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Introduction

1.1 Motives for this study

Adolescents attach considerable importance to being included, to being part of a group. The group context of social relations is assumed to play a central role in personality development during adolescence (Cotterell, 1996). Social relations not only support the adolescent in coping with the wider world, but are also sources of group identity which help to endorse the emerging personal identity. Growth and development occur in interaction with persons who are important to the individual. Severe health problems threaten the quality and maintenance of relationships with family and friends, whereas these relationships play an important role in coping with illness. Disabilities can result in moderate to severe restrictions in the performance of social roles, related to work, leisure, family, and friendships. Unique stressors associated with such disabilities as chronicity, unpredictability, and social stigma place substantial constraints on the ability to maintain and restructure relationships (Lyons, Sullivan & Ritvo, 1995). Stress can be buffered by social support and feeling close to other persons, resulting in a higher sense of well-being and fewer behavioral problems (Cauce, Mason, Gonzales, Hiraga & Liu, 1994; Nestmann & Hurrelmann, 1994).
Introduction

Because so much of what we call social skills is picked up by children incidentally through watching others, blind or visually impaired children who cannot observe social interactions directly often have difficulty in becoming socially adapted. Because the social nuances that are necessary to function in our community are dependent on visual cues and are frequently expressed through gestures rather than speech, visually impaired persons often have difficulty establishing and maintaining social relationships with sighted people.

Although numerous blind and visually impaired children and adolescents have been integrated into public school classrooms and are successful academically, both parents and professionals are deeply concerned that these children are not learning the social skills they need in order to interact adequately with their sighted peers, develop positive relationships, and be successfully employed as adults (Bishop, 1986). It is hypothesized that blind and visually impaired adolescents experience problems in relating to the outside world and this, too, could influence their own development.

Research in the U.S.A. demonstrates that students in regular public schools lack the social skills to start and carry on conversations, play games effectively, and join and feel part of a group; are uncomfortable talking about their visual impairments; and, most important, they try to hide their visual impairments (Sacks, 1992). By concentrating more on interpersonal themes, the ideology of social integration should in the end lead to fewer relationship problems.

Motives for carrying out this study on the personal networks and psychosocial characteristics of visually impaired adolescents originate from previous research results. Especially, the results of a Dutch study into the daily life of young adults with visual impairments are an important starting point (Habekothé & Peters, 1993). This study, the result of a collaboration between the University of Amsterdam and the Federation of Parents of Visually Impaired Children (FOVIG), demonstrated that a lot of the participants experienced difficulties in their daily life with regard to acceptance of themselves and of others, dependency, and social contacts. The relevance of our study into these difficulties is confirmed by other research results into these aspects of psychosocial functioning. Sacks and Wolfe (1998) stated that research on the social networks of adolescents with visual impairments and how these adolescents interact with family members, peers, and teachers may provide the field with strategies to facilitate their successful inclusion in the wider society. Furthermore, experiences of professional caretakers and parents supported the plans for this study. No nationwide scientific research dealing with all the topics described above existed in the Netherlands or any other country.
This study, too, is the result of a collaboration between the University of Amsterdam and FOVIG (Federation of parents of visually impaired children). The project is embedded in a research program of the Faculty for Social and Behavioral Sciences and has the following mission: "Inclusion of troubled youth: possibilities and risks". Research into the meaning of personal network members and their social support for adjustment to blindness or visual impairment and well-being of adolescents, suits this mission well.

The purpose of this study is to gather scientific knowledge in order to improve the possibilities for blind and visually impaired children, adolescents and their parents. An additional aim is to make recommendations to (special) schools, rehabilitation centers and organizations for the blind and visually impaired. In this way, we hope to help improve the rearing and education situation and enhance the development of blind and visually impaired persons.

The three general research questions of this study are:

a What are the structural and functional aspects of the personal networks of blind and visually impaired adolescents, compared with those of sighted adolescents?

b What is the psychosocial development - as measured by psychosocial characteristics, well-being and loneliness - of blind and visually impaired adolescents, compared with that of sighted adolescents?

c What is the association between on the one hand several aspects of the personal network and on the other hand psychosocial characteristics, well-being and loneliness of blind and visually impaired adolescents, compared with that of sighted adolescents?

1.2 Visual impairment

Background
What kinds of societal issues or pedagogical paradigms form the background to our study?

In two recent inaugural addresses (Van Gennep, 1997; Vermeer, 1997), the shifting paradigms in the rehabilitation of and provision of services for impaired and sick persons are elaborated. According to Van Gennep (1997) we nowadays work with the support paradigm instead of the care paradigm. Support for persons who suffer from impairments should be aimed at providing them with access to knowledge and with the means and relations that are
necessary for them to live, work and play in the community. The support should be flexible, meaning that the quantity and quality of the support provided should be geared to the individual in question. The most important and natural support providers are the family members and friends of an individual. Also of importance for giving support is the safety net of regular and special rehabilitation and services.

The extent to which environmental factors influence the rehabilitation of persons with impairments is also pointed out by Vermeer (1997). In his inaugural address he underlined a context-oriented vision for the rehabilitation of and provision of services for impaired individuals. The focus of care or support must be on the interaction between impaired persons and their environment. For in this environment, or context, individuals have their possibilities to act in different ways and to develop. More attention should therefore be paid to interpersonal issues.

This vision is one of the central issues in what is called 'Disability Studies' (Van Hove, 1999). Disability is regarded as a social construct and must be studied in historical, political and cultural contexts. Important concepts in this approach are inclusion, empowerment, diversity, equality and inequality. However, in emphasizing equality and autonomy, attention must always be given to the need for intimacy and solidarity of impaired persons (Van Hove, 1999).

The starting-point in pedagogy in general and in special pedagogy of persons with impairments in particular, is that the development of individuals is strongly influenced by contextual factors. In order to provide adequate care and support, it is important to have insight into the individual, his\(^2\) environment and how persons cope with their environment. Without social support from significant others, adequate behavioral and cognitive skills will not be developed sufficiently (Van der Ploeg, Van den Bergh, Klomp, Knorth & Smit (eds.), 1992).

Van der Wolf (1998) mentioned in his inaugural address the importance of social support, having control, coping skills, a positive self-image, and possibilities for participation in the community, because these will buffer stress and vulnerability and result in fewer emotional or behavioral problems.

The outlooks, or visions, mentioned above appear also in policy notes of the Dutch Department for Public Health, Welfare & Sports (De perken te buiten, 1996). Central issues in the policy of the Dutch government concerning sick or impaired persons for the period 1995 through 1998 are:

- equal (human) rights
- the demand for assistance is more important than the supply of assistance
- integration is promoted, especially in education and work situations

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\(^2\) In this thesis we use the terms 'he' and 'his'.

• more regional collaboration between agencies, adequate regional spreading,
  more small-scale facilities, de-compartmentalization of institutions, more
  cooperation
• independent indication of the support or assistance needed.

The above-mentioned themes are also internationally recognized as relevant
subjects for rehabilitation and scientific research. As a result, the International
Council for Education of Persons with a Visual Impairment (ICEVI) is
stimulating research in this field. One of the most important topics in their
Plan of Action for the 1990s was transition to adulthood. During this transition,
blind and visually impaired adolescents appear to experience a lot of problems.

Visual impairment
How can we characterize our participants, i.e. blind and visually impaired
adolescents?
To provide some insight into the problems people with disabilities or
handicaps may experience, and to shed light on the classification as handled by
researchers and professionals, we explain the current nomenclature. The
WHO's International Classification of Impairments, Disabilities and Handicaps
(ICIDH) (Ruwaard & Kramers, 1993) distinguishes four dimensions with regard
to health problems, i.e. illness, impairment, disability, and handicap.

An 'illness' can be blindness or visual impairment caused by, for example,
cataracts or retinal defects (Bishop, 1996). 'Impairment' is described as any
abnormality of a physical or anatomical structure or its function. This includes
impairments in vision, but also in hearing or cognition. 'Disability' is a
limitation of the ability to perform activities considered normal for a human
being, such as walking, reading, or helping others. 'Handicap' is described as
any disadvantage for an individual that limits the fulfillment of a normal role
or occupation, such as exclusion, lack of social value, social isolation, or stigma.
Handicaps are substantially affected by social values and attitudes toward
disability, which influence accessibility to work, leisure, and relationships as
well as the individual's attitude and adaptational capacity (Lyons, Sullivan &
Ritvo, 1995).

In this thesis, the emphasis is on blind or visually impaired adolescents.
Many illnesses could cause visual problems, and the degree and course of a
visual problem can differ much within one group of adolescents. Some visual
problems are congenital, e.g. cataracts and macular degeneration; others are
acquired later in life, e.g. optic atrophy caused by a metabolic disease or
retinoblastoma, a tumor in the eye. Several disabilities can occur as a
consequence of the visual impairment, such as problems with walking, driving,
self-care, household chores, writing, and helping others. As mentioned before,
these disabilities could lead to limitations in the fulfilment of a normal role in
the community. However, what is a 'normal role' in the community? Nakken
(ed., 1993) distinguishes in this regard between the 'social functioning' of a
person with disabilities, and 'handicaps' if a person experiences disadvantages
or negative reactions in his social functioning.
All the adolescents in this study have a visual impairment. They experience some kind of disability in driving or household tasks, and to some degree they also experience social disabilities. However, they differ very much in the degree to which they feel handicapped, or negatively judged.

An important question in this regard is to what extent the results will be unique for adolescents with a visual impairment. In what way does the blindness or low vision account for the results, or are some results characteristic of persons with impairments, or ‘normal’ adolescents, in general? Two aspects are discussed: the conceivable role of vision and more general mechanisms concerning having impairments and the possible consequences.

Eye contact and facial and physical expressions play an important role in social functioning. Every adolescent in our study to some degree experienced problems in this regard. So, this lack of visual information does have an impact. However, participants differ in the way they cope with this specific problem and in the ways they compensate for it. And in this coping and compensating process, social relations can in turn help.

The second general characteristic of adolescents in our study is a certain degree of dependence on devices or persons for their mobility. The participants have some limitations and are to a certain extent dependent on other persons if they wish to go to a disco or join peers in other leisure activities.

A last factor is that certain aspects of our society are more and more focused on vision. For example, the media and new developments in information and communication technology. Furthermore, one of the statements often heard in the 1990s is ‘time is money’. Many things have to be done fast, and this represents a problem for blind or visually impaired adolescents. However, even politicians in the Netherlands are now advocating a general attitude not to make haste any longer. Besides disadvantages, developments in the media and computer technology also bring about many improvements in the daily functioning of blind and visually impaired persons.

More general mechanisms of persons who are sick or have an impairment also play a part in our study. Sick or impaired persons have to cope with visits to doctors or hospitals, contacts with therapists working in special institutions, special and complex regulations, a less natural working situation, less positive reactions of other persons, and contacts with special education. Another similarity is coping with the fact that certain activities are not possible anymore, while other persons have no problems at all regarding these activities. The family situation of coping with a sick or impaired child also shows similarities, with its possible effects on family support for their impaired children.

How many persons with a visual impairment are there in the Netherlands? Research indicates that there are approximately 320,000. This figure represents 2% of the population of 16 million (Melief & Gorter, 1995). Of all children up to and including the age of 18, around 0.1% have a visual impairment (Meire & Delleman, 1987; Gringhuis, Moonen & Van Woudenberg, 1996). Other research has put this figure at 0.27% (Melief & Gorter, 1995). No recent figures are
available concerning the number of blind and visually impaired adolescents.

The above-mentioned figures should, however, be interpreted with caution, since there are many problems associated with the definition of 'visual impairment'. On top of this, studies into the occurrence of visual impairment have so far been restricted to visual acuity. They have not taken into account other important factors that influence visual functioning, such as reduced peripheral vision, sensitivity to contrast, and the influence of light. Furthermore, the occurrence of visual impairment in childhood is so low that it is very difficult to measure.

We can distinguish between persons who have no visual possibilities at all - we call them blind - and persons who have some vision. The confusion over terminology concerning persons who do have some visual functions left is an international discussion. In the last decade, the following terms have been used for this group: legal blindness, partial sight, functional blindness, low vision, visually impaired. In a recent book, Corn and Koenig (eds., 1996) gave the following definition of persons with low vision: "a person who has difficulty accomplishing visual tasks, even with prescribed corrective lenses, but who can enhance his or her ability to accomplish these tasks with the use of compensatory visual strategies, low vision and other devices, and environmental modifications" (Corn & Koenig, 1996, p.4). Two renowned scientific international journals use the term visually impaired, as most conference participants do. Therefore we, too, use this term.

An important perspective on visual functioning in the 1990s is that clinical measures do not give a full picture of how a person functions visually. Persons with some visual possibilities function in ways that cannot be predicted by clinical measures alone. The extent to which one uses available vision is referred to as visual efficiency (Corn & Koenig, 1996). Regarding this visual efficiency several factors should be considered, such as: the development of visual skills, cognitive abilities, experiences, personality, self-esteem, and expectations of self and others. So, individual and environmental dimensions play a part in determining visual functioning. Societal factors such as prejudices, area planning in a city or developments in information communication technology also advance or hinder visual functioning.

The population aimed at in this study includes all blind and visually impaired Dutch adolescents between 14 and 24 years of age who have no additional impairments such as hearing or cognitive impairments. The period of adolescence was chosen because it involves many changes, especially concerning the psychosocial development. In this phase of life, people want to fit in a group and don't want to be special or different, for example due to their visual impairment. Because of the need for a thorough multivariate analysis, the sample should contain at least 200 blind and visually impaired adolescents (Hoogland & Boomsma, 1997) from all over the Netherlands, including blind and visually impaired adolescents with another cultural and ethnic background than the Dutch.
1.3 Overview

This study is presented in eight chapters. This chapter is the introduction; Chapter 2 contains the theoretical background to the research, paying attention to personal network aspects, psychosocial characteristics, and the meaning of network aspects for psychosocial development in adolescence. Three theoretical approaches are described, resulting in a theoretical framework for this study.

Chapter 3 provides the methodological background of the study. It includes information concerning research questions, methods of data collection, reference projects, instruments, and the pilot study.

Before presenting the results of our study, Chapter 4 deals with the fieldwork. The four sections in that chapter provide information regarding research participants, experiences of these participants and interviewers with the data collection, data quality, and kinds of analysis.

The second part of the thesis consists of three chapters on the results. In Chapter 5 results with regard to the network aspects (research question a) are described, paying attention to structural as well as and functional network aspects. Chapter 6 contains results concerning psychosocial characteristics, loneliness and well-being in order to answer research question b. Finally, in Chapter 7 associations between network aspects, psychosocial characteristics and background characteristics (research question c) using structural equation modeling are described.

Chapter 8 contains conclusions, a discussion, and suggestions for parents, adolescents, carers and policy makers. Future research is also outlined.