. While appropriate social behaviour is learned at a very young age, visually impaired children require direct intervention in the early ages to acquire these. The ability of rehabilitation personnel, teachers and parents to identify the adequacy level of social skills should be based on realistic expectations for individual children and later by the persons themselves. These things should be taken into account in the rehabilitation of visually impaired children and adolescents.

During the adolescent years, the skills necessary to initiate relationships with friends and dates are particularly important.

Negative attitudes and prejudices towards individuals with a handicap are often results of earlier experiences and lack inadequate or lacking knowledge about the nature of the visual impairment (Loijas 1994). Sighted people with inadequate knowledge of visual impairments may feel incapable of helping visually impaired persons and therefore they may avoid providing help to those with visual impairments. Enhancing sighted persons' knowledge of the nature of visual impairments is therefore very important. Adolescents with visual impairments should be encouraged to tell their classmates and friends about the nature of their visual impairment. As an example, one girl in this study reported that she had gone from class to class in school telling other pupils about her visual impairment. She had also shown the special aids and techniques she used in her studies. This has had a positive effect of reducing negative attitudes and prejudices toward her.

One central issue during adolescence is personal independence. Many disabled adolescents may find it difficult to become independent of their families, because of their physical incapacity or psychological dependence, and others may not be allowed by their families to develop distance (McAnarney 1985). The balance between social support and autonomy and independence is an important factor for visually impaired adolescents' healthy development, successful and meaningful integration with peers and adults in school, but is also important in later life.

The present study provided a general cross-sectional view of the psychosocial development and social support among adolescents with visual impairment compared to their sighted peers. Longitudinal studies would provide insight into the causal effects, mechanisms and processes of social relations and support on the psychological wellbeing of visually impaired adolescents. Complementary qualitative data and data from other sources, such as from parents and teachers would also be essential to gain a better understanding of the psychosocial development of adolescents with visual impairment. Visually impaired adolescents' social relationships in particular and support from sighted friends need closer examination with more sophisticated methodology, including a wider scope of instruments and different data collection methods, such as the interview method. Studies concerning of the coping mechanisms and other aspects of well-being may also add our knowledge of differences between boys and girls in psychosocial wellbeing.

7 SUMMARY

The purpose of this study was to investigate psychosocial development and social support among adolescents with visual impairment. Developmental differences and similarities between adolescents with visual impairment, without visual impairment and those with chronic conditions were investigated. Further, the role of social support in promoting psychological wellbeing was of interest.

The study population comprised two age cohorts, one studied in the period 1993-1994 (n=54) and the other in the period 1996-1997 (n=61), of Finnish-speaking adolescents with visual impairment who were integrated in Grades 7-9 in regular comprehensive schools throughout Finland and were free of additional handicapping conditions. There were altogether 76 boys and 39 girls either with low vision (n=94) or blind (n=21). The mean age was 14.1 years (SD 0.87).

The control group consisted of the normally sighted classmates of the 66 visually impaired adolescents throughout Finland (cohort 1: n=410, cohort 2: n=241). Two comparison groups were constructed (1) adolescents with chronic conditions, consisting of 44 fully sighted participants who reported that they had a chronic condition interfering with their daily life (cohort 1: n=25; cohort 2: n=19); and (2) non-disabled controls, consisting of 607 fully sighted adolescents without any chronic conditions (cohort 1: n=385; cohort 2: n=222). There were 19 boys and 25 girls in the group of participants with chronic conditions (mean age 14.1 years, SD=0.87). Of the group of non-disabled controls, 275 were boys and 332 were girls (mean age 14.0 years, SD=0.88).

The data were collected using a self-report questionnaire during school hours. The response rate was 100% in cohort 1 and 88.9 % in cohort 2 among participants with visual impairment, and 98.3% in cohort 1 and 94.9 % in cohort 2 among the normally sighted subjects.

The results showed that the average size and composition of social networks among adolescents with and without visual impairment were quite similar. Adolescents with and without visual impairment turned to their parents (especially to mother) mainly for intimate interaction, material aid, physical assistance, guidance and feedback. Friends were an important source of social support in intimate and social interactions. However, adolescents without visual impairment (especially the girls) reported receiving support from friends more frequently than adolescents with visual impairment. A number of adolescents with visual impairment reported that they would like to have more social support. Some of the adolescents reported that they receive too much support, especially in intimate interaction.

Adolescents with visual impairment did not differ from those without visual impairment in psychological wellbeing and in family relations. There was, however a trend toward an excessive risk of depression and lower self-esteem among visually impaired girls compared to normally sighted girls. Among boys, visually impaired boys

tended to score less often in the depressed range than boys without visual impairment. The prevalence of depression was higher among girls than boys, whether they were visually impaired or not. However, among adolescents with visual impairment the female-to-male ratio was higher (5:1) than among controls (2:1) or in earlier adolescent samples. In addition, visually impaired adolescents less often had many friends and dating experiences than adolescents without visual impairment.

For visually impaired adolescents, higher scores of relations with friends was a more powerful predictor of self-esteem than the quality of relationship with parents. Among adolescents without visual impairment both relationships with friends and parents were important predictors of self-esteem. In addition to male gender, higher scores of relationships with friends was an important protective factor against depression among adolescents with visual impairment. The impact of relationships with friends on depressive symptoms was mediated through self-esteem. Unlike the controls, relationship with parents was not an explanatory factor for depression in adolescents with visual impairment.

Visually impaired adolescents had more difficulties in their relationships with friends than had adolescents with chronic conditions and non-disabled controls. Blind adolescents and those who had been visually impaired since birth especially reported difficulties in relationships with friends. Compared with adolescents with chronic conditions those with visual impairment had fewer problems of psychological wellbeing.

The results indicated that most adolescents with visual impairment traverse this period of life without any significant psychological difficulties. However, it seems likely that in adolescence visual impairment causes stress, especially in girls. This study also showed the importance of relationships with friends for the psychological wellbeing of adolescents with visual impairment.

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9 REFERENCES

- Abolfotouh MA and Telmesani A (1993): A study of some psycho-social characteristics of blind and deaf male students in Abha City, Asir Region, Saudi Arabia. *Public Health* 107:261-269.
- Anderson EM, Clarke L and Spain B (1982): *Disability in adolescence*. Methuen, London.
- Aro H (1988): Parental discord, divorce and adolescent development. *Eur Arch Psychiatr Neurol Sci* 237:106-111.
- Aro H and Taipale V (1987): The impact of timing of puberty on psychosomatic symptoms among fourteen- to sixteen-year-old Finnish girls. *Child Dev* 58:261-268.
- Aro S (1981): Stress, morbidity and health-related behaviour. A five-year follow-up study among metal industry employees. *Scand J Soc Med* 9, Suppl 25.
- Barrera M, Jr (1981): Social support in the adjustment of pregnant adolescents. In: *Social Networks and Social Support*, pp. 69-327. Ed. BH Gottlieb, Sage publications, Beverly Hills.
- Barrera M, Jr (1986): Distinctions between social support concepts, measures, and models. *Am J Community Psychol* 14:413-445.
- Beaty LA (1992): Adolescent self-perception as a function of vision loss. *Adolescence* 27: 707-714.
- Beaty LA (1994): Psychological factors and academic success of visually impaired college students. *RE:view* 26:131-139.
- Bebbington PE (1998): Sex and depression. Editorial. *Psychol Med* 28:1-8.
- Beck AT and Beck RW (1972): Screening depressed patients in family practice. A rapid technic. *Postgrad Med* 52:81-85.
- Beck AT, Rial WY and Rickels K (1974): Short form of depression inventory: cross-validation. *Psychol Rep* 34:1184-1186.
- Bishop VE (1986): Identifying the components of success in mainstreaming. *Journal of Visual Impairment & Blindness* 80:939-946.
- Blos P (1979): *The adolescent passage*. International Universities Press, New York.
- Blyth AD, Hill JP and Smith Thiel K (1982): Early adolescents' significant others: Grade and gender differences in perceived relationships with familial and nonfamilial adults and young people. *J Youth Adolesc* 11:425-450.
- Bois-Reymond M du and Ravesloot J (1994): The role of parents and peers in the sexual and relational socialization of adolescents. In: *Social networks and Social Support in Childhood and Adolescence*, pp. 217-239. Eds. F Nestmann and K Hurrelmann, Walter de Gruyter, New York.
- Bolognini M, Plancherel B, Bettschart W and Halfon O (1996): Self-esteem and mental health in early adolescence: development and differences. *J Adolesc* 19:233-245.
- Cadman D, Boyle M, Szatmari P and Offord DR (1987): Chronic illness, disability, and mental social well-being: findings of the Ontario Child Health Study. *Pediatrics* 79:805-813.
- Caplan G (1974): *Support systems and community mental health: Lectures on concept development*. Behavioral Publications, New York.
- Cassel J (1976): The contribution of the social environment to host resistance. *Am J Epidemiol* 104:107-123.
- Central Statistical Office of Finland (1989): *Classification of socioeconomic groups: Handbook*. Central Statistical Office of Finland, Helsinki.
- Chang S C-H and Schaller J (2000): Perspectives of adolescents with visual impairments on

- social support from their parents. *Journal of Visual Impairment & Blindness* 94:69-84.
- Chubb NH, Ferman CI and Ross JL (1997): Adolescent self-esteem and locus of control: A longitudinal study of gender and age differences. *Adolescence* 32:113-129.
- Clarke-Stewart A, Perlmutter M and Friedman S (1988): *Lifelong human development*. John Wiley & Sons, New York.
- Coates DL (1987): Gender differences in the structure and support characteristics of black adolescents' social networks. *Sex Roles* 17:667-687.
- Cobb S (1976): Social support as a moderator of life stress. *Psychosom Med* 38:300-314.
- Cohen S and Syme SL (1985): Issues in the study and application of social support. In: *Social Support and Health*, pp. 3-22. Eds. S Cohen and SL Syme, Academic Press, Orlando.
- Cohen S and Wills TA (1985): Stress, social support, and the buffering hypothesis. *Psychol Bull* 98:310-357.
- Coleman JC (1989): The focal theory of adolescence: A psychological perspective. In: *The Social World of Adolescents. Interactional Perspectives*, pp. 43-56. Eds. K Hurrelmann and U Engel, Walter de Gruyter, New York.
- Connelly B, Johnston D, Brown I, Mackay S and Blackstock EG (1993): The prevalence of depression in high school population. *Adolescence* 109:149-158.
- Cowen EL, Underberg RP, Verillo RT and Benham FG (1961): *Adjustment to visual disability in adolescence*. American Foundation for the Blind, New York.
- Eaglestein AS (1975): The social acceptance of blind high school students in an integrated school. *New Outlook for the Blind* 69:447-451.
- East PL (1989): Early adolescents' perceived interpersonal risks and benefits: relations to social support and psychological functioning. *Journal of Early Adolescence* 9:374-395.
- Erikson E (1968): *Identity, youth and crisis*. Faber & Faber, London.
- Faust J, Baum CG and Forehand R (1985): An examination of the association between social relationships and depression in early adolescence. *Journal of Applied Developmental Psychology* 6:291-297.
- Freeman RD, Goetz E, Richards DP and Groenveld M (1991): Defiers of negative prediction: A 14-year follow-up study of legally blind children. *Journal of Visual Impairment & Blindness* 85:365-370.
- Frey CU and R othlisberger C (1996): Social support in healthy adolescents. *J Youth Adolesc* 25:17-31.
- Furman W and Buhrmester D (1985): Children's perceptions of the personal relationships in their social networks. *Dev Psychol* 21:1016-1024.
- Gortmaker SL, Walker DK, Weizman M and Sobol AM (1990): Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. *Pediatrics* 85:267-276.
- Greenberg MT, Siegel JM and Leitch CJ (1983): The nature and importance of attachment relationships to parents and peers during adolescence. *J Youth Adolesc* 12:273-386.
- Harter S (1990): Processes underlying adolescent self-concept formation. In: *From Childhood to Adolescence: A Transition Period*, pp. 205-239. Eds. R Montemayor, GR Adams and TP Gullotta, Sage Publications, Newbury Park, California.
- Harter S (1993): Causes and consequences of low self-esteem in children and adolescents. In: *Self-esteem: The Puzzle of Low Self-regard*, pp. 87-116. Ed. RF Baumerster, Plenum Press, New York.
- Harter S and Jackson BK (1993): Young adolescents' perception of the link between low self-worth and depressed affect. *Journal of Early Adolescence* 13:383-407.

- Hartup WW (1983): Peer relations. In: Handbook of Child Psychology, Vol IV Socialization, Personality, and Social Development, pp. 103-196. Ed. PH Mussen (Vol Ed. EM Hetherington), John Wiley & Sons, New York.
- Havill SJ (1970): The sociometric status of visually handicapped student in public school classes. Research Bulletin nr 20. American Foundation for the Blind, New York.
- Helenius A and Lyttinen S (1974): Opiskelijat ja opiskelutyö Tampereen yliopiston ainelaitoksilla. Opiskelijoiden ennalta ehkäisevän mielenterveystyön projekti. Ylioppilaiden terveydenhoitosäätiö ja Tampereen yliopiston psykologian laitos, Tampere.
- Hoben M and Lindstrom V (1980): Evidence of isolation in the mainstream. Journal of Visual Impairment and Blindness 74:289-292.
- Hoffman MA, Ushpiz V and Levy-Shiff R (1988): Social support and self-esteem in adolescence. J Youth Adolesc 17:307-316.
- House JS (1981): Work stress and social support, Addison-Wesley, Reading, MA.
- House JS and Kahn RL (1985): Measures and concepts of social support. In: Social support and Health, pp. 83-108. Eds. S Cohen and SL Syme, Academic Press, Orlando.
- House JS, Umberson D and Landis KR (1988): Structures and processes of social support. Ann Rev Sociol 14:293-318.
- Hunter FT (1985): Individual adolescent's perception of discussions with parents and friends. Journal of Early Adolescence 5:295-305.
- Jan JE, Freeman RD and Scott EP (1977): Visual impairment in children and adolescents. Grune & Stratton, New York.
- Jones RL, Lavine K and Shell J (1972): Blind children integrated in classrooms with sighted children. A sociometric study. The New Outlook for the Blind 66:75-80.
- Kaltiala-Heino R, Rimpelä M, Rantanen P and Laippala P (1999): Finnish modification of the 13-item Beck Depression Inventory in screening an adolescent population for depressiveness and positive mood. Nord J Psychiatry 53:451-457.
- Kef S (1999): Outlook on relations. Personal networks and psychosocial characteristics of visually impaired adolescents. Academisch proefschrift. Universiteit van Amsterdam, Amsterdam.
- Kekelis LS (1992): Peer interactions in childhood: The impact of visual impairment. In: The Development of Social Skills by Blind and Visually Impaired Students, pp. 13-35. Eds. SZ Sacks LS Kekelis and RJ Gaylord-Ross, American Foundation for the Blind, New York.
- Kent D (1983): Finding a way through the rough years: How blind girls survive adolescence. Journal of Visual Impairment & Blindness 77:247-250.
- Kirchler E, Pombeni ML and Palmonari A (1991): Sweet sixteen... Adolescents' problems and the peer group as source of support. European Journal of Psychology of Education 6:393-410.
- Kirchner C (1989): National estimates of prevalence and demographics of children with visual impairments. In: Handbook of Special Education: Research and Practice, vol 3. Low Incidence Conditions, pp. 135-153. Eds. MC Wang, MC Reynolds and HJ Walberg, Pergamon Press, Oxford.
- Kokkonen J and Kokkonen E-R (1993): Does chronic physical illness on childhood increase the risk of psychiatric morbidity in young adulthood. Psychiaria Fennica 24:55-66.
- Kokkonen J and Kokkonen E-R (1995): Psychological and somatic symptoms in young adults with chronic physical diseases. Psychother Psychosom 64:94-101.
- Kuotola U (1976): Näkövammaisten integroituminen yhteiskuntaan. In Finnish, English summary. Acta Universitatis Tamperensis, Ser A, Vol 82. Tampereen yliopisto, Tampere.
- Larsson B and Melin L (1990): Depressive symptoms in Swedish adolescents. J Abnorm Child

- Psychol 18:91-103.
- Lavigne JV and Faier-Routman J (1992): Psychological adjustment to pediatric physical disorders: A meta-analytic review. *J Pediatr Psychol* 17:133-157.
- Loijas S (1994): Rakas rämä elämä. Vammaisten nuorten elämänhallinta ja elämänkulku. In Finnish, English summary. Sosiaali- ja terveystieteiden tutkimus- ja kehittämiskeskus STAKES. Raportteja 155. Gummerus, Jyväskylä.
- Matson JL, Rotatori AF and Helsel WJ (1983): Development of a rating scale to measure social skills in children: The Matson evaluation of social skills with youngsters (MESSY). *Behav Res Ther* 21:335-340.
- Mattlar C-E, Raitasalo R, Putkonen A-R, Hyyppä MT, Englund Ch, Helenius H and Knuts L-R (1987): The prevalence of depression in a random sample of Finns, and the association of depression with various cognitive functions. In International Meeting of the Epidemiological Association. XI Scientific Meeting, Helsinki, Finland 8 - 13 August 1987. (Abstract No. 629), Helsinki.
- McAnarney ER (1985): A challenge forhandicapped and chronically ill adolescents. *J Adolesc Health Care* 6:90-101.
- McAndrew I (1979): Adolescents and young people with spina bifida. *Dev Med Child Neurol* 21:619-629.
- Meighan T (1971): An investigation of the self-concept of blind and visually handicapped adolescents. American Foundation for the Blind, New York.
- Meijer SA, Sinnema G, Bijstra JO, Mellenbergh GJ and Wolters WHG (2000): Social functioning in children with a chronic illness. *J Child Psychol Psychiat* 41:309-317.
- Määttä P (1981): Vammaiset - suuri vähemmistö. Gummerus, Jyväskylä.
- Nemshick LA, Vernon McC and Ludman F (1986): The impact of retinitis pigmentosa on young adults: Psychological, educational, vocational and social considerations. *Journal of Visual Impairment & Blindness* 80:859-862.
- Nestmann F and Hurrelmann K (1994): Child and adolescent research as a challenge and opportunity for social support theory, measurement, and intervention: and vice versa. In: *Social Networks and Social Support in Childhood and Adolescence*, pp. 1-20. Eds. F Nestmann and K Hurrelmann, Walter de Gruyter, New York.
- Nurmi J-E (1997): Self-definition and mental health during adolescence and young adulthood. In: *Health Risks and Developmental Transitions during Adolescence*, pp. 395-419. Eds. J Schulenberg J Maggs and K Hurrelmann, Cambridge University Press, New York.
- Obiakor FE and Stile SW (1989): Enhancing self-concept in students with visual handicap. *The Journal of Visual Impairment & Blindness* 83:255-257.
- Ojamo M (1998): Näkövammarekisterin vuosikirja 1997. Sosiaali- ja terveystieteiden tutkimus- ja kehittämiskeskus STAKES, Näkövammaisten Keskusliitto ry.
- Ojamo M (1999): Näkövammarekisterin vuosikirja 1998. Sosiaali- ja terveystieteiden tutkimus- ja kehittämiskeskus STAKES, Näkövammaisten Keskusliitto ry.
- Olsson G and von Knorring A-L (1997): Depression among Swedish adolescents measured by the self-rating scale Center for Epidemiology Studies - Depression child (CES-DC). *Eur Child Adolesc Psychiatry* 6:81-87.
- Palosaari U, Aro H and Laippala P (1996): Parental divorce and depression in young adulthood: adolescents' closeness to parents and self-esteem as mediating factor. *Acta Psychiatr Scand* 93:20-26.
- Papini DR and Roggman LA (1992): Adolescent perceived attachment to parents in relation to competence, depression and anxiety: A longitudinal study. *Journal of Early Adolescence*

- 12:420-440.
- Patterson J and Blum RW (1996): Risk and resilience among children and youth with disabilities. *Arch Pediatr Adolesc Med* 150:692-698.
- Petersen AC and Hamburg BA (1986): Adolescence: A developmental approach to problems and psychopathology. *Behavior Therapy* 17:480-499.
- Peterson R, Lowman C and Kirchner C (1988): Visual handicap: Statistical data on a social process. In: *Data on Blindness and Visual Impairment in the U.S. A Resource Manual on Social Demographic Characteristics, Education, Employment and Income, and Service Delivery, Second Edition*, pp. 11-18. Ed. C Kirchner, American Foundation for the Blind, New York.
- Piaget J (1977): *The development of thought. Equilibration of cognitive structures*. Viking Press, New York.
- Pierce JW and Wardle J (1996): Body size, parental appraisal, and self-esteem in blind children. *J Child Psychol Psychiatry* 37:205-212.
- Pless IB, Power C and Peckham CS (1993): Long-term psychosocial sequelae of chronic physical disorders in childhood. *Pediatrics* 91:1131-1136.
- Robinson NS (1995): Evaluating the nature of perceived support and its relation to perceived self-worth in adolescents. *Journal of Research on Adolescence* 5:253-280.
- Rosenberg M (1965): *Society and the adolescent self-image*. Princeton University Press, Princeton.
- Rosenberg M (1979): *Conceiving the self*. Basic, New York.
- Rosenblum LR (1997): Adolescents with visual impairments who have best friends: A pilot study. *Journal of Visual Impairment & Blindness* 91:224-235.
- Rosenblum LR (1998): Best friendships of adolescents with visual impairments: A descriptive study. *Journal of Visual Impairment & Blindness* 92:593-608.
- Rutter M, Graham P and Yule W (1970): *A neuropsychiatric study in childhood*. Lippincott, Philadelphia.
- Sacks SZ and Corn AL (1996): Students with visual impairments: Do they understand their disability. *Journal of Visual Impairment & Blindness* 90:412-422.
- Sacks SZ and Wolffe KE (1998): Lifestyles of adolescents with visual impairments: An ethnographic analysis. *Journal of Visual Impairment & Blindness* 92:7-17.
- Sacks SZ, Wolffe KE and Tierney D (1998): Lifestyles of students with visual impairments: Preliminary studies of social networks. *Except Child* 64:463-478.
- Sarason BR, Pierce GR and Sarason IG (1990): Social support: The sense of acceptance and the role of relationships. In: *Social Support: An Interactional View*, pp. 97-128. Eds. BR Sarason, IG Sarason and GR Pierce, Wiley, New York.
- Sarason IG, Sarason BR and Pierce GR (1994): Social support: Global and relationship-based levels of analysis. *Journal of Social and Personal Relationships* 11:295-312.
- Schindele R (1974): The social adjustment of visually handicapped children in different educational settings. *Research Bulletin* 28:125-144. American Foundation for the Blind, New York.
- Schnittjer CJ and Hirshoren A (1981): Factors of problem behavior in visually impaired children. *J Abnorm Child Psychol* 9:517-522.
- Scholl, GT (1986): *Grow and Development*. In: *Foundation of Education for Blind and Visually Handicapped Children and Youth. Theory and Practice*, pp. 65-81. Ed. GT Scholl, American Foundation for the Blind, New York.
- School for the Visually Impaired in Jyväskylä (1998): *Statistics*. Jyväskylä.

- School for the Visually Impaired in Jyväskylä (1999): Statistics. Jyväskylä.
- Schwarzer R and Leppin A (1991): Social support and health: A theoretical and empirical overview. *Journal of Social and Personal Relationships* 8:99-127.
- Seigel WM, Golden NH, Gough JW, Lashley MS and Sacker IM (1990): Depression, self-esteem, and life events in adolescents with chronic diseases. *J Adolesc Health* 11:501-504.
- Sheerber L, Hops H, Alpert A, Davis B and Andrews J (1997): Family support and conflict: Prospective relations to adolescent depression. *J Abnorm Child* 25: 333-344.
- Sroufe LA and Cooper RG (1988): *Child development. Its nature and course.* Alfred A. Knopf, New York.
- Stevens SE, Steele CA, Jutai JW, Kalnins IV, Bortolussi JA and Biggar WD (1996): Adolescents with physical disabilities: Some psychological aspects of health. *J Adolesc Health* 19:157-164.
- Suokas L (1992): Ihminen ihmisten joukossa? Kirjalliseen omaelämäkerta-aineistoon perustuva tutkimus vammaisuuden aiheuttamista elämänmuutoksista. In Finnish, English summary. *Kansaneläkelaitoksen julkaisuja M:83.* Kansaneläkelaitos, Helsinki.
- Suris J-C, Parera N and Puig C (1996): Chronic illness and emotional distress in adolescence. *J Adolesc Health* 19:153-156.
- Tardy CH (1985): Social support measurement. *Am J Community Psychol* 13:187-202.
- Tulisalo UK and Aro HM (2000): Paternal remarriage as modifier of proneness to depression in young adulthood. *J Affect Disord* 57:179-184.
- Tuttle DW (1987): The role of the special teacher-counsellor in meeting students' self-esteem needs. *Journal of Visual Impairment & Blindness* 81:156-161.
- Urponen H (1989): Varhain sairastuneen ja vammaisen sosiaalinen selviytyminen. Sosiologinen seurantatutkimus pitkäaikaissairaiden ja vammaisten lasten sosiaalisesta selviytymisestä. In Finnish, English summary. *Turun yliopiston julkaisuja C:28,* Turku.
- Van Beek R (1988): Sociale vaardigheidstrainingen van sociale gedragsproblemen bij visueel gehandicapt. *Tijdschrift voor Orthopedagogiek* 25:15-21.
- Van Beest M and Baerveldt C (1999): The relationship between adolescents' social support from parents and from friends. *Adolescence* 34:193-201.
- Van Hasselt VB (1983): Social adaptation in the blind. *Clin Psychol Rev* 3: 87-102.
- Van Hasselt VB, Kazdin AE and Hersen M (1986): Assessment of problem behaviour in visually handicapped adolescents. *J Clin Child Psychol* 15:134-141.
- Varni JW, Setoguchi Y, Rappaport LR and Talbot D (1992): Psychological adjustment and perceived social support in children with congenital/acquired limb deficiencies. *Journal of Behavioral Medicine* 15:31-44.
- Vondra J and Garbarino J (1988): Social influence on adolescent behavior problems. In: *Social Networks of Children, Adolescents, and College Students*, pp. 195-224. Eds. S Salzinger, J Antrobus and M Hammer M, LEA, Hillsdale, New Jersey.
- Välilä R, Kannas L and Pötsönen R (1994): Sosiaalisen tuen ja yksinäisyyden kokemisen yhteys itsetuntoon 11 -15 -vuotiailla koululaisilla WHO-Koululaistutkimus. In Finnish, English summary. *Sosiaalilääketieteellinen Aikakauslehti, Supplementti* 31:77-90.
- Välilä R (2000): Nuorten koettu terveys kyselyaineistojen ja ryhmähaastattelujen valossa. In Finnish, English summary. University of Jyväskylä, *Studies in Sport, Physical Education and Health* 68, Jyväskylä.
- Walker LS and Greene JW (1986): The social context of adolescent self-esteem. *J Youth Adolesc* 15:315-322.
- Wallander JL and Varni JW (1989): Social support and adjustment in chronically ill and

- handicapped children. *Am J Community Psychol* 17:185-199.
- Warren DH (1989): Implications of visual impairments for child development. In: *Handbook of Special Education: Research and Practice*, vol 3. *Low Incidence Conditions*, pp. 155-172. Eds. MC Wang MC Reynolds, Pergamon Press, Oxford.
- Wolchik, SA, Beals J and Sandler IN (1989): Mapping children's support networks: Conceptual and methodological issues. In: *Children's Social Networks and Social Support*, pp. 191-220. Ed. D Belle, Wiley, New York.
- Wolffe K and Sacks SZ (1997): The lifestyles of blind, low vision, and sighted youths: A quantitative comparison. *Journal of Visual Impairment & Blindness* 91:245-257.
- Wolman C, Resnick M, Harris L and Blum R (1994): Emotional well-being among adolescents with and without chronic conditions. *J Adolesc Health* 15:199-204.
- World Health Organization (1980): *International classification of impairment, disabilities and handicaps. A manual of relating to the consequences of disease*. WHO, Geneva.
- World Health Organization (1999): *ICIDH-2: International classification of functioning and disability*. Beta-2 draft, full version. WHO, Geneva.
- Youniss J and Haynie DL (1992): Friendship in adolescence. *J Dev Behav Pediatr* 13:59-66.

APPENDICES

Appendix 1.

Table 1. Summary of studies of psychosocial development among adolescents with visual impairment (VI).

SAMPLE:	CONTROL SAMPLE	MEASURES:	MAIN RESULTS:
<p>Abolfotouh & Telmesani 1993 blind and deaf male students in the Institute for the blind/deaf (n=44/n=108) mean age=15.7/13.04</p>		<p>Children Depression Inventory</p>	<p>depression more prevalent among the blind (14 %) than among the deaf (6.5 %)</p>
<p>Beaty 1992 VI public and private school students (n=15) age 12-19 years</p>	<p>sighted adolescents matched on appropriate demographic variables (n=15)</p>	<p>Tennessee Self-Concept Scale</p>	<p>VI adolescents' total positive score on the TSCS was lower than that of sighted controls</p>
<p>Beaty 1994 VI undergraduates from two public schools (n=30) mean age 21.7 years</p>	<p>sighted undergraduates from two public schools (n=43) mean age 20.1 years</p>	<p>Coopersmith Self Esteem Inventory</p>	<p>VI students tended to score higher than sighted students on self-esteem</p>
<p>Cowen 1961 VI adolescents attending public school (n=71), VI adolescents attending residential school (n=56) age 13-18 years</p>	<p>sighted matched controls (n=40), age 13-18 years</p>	<p>measures of adjustment, parental attitude and understanding</p>	<p>no significant differences in adjustment between the groups</p>

Table 1. (continued).
SAMPLE:

SAMPLE:	CONTROL SAMPLE	MEASURES:	MAIN RESULTS:
<p>Eaglestein 1975 blind students in a regular high school (n=9) grades 9,10,11 and 12</p>	<p>nonhandicapped classmates (n=146)</p>	<p>six measures of academic standing and social acceptance</p>	<p>blind students were well integrated into social framework of their classes, however, as length of exposure to the blind students increased, their acceptance by sighted students decreased</p>
<p>Freeman et al. 1991 legally blind young people (n=69) age 16-34 years</p>		<p>follow-up study (Jan et al. 1977), review of original records, prediction of current level of functioning, psychiatric interview</p>	<p>73% reported being teased in a mean way in regular public school classes</p>
<p>Havill 1970 VI children in public school programs (n=63) grades 4-12</p>	<p>a matched group of normally sighted classmates</p>	<p>measures of sociometric status</p>	<p>VI subjects were off lower sociometric status and less well accepted than their normally sighted classmates</p>
<p>Hoben & Lindstrom 1980 VI students in regular classrooms (n=22) grades 1-12</p>	<p>nonhandicapped classmates</p>	<p>Interaction Observation Schedule, Teacher Questionnaire</p>	<p>VI students interacted less frequently than their non-handicapped classmates</p>

Table 1. (continued).

SAMPLE:	CONTROL SAMPLE	MEASURES:	MAIN RESULTS:
<p>Jan et al 1977 legally blind children and adolescents (n=92) mean age 10.8 (range 1-19 years)</p>	<p>a control group matched by gender, age, and neighborhood</p>	<p>parent questionnaire and interview, psychological testing, psychiatric interview, school questionnaire, pediatric neurological examination, health records</p>	<p>46% of VI subjects rated as having moderate or severe psychiatric disorders of which mental handicap (19%), developmental disorder (15%), and adjustment reaction (11%) were the most common. Normal diagnosis: 32 % of the blind, 49% of those with partial vision. VI subjects had fewer social opportunities to relate to their peers, more of them had no friends and more of them were solitary and socially isolated</p>
<p>Jones et al. 1972 blind children integrated in regular classroom for at least half of the school day (n=20) grades 4-6</p>	<p>sighted classmates (n=477)</p>	<p>measures of sociometric status</p>	<p>Blind children tended to be less accepted. Those classmates who listed the blind among their first three choices tended to be below median in acceptance or were isolates</p>

Table 1. (continued).

SAMPLE:	CONTROL SAMPLE	MEASURES:	MAIN RESULTS:
<p>Kef 1999 adolescents with VI (n=354) age 14-24 years</p>	<p>reference projects</p>	<p>Rosenberg Self-Esteem Scale Social Network Map and Grid Personal Network List compared with sighted adolescents</p>	<p>Higher level of self-esteem among VI adolescents Parents and friends were the most important sources of social support</p>
<p>Kent 1983 blind females (n=7) age 15-38 years</p>		<p>questions related to problems and coping mechanisms during adolescence</p>	<p>mothers were important sources of social support in questions related to daily functioning (e.g. dressing, make-up)</p>
<p>Loijas 1994 young people with visual, hearing and motor impairments (n=23) age 17-35 years</p>		<p>questions related to perceived problems the life-course, and the way of controlling their lives</p>	<p>family members and relatives were important sources of social support in daily functioning</p>
<p>Meighan 1971 VI adolescents attended Schools for the Blind (n=203) age 14-20 years</p>	<p>Tennessee self concept scale normative scores</p>	<p>Tennessee self concept scale</p>	<p>lower self concept scores among adolescents with VI compared with the norm group</p>

Table 1. (continued).

SAMPLE:	CONTROL SAMPLE	MEASURES:	MAIN RESULTS:
<p>Nemshick et al. 1986 adolescents and young adults with retinitis pigmentosa (n=307) age 13-30 years</p>		<p>measures of psychological educational, vocational and social considerations</p>	<p>A large majority reported to receive social support from their family regarding VI and that their VI interferes with their social activities</p>
<p>Pierce & Wardle 1996 blind children attended schools for the blind (n=46) age 9-11 years</p>	<p>pupils from a county primary school (n=48)</p>	<p>Pier-Harris Children's Self-Concept Scale</p>	<p>the total mean score of the blind children higher than that of sighted controls</p>
<p>Rosenblum 1997 VI adolescents (n=22) age 13-19 years</p>		<p>IFS (level of intimacy in a friendship), Telephone survey including questions related to friendships</p>	<p>the friends engaged in a variety activities, only few reported that VI affected what they did with their friends</p>
<p>Rosenblum 1998 VI adolescents (n=40) age 13-19 years</p>	<p>best friends of VI adolescents (N=23)</p>	<p>IFS (level of intimacy in a friendship), Telephone survey including questions related to friendships</p>	<p>VI affected the activities the friends could do together, but these limitations did not have a strong negative impact on their friendships</p>

Table 1. (continued).

SAMPLE:	CONTROL SAMPLE	MEASURES:	MAIN RESULTS:
<p>Sacks et al. 1998 & Wolfe & Sacks 1997 blind (n=16), low vision (n=16) students</p>	<p>sighted students (n=16) age 15-21 years</p>	<p>interview questionnaires for students and parents including questions related to leisure and recreational activities</p>	<p>VI subjects spent more time alone in passive activities, they had to work harder to maintain their friendships, low vision students involved in the fewest activities, parents were the most important source of support related to questions of homework</p>
<p>Sacks & Wolfe 1998 adolescents with VI (n=3) ages 16-17 years</p>		<p>an observation checklist to evaluate lifestyles (e.g. social interactions, daily living and recreational activities), Quality of Involvement Measure, field notes on the observation</p>	<p>interactions with both sighted and visually impaired age mates low, spent more time at home by themselves, had to work harder to maintain social relationships with their sighted friends</p>
<p>Schindele 1974 VI students integrated in regular schools (n=36), 36 residential school students, grades 5-6</p>	<p>sighted matched controls (n=36)</p>	<p>social adjustment measured by Self-concept Adjustment Score</p>	<p>no significant differences in social adjustment between VI and sighted students</p>

Table 1. (continued).

SAMPLE:	CONTROL SAMPLE	MEASURES:	MAIN RESULTS:
<p>Schnittjer & Hirshoren 1981 Blind children and young people attending residential school (n=104), age 6-21</p>	previous studies	Behavioral Problem Checklist	Factor analysis revealed 3 dimensions:conduct disorder, personality problem and inadequacy-immaturity that correspond to factors found in other populations
<p>Suokas 1992 100 autobiographical accounts written by disabled persons</p>		disability-induced life changes on the basis of autobiographical material	support from the closest to the disabled person was the best guarantee for coping with the crisis of becoming disabled and difficulties caused by disability in everyday life
<p>Urponen 1989 Chronically ill and disabled children in early adulthood (n=488) age 22-25 years</p>	healthy controls of the same age a) siblings (n=488), b) best friend from school (n=236)	questions related to social coping (resources and living conditions, perceived health, coping as members of society)	majority of chronically ill and disabled young people (72 %) evaluated their coping matched that of controls', difficulties in social interaction

Table 1. (continued).
SAMPLE:

CONTROL SAMPLE

MEASURES:

MAIN RESULTS:

Van Hasselt et al. 1986

VI male adolescents
in residential school (n=19),
in public schools (n=17),
mean age 17.2

sighted adolescents
in public schools (n=17)

Child Behavior Checklist
(parents and teachers form),
and Youth Self-Report Form

VI males more disturbed than
the controls. VI males in the
residential placement evinced
greater dysfunction than other
subjects

Appendix 2. The questionnaire of the study

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LUOTTAMUKSELLINEN

Hyvä Oppilas!

Teemme tutkimusta nuorten terveyteen, perheeseen, ihmissuhteisiin ja sosiaaliseen tukeen liittyvistä asioista. Tutkimukseen osallistuu yli 100 peruskoulun yläasteella lukuvuosinsa 1993-1994 ja 1996-1997 integroituneena opiskevaa nuorta, jolla on jokin silmäsairaus tai näkövamma ja noin 600 heidän luokkatoveriaan ympäri Suomea. Tutkimukseen osallistuminen on vapaaehtoista ja sen voi halutessa keskeyttää.

Tutkimuksen tiedot kerätään kyselylomakkeella. Vastaukset käsitellään nimettöminä kaikkien oppilaiden vastauksista koottuina keskiarvolukuina, ei yksittäisen oppilaan vastauksina. Nimeäsi tiedustellaan ainostaan vastausten palautuksen tarkistusta varten. Kaikki antamasi tiedot ovat **täysin luottamuksellisia ja tulevat vain tutkijoiden käyttöön.**

Vastaukset antavat arvokasta tietoa nuorten omista kokemuksista, elämäntilanteesta, koetusta terveydentilasta ja ihmissuhteista. Tuloksia tullaan hyödyntämään kuntoutus-, koulutus- ja muiden tukipalvelujen suunnittelussa. On erittäin tärkeää, että vastaat mahdollisimman huolellisesti ja rehellisesti jokaiseen kysymykseen. Jokaisen vastaus on arvokas tämän tutkimuksen onnistumiselle.

Kun olet vastannut lomakkeeseen, palauta täytetty kyselylomake suljetussa kirjekuoressa opettajalle. Opettaja lähettää kuoren meille.

Suurkiitokset jo etukäteen vastauksestasi ja hyvää jatkoa koulutyöllesi!

Taina Huurre
Tutkija

Erkki Komulainen
Kasvatustieteen dosentti

Hillevi Aro
Professori,
Ylilääkäri

VASTAAMISOHJEET: Vastaaminen on helppoa. Lue ennen vastaamista koko kysymys huolellisesti läpi. Vastaa kysymyksiin rengastamalla sopivimman tuntuinen vaihtoehto tai kirjoita vastaus sille varattuun tyhjään tilaan.

1. Nimi _____
2. Millä luokalla olet? _____
3. Mikä on sukupuolesi 1= poika
 2= tyttö
4. Mikä on syntymäaikasi _____/_____19_____
5. Mikä on asuinpaikkasi
 1= kaupunki, keskusta
 2= kaupunki, lähiö
 3= maaseutu, taajama
 4= maaseutu, haja-asutusalue
6. Kuinka monta kertaa olet muuttanut viimeisen viiden vuoden aikana
 1= en kertaakaan
 2= yhden kerran
 3= kaksi kertaa
 4= kolme kertaa
 5= neljä kertaa tai enemmän
7. Mikä oli kaikkien aineiden keskiarvo viime todistuksessasi? _____
8. Oletko käynyt erityiskoulua
 1= en
 2= kyllä, millä luokilla? _____
9. Minkä ikäinen olit, kun silmäsairaus/näkövamma todettiin? _____
10. Onko sinulla jokin lisävamma tai -sairaus
 1= ei
 2= kyllä, mikä _____
11. Millä tavoin olet näkövammaisen oman arviosi mukaan

- 1= olen heikkonäköinen
 2= olen sokea
 3= en koe olevani näkövammainen

12. Millainen liikkumisenäkö sinulla on

- 1= liikun vain sokeiden tekniikoilla
 2= liikun tutussa ympäristössä näön turvin
 3= liikun oudossa ympäristössä näön turvin auttavasti
 4= liikun näön avulla täysin normaalisti

13. Onko sinulla viimeisen **PUOLEN VUODEN** aikana ollut joitakin seuraavista oireista ja kuinka usein? (Pelkästään kuukautiskiertoon liittyviä säännöllisesti toistuvia vaivoja ei lasketa mukaan). Rengasta sopiva vaihtoehto **JOKA RIVILTÄ**.

	Ei lain- kaan	Silloin tällöin	Melko usein	Usein tai jat- kuvasti
	1	2	3	4
Vatsakipuja	1	2	3	4
Ruokahaluttomuutta	1	2	3	4
Päänsärkyä	1	2	3	4
Haluttomuutta tai tarmottomuutta	1	2	3	4
Vaikeuksia päästä uneen tai heräilemistä öisin	1	2	3	4
Pahoinvointia tai oksentelua	1	2	3	4
Jännittyneisyyttä tai hermostuneisuutta	1	2	3	4
Huimauksen tunnetta	1	2	3	4
Käsien vapinaa	1	2	3	4
Painajaisunia	1	2	3	4
Ripulia tai epäsäännöllistä vatsantoimintaa	1	2	3	4
Väsymystä tai heikotusta	1	2	3	4
Runsasta hikoilua ilman ruumiillista ponnistelua	1	2	3	4
Närästystä tai happovaivoja	1	2	3	4
Ärtyneisyyttä tai kiukunpurkauksia	1	2	3	4

Hengitysvaikeuksia tai ahdistuksen

tunnetta ilman ruumiillista ponnistelua 1 2 3 4

Sydämen tykytystä tai

epäsäännöllisiä sydämenlyöntejä 1 2 3 4

14. Kuuluuko perheeseesi

1= äiti ja isä

2= äiti ja isäpuoli

3= isä ja äitipuoli

4= vain äiti tai isä

5= joku muu huoltaja, kuka? _____

15. Onko sinulla siskoja

1= ei

2= kyllä, minkä ikäisiä? _____

16. Onko sinulla veljiä

1= ei

2= kyllä, minkä ikäisiä? _____

17. Ovatko vanhempasi eronneet

1= ei

2= kyllä, kuinka vanha olit silloin? _____

18. Onko jollakin muulla perheenjäsenelläsi näkövamma

1= ei

2= kyllä, kenellä? _____

19. Mikä on isäsi tai isäpuolesi työ tai ammatti? Merkitse ammatin tai työn nimi mahdollisimman tarkasti esimerkiksi opettaja, sähköasentaja, pankkitoimihenkilö

20. Mikä on äitisi tai äitipuolesi työ tai ammatti? Merkitse ammatin tai työn nimi

mahdollisimman tarkasti

21. Useimmilla meistä on joku tai joitakin sellaisia ihmisiä tai ihmissuhteita, jotka ovat meille tärkeitä. Heitä voivat olla esimerkiksi isä, äiti, sisarukset, sukulaiset, naapurit, koulukaverit, tyttö- tai poikaystävä, opettajat, viranomaiset tai jotkut muut meille tärkeät ihmiset. **Luettele sinulle tärkeät ihmiset ja heidän lukumääränsä** perheen, sukulaisten, muiden tärkeiden aikuisten, koulukavereiden parissa. Jos sinulla ei ole tärkeitä ihmissuhteita, älä jätä kohtaa tyhjäksi, vaan kirjoita kohtaan esimerkiksi "ei ketään".

Luettele sinulle tärkeät ihmiset **PERHEEN** parissa (vastaustapa esimerkiksi äiti, isä, 2 siskoa, 1 veli).

Luettele sinulle tärkeät henkilöt **SUKULAISTEN** parissa (esimerkiksi 2 serkkua, täti, 2 isoäitiä).

Luettele sinulle **MUUT TÄRKEÄT AIKUISET** (esimerkiksi 3 naapurua, 2 opettajaa, koulunkäyntiavustaja, kuntoutusohjaaja)

Luettele sinulle tärkeät **KOULUKAVERIT**. Merkitse koulukavereiden etunimet (esimerkiksi Matti, Maija, Leena).

Seuraavissa kysymyksissä sinua pyydetään valitsemaan **SINULLE KOLME ERITTÄIN TÄRKEÄÄ IHMISTÄ KODIN ULKOPUOLELLA**. Jokaisen kolmen tärkeän ihmisen kohdalla tiedustellaan hänen nimeään, sukupuoltaan, ikäänsä, henkilön suhdetta sinuun, tapaamisen tiheyttä, yhteydenpitotapaa, henkilön asuinpaikkaa ja sitä, kuinka kauan olet tuntenut hänet. Jos sinulla ei ole tärkeitä ihmisiä kodin ulkopuolella, älä jätä kohtaa tyhjäksi, vaan kirjoita nimen kohdalle esimerkiksi "ei ketään".

22. VALITSE NYT SINULLE ENSIMMÄINEN TÄRKEÄ KODIN ULKOPUOLINEN IHMINEN.

Hänen nimensä (tai nimikirjaimensa) on _____

23. Mikä on ensimmäisen tärkeän ihmisen sukupuoli

1= mies

2= nainen

24. Kuinka vanha ensimmäinen tärkeä ihminen on? _____

25. Millainen suhde ensimmäisellä tärkeällä ihmisellä on sinuun

1= sukulainen

2= seurustelukumppani

3= ikätoveri

4= opettaja

5= jokin muu, mikä _____

26. Kuinka usein olet yhteydessä henkilöön? (esimerkiksi joka päivä, 2 kertaa viikossa, kerran kuukaudessa, kaksi kertaa vuodessa)

27. Millä tavoin olet pääasiassa yhteydessä ensimmäisen tärkeän henkilön kanssa

1= tapaamalla koulussa

2= vierailemalla toistemme kotona

3= harrastusten parissa

4= puhelimitse

5= kirjeitse

6= muu tapa, mikä? _____

28. Kuinka kaukana kotoasi ensimmäinen tärkeä henkilö asuu _____ km

29. Kuinka kauan olet tuntenut ensimmäisen tärkeän ihmisen (esim. 2 kk, 3 vuotta) _____

30. Onko ensimmäinen tärkeä henkilö näkövammainen
1= ei
2= kyllä

31. VALITSE NYT SINULLE **TOINEN TÄRKEÄ KODIN ULKO-PUOLINEN IHMINEN.**

Hänen nimensä (tai nimikirjaimensa) on _____

32. Mikä on toisen tärkeän ihmisen sukupuoli
1= mies
2= nainen

33. Kuinka vanha toinen tärkeä ihminen on? _____

34. Millainen suhde toisella tärkeällä ihmisellä on sinuun
1= sukulainen
2= seurustelukumppani
3= ikätoveri
4= opettaja
5= jokin muu, mikä _____

35. Kuinka usein olet yhteydessä henkilöön? (esimerkiksi joka päivä, 2 kertaa viikossa, kerran kuukaudessa, kaksi kertaa vuodessa)

36. Millä tavoin olet pääasiassa yhteydessä toisen tärkeän henkilön kanssa
1= tapaamalla koulussa
2= vierailemalla toistemme kotona
3= harrastusten parissa
4= puhelimitse
5= kirjeitse
6= muu tapa, mikä? _____

37. Kuinka kaukana kotoasi toinen tärkeä henkilö asuu _____ km

38. Kuinka kauan olet tuntenut toisen tärkeän ihmisen (esim. 2 kk, 3 vuotta)

39. Onko toinen tärkeä henkilö näkövammainen

1= ei

2= kyllä

40. VALITSE NYT SINULLE **KOLMAS TÄRKEÄ** KODIN UL-
KOPUOLINEN IHMINEN.

Hänen nimensä (tai nimikirjaimensa) on _____

41. Mikä on kolmannen tärkeän ihmisen sukupuoli

1= mies

2= nainen

42. Kuinka vanha kolmas tärkeä ihminen on? _____

43. Millainen suhde kolmannella tärkeällä ihmisellä on sinuun

1= sukulainen

2= seurustelukumppani

3= ikätoveri

4= opettaja

5= jokin muu, mikä _____

44. Kuinka usein olet yhteydessä henkilöön? (esimerkiksi joka päivä, 2 kertaa viikos-
sa, kerran kuukaudessa, kaksi kertaa vuodessa)

45. Millä tavoin olet pääasiassa yhteydessä kolmannen tärkeän henkilön kanssa

1= tapaamalla koulussa

2= vierailemalla toistemme kotona

3= harrastusten parissa

4= puhelimitse

5= kirjeitse

6= muu tapa, mikä? _____

46. Kuinka kaukana kotoasi kolmas tärkeä henkilö asuu _____ km

47. Kuinka kauan olet tuntenut kolmannen tärkeän ihmisen (esim. 2 kk, 3 vuotta)

48. Onko kolmas tärkeä henkilö näkövammaisen

1= ei

2= kyllä

Seuraavissa kysymyksissä (49-62) sinua pyydetään luettelemaan ensin ne henkilöt, joiden puoleen käännyt esitetyissä esimerkkitalanteissa. Vastaa merkitsemällä esimerkiksi äiti, veli, serkku, seurustelukumppani, kaveri, opettaja, viranomainen jne. Jos sinulla ei ole ketään, jonka puoleen voit kääntyä, merkitse kohtaan esimerkiksi "ei ketään" (älä jätä kohtaa tyhjäksi). Arvioi tämän jälkeen, minkä verran haluaisit keskustella, saada tavaroita, neuvoja, palautetta, käytännön apua tai haluaisit viettää aikaa eri ihmisten kanssa ympäröimällä sopivin vastausvaihtoehto (myös siinä tapauksessa, että sinulla ei ole ketään, jonka puoleen voit kääntyä).

49. Kun haluat keskustella sinulle tärkeistä **HENKILÖKOHTAISISTA ASIOISTA JA TUNTEISTA** esim. ihmissuhteisiin ja ulkonäköön liittyen, niin keiden ihmisten puoleen käännyt näissä kysymyksissä. Luettele heidät. (esimerkiksi äiti, sisko, ikätoverit)

50. Haluaisitko keskustella henkilökohtaisista asioista ja tunteista jonkun kanssa

1= selvästi nykyistä enemmän

2= vähän enemmän

3= en haluaisi enempää

4= minulla on jo liikaakin mahdollisuuksia puhua henkilökohtaisista asioistani

51. Luettele ne ihmiset, joiden puoleen voit kääntyä, kun tarvitset **RAHAA TAI ERILAISIA VÄLINEITÄ/TAVAROITA LAINAKSI** (esimerkiksi vanhemmat, sisko, ikätoverit, viranomaiset)

52. Haluaisitko saada rahaa tai välineitä

1= selvästi nykyistä enemmän

2= vähän enemmän

3= en haluaisi enempää

4= minulla on jo liikaakin mahdollisuuksia saada rahaa tai erilaisia tavaroita tai välineitä

53. Luettele ne ihmiset, joiden puoleen voit kääntyä, kun tarvitset **NEUVOJA**, esimerkiksi koulunkäyntiin liittyvissä asioissa (esimerkiksi vanhemmat, sisar, veli, koulunkäyntiavustaja, matkaopettaja)

54. Haluaisitko saada

1= selvästi nykyistä enemmän neuvoja

2= vähän enemmän neuvoja

3= en haluaisi enempää

4= minusta tuntuu, että saan jo liikaakin neuvoja eri asioissa

55. Luettele ne ihmiset, jotka antavat sinulle **MYÖNTEISTÄ PALAUTETTA** tekemistäsi tai ehdottamistasi asioista, esimerkiksi saat henkilöltä kehuja onnistuessasi kokeissa tai harrastuksissa (esimerkiksi vanhemmat, sisarukset, ikätoverit, opettajat)

56. Haluaisitko saada

1= selvästi nykyistä enemmän myönteistä palautetta

- 2= vähän enemmän myönteistä palautetta
- 3= en haluasi enempää
- 4= saan jo mielestäni liikaakin myönteistä palautetta

57. Luettele ne ihmiset, joiden puoleen voit kääntyä, kun tarvitset apua esimerkiksi **LIKKUMISESSA, VAATTEIDEN OSTAMISESSA TAI MUISSA KÄYTÄNNÖN TILANTEISSA** (esimerkiksi äiti, isä, sisarukset, henkilökohtainen avustaja)

58. Haluaisitko saada

- 1= selvästi nykyistä enemmän apua käytännön tilanteissa
- 2= vähän enemmän
- 3= en haluaisi enempää
- 4= saan jo liikaakin apua käytännön tilanteissa

59. Luettele, keiden kanssa **VIETÄT** useimmiten **VAPAA-AIKAASI HARRASTUSTEN, RENTOUTUMISEN TAI HAUSKANPIDON MERKEISSÄ?** (esim. vanhemmat, sisarukset, ikätoverit)

60. Haluaisitko saada

- 1= selvästi nykyistä enemmän mahdollisuuksia viettää aikaa muiden kanssa
- 2= vähän enemmän
- 3= en haluaisi enempää
- 4= minulla on jo liikaakin mahdollisuuksia viettää aikaani muiden kanssa

61. Luettele ne ihmiset, joiden puoleen voit kääntyä **SILMÄSAIRAUTEEN TAI NÄKÖVAMMAAN** liittyvissä asioissa (esimerkiksi vanhemmat, opettaja, koulunkäyntiavustaja, silmälääkäri)

62. Haluaisitko saada

- 1= selvästi nykyistä enemmän tukea silmäsairauteen/näkövammaan liittyvissä kysymyksissä
- 2= vähän enemmän
- 3= en haluaisi enempää
- 4= saan jo liikaakin tukea

Seuraavat kysymykset (63-68) koskevat perheenjäsenten välisiä suhteita ja seurustelusuhteita. **Ympyröi sopivin vastausvaihtoehto.**

63. Millaiseksi koet kotisi ilmapiirin

- 1= erittäin hyväksi
- 2= melko hyväksi
- 3= ei hyväksi eikä huonoksi
- 4= melko huonoksi
- 5= erittäin huonoksi

64. Arvioi, millainen suhde sinulla on äitisi/äitipuolesi kanssa.

- 1= erittäin läheinen
- 2= melko läheinen
- 3= ei erityisen läheinen eikä etäinen
- 4= melko etäinen
- 5= erittäin etäinen

65. Arvioi, millainen suhde sinulla on isäsi/isäpuolesi kanssa.

- 1= erittäin läheinen
- 2= melko läheinen
- 3= ei erityisen läheinen eikä etäinen
- 4= melko etäinen
- 5= erittäin etäinen

66. Arvioi, millainen suhde sinulla on ainoaan tai läheisimpään sisarukseesi

- 1= erittäin läheinen
- 2= melko läheinen
- 3= ei läheinen eikä etäinen
- 4= melko etäinen

5= erittäin etäinen

6= ei sisaruksia

67. Oletko koskaan seurustellut

1= en

2= kyllä

68. Seurusteletko tällä hetkellä

1= en

2= kyllä

69. Seuraavassa on erilaisia itseesi liittyviä väittämiä. **Rengasta jokaisen väittämän kohdalla yksi vastausvaihtoehto sen mukaan, minkä verran väittämiestäsi sopii sinuun itseesi.** Vastaa lähinnä ensimmäisen mieleentulevan vaihtoehdon mukaan.

	Ei sovi ollen- kaan	Ei sovi kovin hyvin	Sopii jonkin verran	Sopii melko hyvin	Sopii täysin
1. Uskon itseeni ja mahdollisuuksiini	5	4	3	2	1
2. Haluaisin olla erilainen kuin olen	5	4	3	2	1
3. Minua vaivaavat alemmuudentunteet	5	4	3	2	1
4. Mielestäni minulla on paljon hyviä ominaisuuksia	5	4	3	2	1
5. Tunnen kipeästi, että minulta puuttuu itseluottamusta	5	4	3	2	1
6. Pystyn siihen, mihin muutkin	5	4	3	2	1
7. Olen usein tyytymätön itseeni	5	4	3	2	1
8. Menen toisten luo ja aloitan keskustelun	5	4	3	2	1
9. Haluan olla yksin	5	4	3	2	1

10. Pelkään jutella muiden kanssa	5	4	3	2	1	
11. Ystävystyn helposti	5	4	3	2	1	
12. Tunnen itseni yksinäiseksi	5	4	3	2	1	
13. Liityn toisten nuorten peleihin ja tekemisiin	5	4	3	2	1	
14. Minulla on useita ystäviä		5	4	3	2	1
15. Painelen toisinaan silmiäni	5	4	3	2	1	
16. Heilutan toisinaan vartaloani tai vartalon osiani	5	4	3	2	1	

Seuraavat kysymykset käsittelevät mielialan erilaisia piirteitä. Vastaa kuhunkin kysymykseen siten, millaiseksi tunnet itsesi tänään. Valitse kustakin kysymyksestä vain **yksi** vaihtoehto, älä jätä yhtään kysymystä väliin.

70. Millainen mielialasi on

- 0= mielialani on melko valoisa ja hyvä
- 1= en ole alakuloinen tai surullinen
- 2= tunnen itseni alakuloiseksi ja surulliseksi
- 3= olen alakuloinen jatkuvasti enkä pääse siitä eroon
- 4= olen niin masentunut ja alavireinen, etten kestä enää

71. Miten suhtaudut tulevaisuuteesi

- 0= suhtaudun tulevaisuuteeni toiveikkaasti
- 1= en suhtaudu tulevaisuuteen toivottomasti
- 2= tulevaisuus tuntuu minusta melko masentavalta
- 3= minusta tuntuu, ettei minulla ole tulevaisuudelta mitään odotettavaa
- 4= tulevaisuus tuntuu minusta toivottomalta, enkä jaksa uskoa, että asiat muuttuisivat parempaan päin

72. Miten katsot elämäsi sujuneen

- 0= olen elämässäni onnistunut huomattavan usein
- 1= en tunne epäonnistuneeni elämässäni
- 2= minusta tuntuu, että olen epäonnistunut pyrkimyksissäni tavallista useammin
- 3= elämäni on tähän saakka ollut vain sarja epäonnistumisia
- 4= tunnen epäonnistuneeni täydellisesti ihmisenä

73. Miten tyytyväiseksi tai tyytymättömäksi tunnet itsesi
0= olen varsin tyytyväinen elämäni
1= en ole erityisen tyytymätön
2= en nauti asioista samalla tavalla kuin ennen
3= minusta tuntuu, etten saa enää tyydytystä juuri mistään
4= olen täysin tyytymätön kaikkeen
74. Minkälaisena pidät itseäsi
0= tunnen itseni melko hyväksi
1= en tunne itseäni huonoksi ja arvottomaksi
2= tunnen itseni huonoksi ja arvottomaksi melko usein
3= nykyään tunnen itseni arvottomaksi melkein aina
4= olen kerta kaikkiaan arvoton ja huono
75. Onko sinulla pettymyksen tunteita
0= olen tyytyväinen itseeni ja suorituksiini
1= en ole pettynyt itseni suhteen
2= olen pettynyt itseni suhteen
3= minua inhottaa oma itseni
4= vihaan itseäni
76. Onko sinulla itsesi vahingoittamiseen liittyviä ajatuksia
0= minulla ei ole koskaan ollut itsemurha-ajatuksia
1= en ajattele enkä halua vahingoittaa itseäni
2= minusta tuntuu, että olisi parempi, jos olisin kuollut
3= minulla on tarkat suunnitelmat itsemurhasta
4= tekisin itsemurhan jos siihen olisi mahdollisuus
77. Miten suhtaudut vieraitten ihmisten tapaamiseen
0= pidän ihmisten tapaamisesta ja juttelemisestä
1= en ole menettänyt kiinnostustani muihin ihmisiin
2= toiset ihmiset eivät kiinnosta minua niin paljon kuin ennen
3= olen melkein kokonaan menettänyt mielenkiintoni sekä tunteeni toisia ihmisiä kohtaan
4= olen menettänyt mielenkiintoni muihin ihmisiin enkä välitä heistä lainkaan
78. Miten koet päätösten tekemisen
0= erilaisten päätösten tekeminen on minulle helppoa
1= pystyn tekemään päätöksiä samoin kuin ennenkin
2= varmuuteni on vähentynyt ja yritän lykätä päätösten tekoa
3= minulla on suuria vaikeuksia päätösten teossa

4= en pysty enää lainkaan tekemään ratkaisuja ja päätöksiä

79. Minkälaisena pidät olemustasi ja ulkonäköäsi

0= olen melko tyytyväinen ulkonäkööni ja olemukseeni

1= ulkonäössäni ei ole minua haittaavia piirteitä

2= olen huolissani siitä, että näytän epämiellyttävältä

3= minusta tuntuu, että näytän rumalta ja vastenmieliseltä

4= olen varma, että näytän rumalta ja vastenmieliseltä

80. Minkälaista nukkumisesi on

0= minulla ei ole nukkumisessa minkäänlaisia vaikeuksia

1= nukun yhtä hyvin kuin ennenkin

2= herätessäni aamuisin olen paljon väsyneempi kuin ennen

3= minua haittaa unettomuus

4= kärsin unettomuudesta, nukahtamisvaikeuksista tai liian aikaisin heräämisestä

81. Tunnetko väsymystä tai uupumusta

0= väsyminen on minulle lähes täysin vierasta

1= en väsy helpommin kuin tavallisestikaan

2= väsyn nopeammin kuin ennen

3= vähäinenkin työ väsyttää ja uuvuttaa minua

4= olen liian väsynyt tehdäkseni mitään

82. Minkälainen ruokahalusi on

0= ruokahalussani ei ole mitään hankaluuksia

1= ruokahaluni on ennallaan

2= ruokahaluni on huonompi kuin ennen

3= ruokahaluni on nyt paljon huonompi kuin ennen

4= minulla ei ole enää lainkaan ruokahalua

83. Kerro omin sanoin, millaisia haittoja tai mahdollisia myönteisiä asioita silmänsairaudesta tai näkövammasta on ihmissuhteiden luomissa ja ylläpitämisessä.

84. Jos saisit esittää kolme toivomusta, niin mitä toivoisit?

1. _____

2. _____

3. _____

85. Lopuksi, miten tärkeänä pidät tällaisen tutkimuksen tekemistä. Tutkimuksen tekeminen on

1= erittäin tärkeää

2= melko tärkeää

3= en osaa sanoa

4= ei kovinkaan tärkeää

5= ei lainkaan tärkeää

KIITOS SINULLE AVUSTASI!

HUOM! Kyselylomakkeen kysymykset 8-12, 18, 30, 39, 48, 61, 62, 69 (väittämät 15 ja 16) ja 83 esitetty vain näkövammaisille. Vertailuryhmän nuorille esitetty lisäksi kysymys: Onko sinulla jokin pitkäaikaissairaus tai vamma, josta on sinulle haittaa jokapäiväisessä elämässä 1=ei, 2=kyllä, mikä?

ORIGINAL PUBLICATIONS