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Social Pediatrics

Quality of life for children with disabilities

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Because of the complexity of measuring health, one usually ends up measuring its opposite, i.e. death and disease, especially when professions which have a disease-orientated tradition are involved. It is also extremely difficult to discuss the positive aspects of health, since the concept has been so intimately connected with disease. The World Health Organization (WHO) Constitution of 1946 included a health definition that shifted the focal point of the health concept away from the strict-medical orientation by stating that health is dependent on physical, social and mental wellbeing. Since then, the spiritual dimension has been added[1]. In spite of this basically positive definition health is still far from being perceived as an asset and resource for the general public.

The European WHO *Health for All* strategy[2] emphasises the need to create a positive health outcome for the coming generations, i.e. to enable children to lead to fulfilling, healthy and productive life in a healthy environment. Therefore the development of concepts such as quality of life (QoL), which are based on peoples' resources, is a future direction for health research. Creating equal opportunities for vulnerable groups in society probably enhances the general quality of life for the society as a whole[3].

This paper will present a model used for the evaluation of the quality of life of two samples of children with specific disabilities, 390 children with cystic fibrosis (CF) and 561 children with myelomeningocele (MMC) aged 2–18 years. These children are representative of all cases of CF and MMC in the five Nordic countries. Their QoL is compared to that of a random sample of 10290 children of the same age.

Theoretical Considerations: For a Quality of Life Model for children

Generally a QoL model should take into account life as a whole, using both objective and subjective measures. Within QoL research there are few models which have this approach. One such model has been developed in behavioural science by Kajandi[4], who described QoL for psychiatric patients using three life spheres: external, interpersonal and personal conditions. This model has been further developed for use with a child population[5,6]. There are in principle no structural differences in QoL for children as compared to other age groups, but the areas described should be seen from a child's perspective[7].

The life spheres included in the model are:

1. External conditions: describing the dimensions of social, economic and housing conditions including people's subjective perceptions of them. In the context of children this sphere represents the conditions of the family the child is living in, but evaluated from the point of view of the child.
2. Inter-personal conditions: describing the structure and function of the social networks surrounding the child both objectively and subjectively.
3. Personal conditions: describing the dimensions activity, self-esteem and basic mood of the child.

Disabilities and Quality of Life

The following presentation of QoL for families with disabled children is derived using present research knowledge as a basis. Since the family forms the contextual framework for the child's quality of life, reports on both family and child are included.

External conditions

Work, economic situation of the parents and housing conditions are the dimensions that describe the external conditions. There are several reports of the working and educational situation of the parents being negatively affected by the child's disability. The key elements are, firstly, the child's increased need of care. This usually leads to a decrease in work outside the family for the mother which reduces her education and career possibilities[8]. Secondly, this increases the financial burden on the family, where the father may become the sole economic provider, working extra hours[9]. Satisfaction with work is also changed, mothers of disabled children are more inclined to work solely for economic reasons, as compared to controls[10]. Financial worry, and a significant financial burden, are reported as the main concerns of families with disabled children[11]. Unless there are subsidies for families with disabled children, lack of finance may eventually affect the possibility of obtaining appropriate housing, and of providing the child with an adequate room of his own.

Inter-personal relationships

Inter-personal relationships include the structure and function of the social networks, such as the size of the family and the way it functions, the time available for the child, the stability of family relationships, the satisfaction with family life, and also the support the family receives from other supportive networks and the society. Family breakdown has been reported to be much increased in families with disabled children[12]. More recent reports present less marked differences, and also point out several methodological difficulties in the earlier studies[13]. There are also contradictory positive results, such as a Norwegian study of parents of a mixed group of disabled children, where no breakdowns were reported. However, these parents had been recruited to courses for parents of disabled children, which may have caused some bias[14].

Chronic illness can result in there being fewer siblings, because of the increased burden with the care of the child and also, in the case of a genetic disease, the risk of a further disabled child[9,15]. The time parents use for the care of the child may, in severe cases, exceed 50 per cent of their waking time[16].

Dissatisfaction with family life, and periods of depression, may be part of the everyday life of the families[17]. Again, there are also reports of positive development within families, where the mothers have been employed outside the family or are actively involved in society[18].

Sommershild[14] described family satisfaction before and after a disabled child enters the family. Her studies showed that the outcome was dependent on previous satisfaction and coping skills, and that a high earlier level could even be enhanced when the family was met by the challenge of a disabled child.

Psychological conditions

The psychological conditions include activity, self-esteem and basic mood. Simply the lack of available time can explain a decreased level of activities. Further, physical immobilisation or the risk of infections may isolate the family and decrease the level of social activities[19]. The emotional tone and thus the family climate can be reduced[20]. The self-esteem and adjustment of the child have been reported to correlate strongly with the self-esteem and attitudes of the parents[21]. Being different in achievement and appearance has led to negative peer reactions or bullying[22]. Finally, being faced with so may possible obstacles may have a negative effect on the basic mood[23].

The present study

The objective of this study is to compare the quality of life of normal children with that of children with potentially severe physical disabilities. In the model, both objective conditions and subjective perceptions are included.

A main feature is the use of child's perspective in the description of QoL. For each variable a base value or floor value is determined, above which a positive influence on the child's well-being is expected. The level of the base value is determined by factors known to promote the quality of life of children. As the study was carried out in the Nordic countries the base values were set in the perspective of these societies as a "Nordic standard" for quality of life. The same structure can be used in any society, but the base values would have to be adjusted. For each variable, the percentage of children above the base value was calculated. Successive means were used to give the QoL for dimensions, spheres and totally.

Material

The study groups consisted of children with myelomeningocele (MMC) and Cystic fibrosis (CF) aged 2–18 years. An effort was made to include all the known cases in the Nordic countries. Children with MMC in the central region of Sweden did not participate, because of a decentralised procedure of data collection in Sweden. It is assumed that the conditions for these children do not differ systematically from those for other MMC children in Sweden. The conclusions made about the study group are therefore considered valid for all children with the diseases in the age group. The number of children with disabilities was 951; 561 with MMC and 390 with CF.

A reference population was obtained by random sampling of children aged 2–18 years drawn from the population register of the Nordic countries. The number of children per sample was planned as 3000. Since a pseudo-systematic approach was used, the numbers differ between the countries. Certain fractions of all children in the age span 2–18 and born on the 4th of each month were selected. The total number of children responding in the reference population was 10290.

The non-response rate for the disability groups was 5.6 per cent for CF and 13 per cent for MMC. The non-respondents of the MMC group showed no difference as to severity of the disability[24]. The response rates of the reference children varied between 55.8 and 83.2 per cent for different countries. A further analysis of the non-respondents was performed, including telephone interviews in a sample of non-respondents and weighting of the material[25]. In this type of study there are often higher non-respondent rates in lower socio-economic groups. An analysis based on the telephone interviews, and weighting of the reference material, showed that the differences were small enough to allow analysis of the data. The response rates were much higher in the two disability groups, but socio-economic differences are still possible. This could have been controlled for, but it was considered unethical to use other sources of information on families who refused to respond. It was concluded that a valid analysis of the data could be untertaken. Questionnaires directed to children may require proxy respondents, especially when young children are included. Here the parents served as proxys, and about 30 per cent of the disabled children participated in the filling in. The older the children were, the more they participated; 5.3 per cent of the children aged 2–6, 26.3 per cent of the children aged 7–12 and 45.4 per cent of the teenagers participated in the completion of the questionnaire. The only significant difference between the two disability groups was the lower participation of teenagers with MMC. The participation of the comparison children was higher, 10 per cent among the youngest, 41.9 per cent of the school age children and 58.6 per cent of the teenagers.

For the analysis, all variables were dichotomized, i.e. reduced to give only two values. The value one corresponds to being above a certain base level, zero to being below.

All proportions for the study groups were standardized for age using the direct method, with the reference group as standard population. The reference proportions were given weights equal to the numbers of families with children for the countries. The influence of random variation was assessed by means of standard errors. The standard errors for differences between the proportions for the reference group and one of the disease-specific study groups are of the order 2.5. To conclude that such a difference is statistically significant at the 5 per cent level it should exceed approximately 5.

Results

In this presentation the national groups are compiled together, thus the results will be presented for one group of children with myelomeningocele (MMC), one with cystic fibrosis (CF), and one reference group (N). The groups were standardised according to the age of the reference children and the mean for the five Nordic countries was used as standard.

I. External Conditions

Work, economic situation of family and housing conditions are the dimensions that describe the external conditions. The emphasis is on what resources are available for the child in socio-economic terms, including housing. The details are presented below:

1. Working conditions (educational level, profession and satisfaction with work)
2. Economic conditions (income level, income per family member and satisfaction)
3. Housing conditions (type, space and private room for the child)

The differences between the three groups were small regarding external conditions. The educational level was lower in the disability groups, but professions were equal to those of the reference group. The economic conditions included the disposable in-

Tab. 1. Design of the study instrument.

Sphere		Dimensions:	
External conditions	Working	Economy	Housing
	education social class satisfaction	income level distribution satisfaction	type space room
Inter-personal conditions	family	intimate relationship	social support
	siblings available time satisfaction	number of parents lack of events size of household	satisfaction with: relatives society overall
Personal psychological conditions	activity	self-esteem	basic mood
	child activity parent-child activity satisfaction	six opposite pairs (such as happy-depressed)	psychosomatics peer acceptance satisfaction

The complete questionnaire and the list of base values can be obtained from the authors.

Tab. 2. External conditions.

	N	CF	MMC
Working conditions:			
– Education	37.8	33.9*	33.1*
– Profession	63.5	65.8	61.9
– Satisfaction	74.4	62.5*	65.7*
Economic conditions:			
– Income level	51.7	51.5	52.4
– Distribution	73.6	77.7*	77.8*
– Satisfaction	58.7	50.5*	56.5
Housing conditions:			
– Type	79.7	78.4	80.0
– Space	79.3	91.8*	83.9*
– Child room	73.1	88.3*	74.3
External sphere total mean:	65.7	66.7	65.2

* Statistically significant at 5 per cent level.

Tab. 3. Inter-personal conditions.

	N	CF	MMC
Family networks:			
– Siblings	75.9	68.9*	74.5
– Available time	56.6	57.4	54.2
– Satisfaction	86.9	77.6	76.8*
Intimate relationships:			
– Two parents	91.5	86.9*	90.8
– Life events	87.4	83.9	86.8
– Household	72.4	64.1*	69.9
Extended networks : Satisfaction:			
– Relatives' support	56.5	72.2*	71.5*
– Societal support	36.8	39.3	44.1*
– Overall	80.6	74.0*	73.7*
Inter-personal sphere total mean:	71.6	69.3	71.4

* Statistically significant at 5 per cent level.

come and possible subsidies. The three groups had equal total incomes, but the disability groups had higher incomes per family member. Housing conditions were better in the disability groups. Satisfaction with work was lower in the disability groups, and in addition the CF group had lower satisfaction with the economic conditions.

II. Inter-personal Conditions

The inter-personal conditions describe the extent and function of the social networks surrounding the children and satisfaction with them. They include the structure of the family, available parental time, the lack of negative life events (separation, divorce or death), the satisfaction with family life and the support the family receives from extended social networks and society.

Detailed results were obtained for the following three dimensions:

Tab. 4. Personal conditions.

	N	CF	MMC
Activity:			
– Child activity	62.5	60.6	44.8*
– Activity child-parent	69.4	73.0	73.4*
– Satisfaction	73.6	64.2*	62.1*
Self-esteem:	52.0	43.2*	29.6*
Basic mood:			
– Psychosomatics	85.5	50.3*	72.6*
– Daily activity	93.2	93.2	93.0
– Peer acceptance	88.3	89.4	76.0*
Personal sphere total:	69.0	62.2*	56.7*

* Statistically significant at 5 per cent level.

1. Family networks (number of siblings, available parental time for the children, satisfaction with family)
2. Intimate relationships (number of parents, major life events, number of people in the household)
3. Extended networks (support from relatives and society, satisfaction with overall support)

The total outcome for inter-personal conditions was almost equal for the three groups. The CF children had fewer siblings. Major life events were as frequent in all groups. The families of disabled children indicated that they received much better support from their extended families, and somewhat better from society, but they were less satisfied with family life and social support in general.

III. Personal Conditions

The psychological conditions describe the prerequisites for mental well-being, such as the child's activity level, how parents rate the child's self-esteem, and factors that influence the basic mood of the child.

The results and the structure of the three dimensions are presented below:

1. Activity (individual, parent-child activity, satisfaction)
2. Self-esteem of the child as rated by parents in six opposite pairs (as happy – distressed...)
3. Basic mood (lack of psychosomatic problems, satisfaction with daily activity (school, daycare, work) and peer acceptance)

The MMC children had a much lower independent activity level but they were more active with their parents. Satisfaction was highest among the reference population. The parents rated the self-esteem of the disabled children much lower than did parents of reference children. The difference between the CF and MMC groups was remarkable big here, with the MMC group rating much lower. An analysis of self-esteem related to the age of the

Tab. 5. Overall quality of life and objective/subjective separately.

Total means	N	CF	MMC
External	65.7	66.7	65.2
Inter-personal	71.6	69.3	71.4
Personal	69.0	62.2*	56.7*
Total	68.8	66.1	64.4*
Objective	70.2	70.1	69.3
Subjective	70.6	64.1*	63.6*

* Statistically significant at 5 per cent level.

children showed that the self-esteem did not change with age for the reference children but decreased for the disabled, especially in adolescence. Peer acceptance was lowest in the MMC group, while there were more psychosomatic symptoms in the CF group. The results reflected that the disabled children had a more isolated, family-centered life, but they enjoyed daily activities such as school just as much as their peers.

IV. Overall quality of life

The combination of the three spheres gives the following results:

The disabled children rate well within the external and inter-personal spheres, but clearly lower within the personal sphere. The objective conditions are on the same level in all groups but the subjective perception of them are lower in both disability groups. The overall differences are rather small.

Discussion and conclusions

Through the WHO HFA policy, the international public health scene has reached an agreement over the past decades on the basic objectives and priorities for a global health policy. In Europe, achieving equal opportunities for children and disabled persons has been considered a priority area. International comparative statistics on economics, welfare and health generally give a positive impression for the five Nordic countries (Denmark, Finland, Iceland, Norway and Sweden). The Human Development Index presented by the United Nations Development Report[26] placed three of the Nordic countries among the top ten. The physical Quality of Life Index developed by the World Bank in the late 1970s ranked four Nordic countries first[27]. The only existing Quality of Life Index for children, the National Index Children is Quality of Life (NICQL)[28], ranked Iceland first. Health indicators such as life expectancy, infant mortality and perinatal mortality usually rank the Nordic countries among the top ten in the world[29]. This study has been an attempt to develop a quality of life instrument to evaluate the HFA objectives of equity and "adding life to years". Children's QoL was analysed in three life spheres; external, inter-personal and personal conditions, investigating the resources available for children and comparing them to those of children with disabilities. A base level for quality of life based on essential resources available to the child was used as a QoL standard.

The results give an indication that the inequities for children with disabilities in the Nordic countries as compared to their normal peers are rather small, for instance, in material well-being. This result differs from most previous research that claim that families with disabled children have a lower level of socio-economic resources than average families. The literature generally claims that social support networks are less developed, and family breakdowns more common, in families with disabled children. This result was to some extent repeated here, but the differences were smaller than expected. The greatest differences occurred when personal conditions were considered. It seemed that a visible motor handicap, like MMC, reduces the peer acceptance, whereas CF children have more psychosomatic symptoms. The self-esteem of the disabled children was rated much lower by the parents than it was among the control group. It also decreased for the disabled the older they were.

A high level of satisfaction with the various aspects of life was found in the reference population. Over 60 per cent indicated they were satisfied. The proportion that indicated they were "very satisfied" was higher in the disability groups. The total quality of life ratings in the three groups give the impression that children have a reasonable QoL in the Nordic countries.

The advantage of using this QoL instrument lies in the possibility of covering most relevant aspects of children's life in a comprehensive model. On the other hand, if one only looks at the collective data of total QoL, some important variations may be overseen. Therefore detailed analyses of the various dimensions should be undertaken. The use of a questionnaire is practical on a population basis, although sensitive questions cannot be included. Probably it will only be possible to obtain a deeper understanding of children's QoL from qualitative research, possibly in combination with quantitative results like those presented here. A follow up study based on this design is planned.

The policy implications of this study suggest that one of the main objectives of the WHO HFA strategy, that of equity, has generally been met for children with disabilities in the Nordic countries, at least on the socio-economic level. The majority of the families have adequate resources available, and indicate that they are satisfied with them. Also, the social support systems seem to meet the needs of these target groups, in spite of the fact that families of children with disabilities proved to have slightly weaker social networks. The personal conditions, which reflect the mental well-being of the children, were lower for the disability groups. This would suggest that this is a priority area for future health policy and for interventions. Improvement of the personal psychological conditions of the disabled, and enhancement of an accepting family climate with positive attitudes towards the disabled children, will also require health personnel with good knowledge of the prerequisites for children's quality of life. In a broader context, societies that accept the disabled as equal citizens and are ready to allocate sufficient collective resources for this purpose.

Summary

Studies on children with special needs mainly concentrate on disease-oriented health problems and neglect the positive aspects of quality of life. In this study the quality of life of children with *Cystic Fibrosis* and *Myelomeningocele*, 951 children in all, in the five Nordic countries is compared to that of a random sample of 10290 children. The aim of the study was to see how the issue of equity, a main objective of the WHO health for all policy, has been met in the Nordic countries. Quality of life is defined as one of the essential resources of a population in terms of external, inter-personal and personal conditions. The study shows that children with disabilities have, and perceive that they live in good material and socio-economic conditions. However, the personal psychological conditions are less favourable, which indicates that this is a priority area for future health policies.

Zusammenfassung

Lebensqualität bei Kindern mit Gesundheitsproblemen

Studien von Kindern, die besonderer Betreuung bedürfen, sind in der Regel vorwiegend auf die krankheitsbezogenen Gesundheitsprobleme ausgerichtet und die Lebensqualität wird vernachlässigt. In der vorliegenden Studie geht es um die Lebensqualität von Kindern, die an Zystischer Fibrose oder einer Myelomeningozele leiden. Es werden 951 Patienten aus fünf nordeuropäischen Ländern mit einer Zufallstichprobe verglichen, die 10290 Kinder umfasst. Wie weit wurde in diesem Bereich die Forderung der Chancengleichheit erfüllt? Diese Forderung gehört ja zu den Hauptzielen des WHO-Aktionsprogrammes „Gesundheit für alle 2000". Der Begriff Lebensqualität bezieht sich dabei auf die Umwelt, die zwischenmenschlichen Beziehungen und die Situation des Einzelnen. Die Resultate zeigen, dass behinderte Kinder in den nordeuropäischen Staaten unter guten materiellen und sozioökonomischen Bedingungen leben und dies auch so empfinden. Hingegen ist die psychologische Situation weniger zufriedenstellend, was dazu führen muss, in Zukunft diesem Bereich mehr Beachtung zu schenken.

Résumé

Qualité de vie chez les enfants souffrant de problèmes de santé

Des études faites sur les enfants ayant des besoins particuliers se sont surtout concentrées sur des problèmes de santé orientés vers les maladies et ont négligé les aspects positifs de la qualité de vie. Dans cette étude-ci, la qualité de vie des enfants souffrant de CF (Cystic Fibrosis) et de MMC (Myelomeningocele), en tout 951 enfants dans les cinq pays nordiques, a été comparée avec un échantillon aléatoire de 10290 enfants. L'objet de cette étude était de voir comment la question d'équité, un des buts principaux dans les directives de l'OMS «Santé pour Tous», avait été traitée dans les pays nordiques. L'étude témoigne que les enfants souffrant d'incapacités trouvent qu'ils vivent dans de bonnes conditions au point de vue matériel et socio-économique. Cependant, les conditions personnelles et psychologiques sont moins favorables, et ce champ-ci doit être une priorité dans la future politique de santé.

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