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Children, adolescents and young adults with a chronic illness: quality of life, social participation and health care service - a patient and family perspective

Bibliography 1995 – 2003

Volume 1: 1995 -1999

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*Adjustment to one's illness during childhood
sets the stage for later adjustment in adulthood*
(Patterson, 1988) ⁱ

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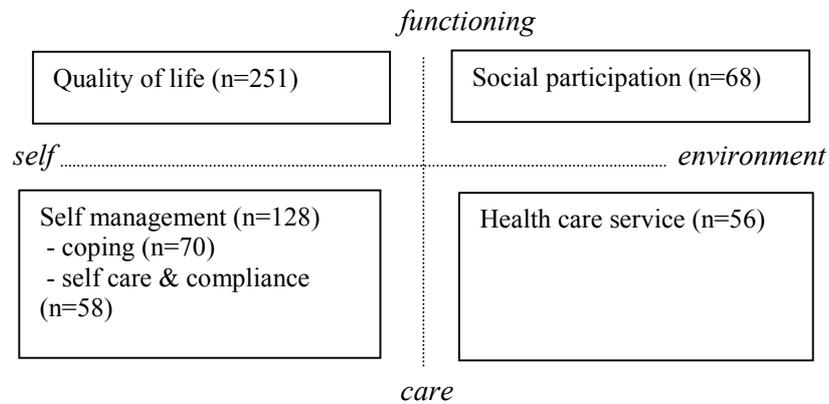
Introduction

a Objectives

The changes of growing up is a challenge for many children and adolescents, even for healthy ones. A chronic illness can be considered to add tasks that need adaptation, for example complaints, such as pain or lack of energy, and self care tasks like medication intake or the need to adhere to a diet. In general, studies on the consequences of a chronic illness for the daily life were generated in adult populations. In this perspective, subjects of research often relate to concepts of quality of life, social participation and self management. Subsequently, in the past decade, scientific attention to these themes more and more emerged in younger populations, as in children and adolescents. In these studies, the impact of a chronic illness on siblings and family relations is often taken as point of departure as well. Together with this scientific attention, social participation and daily functioning in chronically ill children and adolescents are recently getting more and more attention of politics. Therefore, it was decided to perform a literature search on these subjects, aiming to provide an overview of scientific studies that have been conducted since 1995. Such an overview can be used to get insight into the current status of scientific research and to uncover fields that run the risks to develop into scientifically underexposed themes. Additionally, this overview can be used to support decision making processes in politics. In order to be of optimal use for policy makers, topics referring to the needs and utilisation of health services have been integrated in this bibliography as well.

The point of departure of this bibliography is the perspective of young patients themselves, children, adolescents and young adults in the age of 0 to 25 years, and that of their parents and siblings. The bibliography covers a broad range of subjects relating to quality of life, social participation, self management and professional care. Studies on medical aspects, epidemiology and aetiology are left out of consideration. In order to classify the documents, a schematically arrangement was developed (Figure 1).

Figure 1 Schematically arrangement of this bibliography (number of documents enclosed)



In this scheme, the subjects above the line relate to the functioning of children and adolescents with a chronic illness, or that of their siblings and parents. The subjects beneath the line represent care activities or dealing processes. In the same way, the subjects on the left side refer, more or less, to the functioning and care activities close to the child and adolescent or to their siblings and parents, whereas the subjects on the right side generally can be considered to reflect the functioning and care activities in the environment of the child or family member.

The subject *quality of life* covers several concepts relating to physical and psycho-social adaptation or functioning. In addition, quality of life is often used as a general concept of well-being. This bibliography does not differentiate between different views on quality of life.

Social participation refers to distal aspects, such as leisure activities, school performance, friendships and the entrance to the labour market.

The consequences of a chronic illness obviously are diverse, varying from pain, functional restrictions, anxiety, adherence to a diet, medication use, to hospital admissions. These consequences can be considered additional tasks children and adolescents with chronic illnesses have to deal with to live a life that is as normal as possible. These 'dealing processes' can be summarised in the concept of *self management*, an overall concept referring to the individual's ability to manage and cope with the symptoms and physical and psychosocial consequences inherent in living with a chronic disease.ⁱⁱ Apart from self management, it was aimed to provide an overview of studies on the

patient and family perspective of *health care service*, including studies on the needs and utilisation of professional health care, as well as on the quality of care. In addition, it must be mentioned that utilisation of care is not only determined by patients' demands, but by the supply of care as well. This aspect of health care service, however, will not be addressed in this bibliography.

b Databases

Searches were conducted for the period of January 1995 - April 2003. The following databases were consulted:

Bibliographic databases:

1. Pubmed: This is a version of Medline, a database which has been set up by the National Library of Medicine of the United States and which contains references to articles of approximately 4300 scientific medical journals in many different languages. Pubmed also includes references to medical articles from non-medical periodicals.
2. Psychinfo, a database containing references to articles of approximately 1300 international journals, books, chapters and dissertations in different languages, in the discipline of psychology, and psychological aspects in medicine, psychiatry and nursing.
3. Cinahl, a database which contains references to English journal articles in the field of nursing and allied health care.
4. Sociological Abstracts, an international database containing references to articles of approximately 2500 journals in the disciplines of sociology, social psychology, political sciences and environmental studies.
5. ERIC, an international database containing references to articles, reports and dissertations in the field of educational science.

Catalogues, containing references to books, reports and journal articles, mostly in Dutch or English, of the following institutions:

6. Netherlands institute for health services research (NIVEL).
7. Netherlands Institute of Mental Health and Addiction (Trimbos Instituut).
8. Dutch Institute of Health Promotion and Prevention of Illness (NIGZ).
9. Dutch Council of the Chronically ill and the Disabled (CG-raad).
10. Netherlands Institute for Care and Welfare / Youth (Nederlands Instituut voor Zorg en Welzijn / Stichting Jeugdinformatie Nederland).
11. Dutch ministry of Health, Welfare and Sport (Ministerie van VWS).

12. Dutch ministry of Education, Culture and Science (Ministerie van OC &W).
13. Dutch ministry of Social Affairs and Employment (Ministerie van SZW).
14. TNO Prevention and Health (TNO Preventie en Gezondheid). In this database only references from the period 1995 – 1999 could be found, because the database has been closed at the beginning of 2000.

c Selection criteria

The following inclusion criteria were used:

1. The document deals with children, adolescents and/or young adults.
2. The document deals with a physical illness, with an expected illness duration of at least 6 months. Traumatic brain injury is included, if the criterion of a duration of at least 6 months is met.
3. The document deals with the patient and/or family perspective, that is how patients or family members experience the situation or what the consequences are for their personal or social situation.
4. The document has to be based on scientific research.
- 5a. The subject of research relates to quality of life, social position or health care needs, health care utilisation or quality of care from the patient's or family's perspective, or
- 5b. the subject of research relates to self-management, i.e. coping, compliance or self care, or intra- or extra-individual factors, such as self-esteem and parental protection, in relation to quality of life, social position or health care service.

The following criteria were used to exclude documents from the bibliography:

1. The document deals with clinical or medically oriented research.
2. The document deals with the epidemiology or aetiology of a chronic illness.
3. The emphasis lies on methodology or statistical methods. Studies on questionnaire development and evaluation were included when related to quality of life, social position or health care.
4. The study population is very specific, for instance "minorities in Africa".
5. The document is not based on scientific research.
6. The document deals with a population older than 24 years of age. Studies in adult population from the age of 18 years were also excluded.

7. The subject of research deals with information supply, patient education, intervention, treatment and health care strategies from the perspective of the health care worker.
8. Coping, or other intra- or extra-individual factors, when they are treated as a separate subject, thus not in relation to quality of life, social position or health care.
9. Remaining issues, like psychiatric problems, prevention or languages other than English, Dutch, German, Spanish and French.

d Search strategies

The complexity of search strategies depended on the database in which the search was performed. The framework for the search strategies that were conducted for this bibliography globally consisted of the following combinations:

1. the concepts 'children' and 'chronic illness'
2. the concepts 'children' and chronic diseases which are specific or common in children. These diseases are: cancer, leukaemia, haemophilia, AIDS, congenital heart disease, rheumatoid arthritis, muscular diseases, congenital nervous system diseases, spina bifida, epilepsy, migraine, asthma, eczema, endocrine diseases, celiac diseases, cystic fibrosis and diabetes.

Pubmed needed an extra restriction in the search strategy to prevent the search resulting in too many irrelevant titles. Therefore, the above mentioned global search strategy was restricted by the following concepts: quality of life, stress, patient satisfaction, family and social circumstances, educational and social status, health services needs and coping. The same restriction, for the same reason, was used in Psychinfo. Appendix 1 (see Volume 2, p.241) gives a global overview of the search profile.

e Search results

Process of selecting relevant documents

The first rough search results (hits) were screened by the documentalist by reading the abstracts. Irrelevant references were excluded on the basis of one of the exclusion criteria. However, not every reference allowed this kind of evaluation; therefore, selections were made of 'questionable references'. The first selections obtained in this way were then evaluated by the researcher.

For those references which were considered relevant the complete documents were applied for, as well as the documents relating to abstracts which could not be clearly classified as relevant. Documents that could be obtained (not all documents were available) were evaluated by the researcher. Questionable documents were evaluated by both the researcher and the documentalist.

Number of relevant documents

Table 1 shows the results for all searches, including the total number of titles (hits), the number of relevant titles and the number of relevant documents which appeared not to be available. Because of the large number of relevant documents, it was decided to exclude documents which are also referred to in included reviews. The references to these documents (n=46) are listed in Appendix 2 (see Volume 2, p.243), without abstracts or keywords. Table 1 also includes the number of documents that was excluded for this reason. Furthermore, some documents were found accidentally and considered relevant. These documents are mentioned under the database name 'browse'. Three documents which were published before 1995 were included because they were considered highly relevant. It must be mentioned that the number of included documents in Table 1 exceeds the real number of included documents, because several references were found in more than one database.

Table 1

Database name	Total number of hits	Relevant titles	Relevant documents not available	Relevant documents cited in reviews	Included in bibliography
Medline/Pubmed	1083	302	22	14	266
Psychinfo	1133	243	68	20	155
Cinahl	130	35	8		27
Sociological Abstracts	838	73	31	7	35
ERIC	691	30	15	1	14
Cat NIVEL	171	37		3	34
Cat Trimbos	15	6			6
Cat NIGZ	56	2			2
Cat NPCF/CG-raad	52	8			8
Cat Jeugdinformatic Nederland	45	7			7
Cat Min VWS	88	4		1	3
Cat Min OC&W	17	0			0
Cat Min SZW	103	2	1		1
Cat TNO-PG	49	5	1		4
Browse	4	4			4
Total number	4475	758	146	46	566

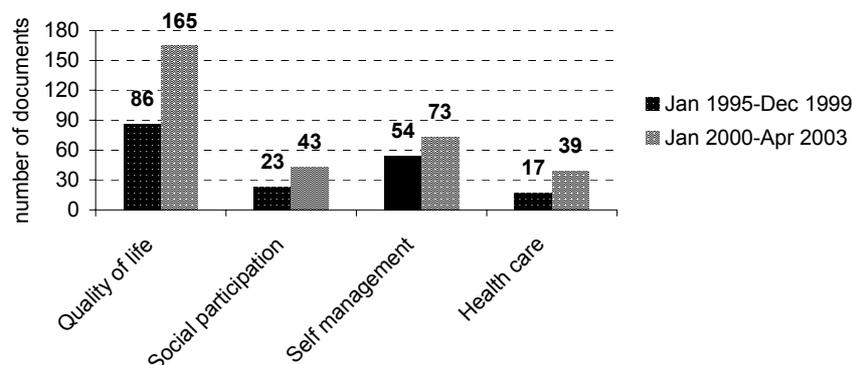
*Reasons for exclusion*ⁱⁱⁱ

The majority of the excluded documents (44 %) was excluded because of the age criterion (criterion number 6). Also, criterion number 9 ('other reasons') appeared to be frequently used (23 %), i.e. because the document dealt with prevention, mental disorders or diseases that are not chronic. Ten percent was excluded because of a health care worker's perspective, instead of the patient or family perspective (criterion number 7). Finally, 10% was excluded because it was not based on scientific research (criterion number 5).

Relevant documents distributed to period of publication

Figure 1 gives an overview of the number of relevant documents distributed to the period of publication. During the years 2000-2003 more scientific attention was paid to the subjects of this bibliography in comparison with the former period of 1995-1999. In total, 180 documents were found to be published in the period 1995-1999, whereas the number of documents found in the (shorter) period 2000-2003, amounts to 320. This increase concerns each topic.

Figure 1 Number of documents distributed to period of publication



f Review of the literature

Many documents included in this bibliography deal with different chronic diseases or with chronic illness in general (20%). In addition, frequently discussed chronic diseases are diabetes (15%), asthma (13%), cancer (10%), epilepsy (7%), cystic fibrosis (6%) and rheumatoid arthritis (4%). This leaves 45% of the documents in which other chronic diseases are subject of research, not seldom in only one document (n=30, 13%). All chronic diseases are listed in the subject index at the back of this bibliography (Volume 2). This paragraph shortly reviews the literature, using the schematic arrangement as a classification.

Quality of life

A majority of the documents covers the concept of quality of life: in 50% of the documents (n=251) quality of life-related topics have been investigated from the patient or family perspective.

Patient's perspective

In 106 documents, quality of life has been investigated from the perspective of children, adolescents and young adults.

15 Articles are based on *reviews*, of which 14 deal with generic measurement of quality of life. One review includes a combination of generic and disease-specific measures (in children with asthma). Seven reviews report on quality of life studies in chronic illness in general, the other reviews cover quality of life studies in children and adolescents with

epilepsy (two reviews), asthma (2 reviews), HIV/AIDS, leukaemia, diabetes and chronic arthritis (one review on each illness). One review, on asthma, turned out to be Dutch. With regard to quality of life aspects, many reviews (n=6) mainly report on psychological measures, e.g. psychological functioning, or anxiety and depression. Especially studies in children and adolescents with epilepsy were found to be focusing on (neuro)psychological functioning, i.e. depression, anxiety and locus of control. In most reviews, quality of life is reflected by a combination of outcome measures, such as psychosocial adjustment, psychosocial wellbeing or an overall measure of health-related quality of life.

Apart from the reviews, some documents are based on *theory or discussion* (n=5). One theory-related document discusses disease-specific quality of life aspects in children with cancer. The other documents deal with generic quality of life aspects. All documents discuss a combination of outcomes, like psychosocial problems or physical and psychological stress.

Most documents on quality of life from the patient's perspective are based on *empirical studies* (n=86). A few studies in this category (n=12) were found to concentrate on disease-specific measurement of quality of life: in children and adolescents with diabetes (four studies), cystic fibrosis (two), cancer (two) and with asthma, epilepsy, chronic arthritis and ischemic stroke (one study on each disease). In most of these studies a combination of aspects of quality of life has been investigated, e.g. clinical and psychological course, physical and cognitive outcome or life changes and well-being. In one study a more psychologically-oriented aspect is investigated, namely the attitudes of children towards diabetes.

The remaining studies in this category, a majority (n=74), deal with quality of life in a generic way, e.g. by means of the Child Behavioural Check List (CBCL), PedQol, How are You (HAY), Child Health Questionnaire (CHQ) or the TNO-AZL Children Quality of Life (TACQOL). Six documents are based on Dutch studies. Again, quality of life has been operationalised as a combination of psychological, social and physical measures or as a psychological concept.

► go to page 21 (Volume 1) and 3 (Volume 2) to find abstracts on quality of life, patient perspective.

Family's perspective

Almost just as many documents as in the former paragraph have used the family perspective in investigating quality of life issues in chronically ill children and adolescents (n=105).

Twelve documents are based on *reviews*: nine use generic measures, whereas three reviews are directed at disease-specific measurement: in children and adolescents with cancer (two reviews) and diabetes. Six reviews report on quality of life studies in several diagnostic groups, the other reviews cover quality of life studies in children and adolescents with diabetes (two reviews), cancer (two reviews), epilepsy and cystic fibrosis (one review on each illness). All reviews are foreign studies. As in the former paragraph on the patient perspective, these reviews mainly report on psychological measures or a combination of outcome measures. Furthermore, half of the reviews are purely directed at the quality of life of family members, like the impact of paediatric chronic illness on sibling psychological functioning. In the other half, quality of life has been assessed in both patients and their family, or relationships are investigated, i.e. the relation of parent and family functioning to the psychological adjustment of children with chronic health conditions.

Apart from review articles, some documents are based on *theory or discussion* (n=7). Like in the patient-oriented documents, one theory-related document discusses disease-specific quality of life aspects in children with cancer. The other documents deal with generic aspects. Two documents are directed at children or adolescents as point of departure, i.e. a discussion on the adjustment of children with chronic health conditions in relation to family functioning.

The remaining documents on quality of life from the family's perspective are based on *empirical studies*, the same number as in the former paragraph on the patient's perspective (n=86). Of these documents, 18 studies were found to use disease-specific measures of quality of life: in families with children and adolescents suffering from cancer (n=4), epilepsy (n=3), diabetes (n=2), chronic pain (n=2), from kidney disease or chronic renal failure (n=2), or from cystic fibrosis, spina bifida, thrombocytopenia, sickle cell disease and or congenital heart disease (one study in each illness). Half of these disease-specific studies are directed at family members, like the psychosocial functioning of parents. Seven out of 18 are Dutch studies, e.g. two studies on cancer, measuring the psychosocial functioning of parents of children who survived cancer, and the contribution of parental hope on the quality of life of children with spina bifida.

Finally, the majority (n=68) deals with generic quality of life aspects. In more than half of these studies, quality of life has been merely investigated in family members of children and adolescents with chronic illnesses using, for instance, the Impact on Family Scale (IFS). Only one study was found to be Dutch. Quality of life has been operationalised into psychological measures or as a combination of psychological, social and physical issues.

► go to page 43 (Volume 1) and 51 (Volume 2) to find abstracts on quality of life, family perspective.

Measurement

In total 40 documents on measurement aspects of quality of life in children and adolescents or in siblings or primary caregivers could be included, i.e. on development and validation of questionnaires. Three documents are based on *reviews*. These reviews deal with both generic and disease-specific measurement instruments, with the intention to measure quality of life aspects in children and adolescents with different chronic illnesses. All reviews are foreign studies.

Two documents comprise a *discussion*, one on the assessment of psychological aspects of having a chronic illness, the other on the disease-specific measurement of psychological functioning of children with cancer. Both discussions are directed at children and adolescents, the latter is a Dutch document.

In 14 documents a *disease-specific measurement* of quality of life has been investigated: four documents on quality of life measures in children and adolescents with epilepsy, four on cystic fibrosis, three in asthma, and three documents on disease-specific measurement in chronic pain, cancer, and cerebral palsy. Two studies are Dutch: one on chronic pain and one on cancer. Additionally, most of these studies are directed at the measurement of quality of life in children and adolescents.

However, the majority of the measurement documents deal with empirical studies on generic measurement of quality of life. The measurement instruments in these documents, again, are mainly developed or validated for use in children or adolescents, for instance, the Child Health Questionnaire (CHQ), the Child Behavioral Check List (CBCL) or the Short Form-36 (SF-36). Five documents are Dutch, for instance concerning the TNO-AZL Children Quality of Life (TACQOL), the Life Course Questionnaire and the Dutch version of How Are You (HAY). Six documents deal with generic measurement instruments focusing on the family, e.g. a Dutch study on the Impact on Family Scale (IFS).

► go to page 65 (Volume 1) and 95 (Volume 2) to find abstracts on quality of life measurement.

Social participation

Social participation covers 14% of this bibliography, which means that 68 documents were found dealing with topics relating to social participation.

Most studies used the patient perspective (n=55). Topics that are dealt with in these studies are school issues like academic achievement and school absenteeism (in 27 documents), peer relationships or friendship (in 20 documents), employment, labour participation, entrance on the labour market (in 13 documents), leisure or recreational activities (in seven documents), romantic relationships (marital status, partnership, sexual development) (in eight documents). In 10 documents social participation is investigated as a general concept (social performance, social adjustment, social activities, social interaction). Most documents are based on empirical studies; four documents are reviews of the literature. 17 Documents were found to be based on Dutch empirical studies.

Eleven documents were found with a family perspective as point of departure. Two studies and one review deal with a general concept of social participation, i.e. social adjustment, social activities or everyday functioning. Furthermore, in three studies leisure time activities is the subject, or one of the subjects, of research. Peer relations or social relationships is investigated in three studies as well. Also, three studies deal with work or employment. In two studies school performance is investigated (school absence, parents' concerns at school re-entrance of their child). Finally, one study on marital relationships and one socioeconomic study about the costs of disabilities in poor families was found. Ten documents, including the review, are foreign studies, one empirical study is Dutch.

Two foreign studies were found on measurement aspects. In one of these studies 'Living with a Chronic Illness' (LCI) is evaluated. This is a measurement instrument of the social functioning of children and adolescents with chronic medical conditions. The other study is on neuropsychological measurement of children's every day functioning ('real-world functioning') after traumatic brain injury.

► go to page 69 (Volume 1) and 118 (Volume 2) to find abstracts on social participation.

Self management

The subject of self management can be considered to cover the concepts coping, self care and compliance. In total, 128 documents (25% of this bibliography) could be categorised into these themes: 70 relating to coping and 58 relating to topics such as self care or compliance.

Coping

Coping is a complex concept which can be used in different ways, for example coping with a specific disease (disease-specific), situation specific coping (school exams) or generic coping, that is coping with stress and problems in general. No difference was made for this bibliography; if the concept of coping or adaptation process was subject of research in relation to quality of life, social participation of health care issues, the document was included.

In 32 documents the concept of coping has been investigated from the patient perspective. About half of these documents reports on the role of disease-specific coping, i.e. coping with cancer, coping with pain, or coping with a chronic illness in general (situation specific). One study focuses on coping with hospital experiences, a situational context as well. In the other documents, coping has been investigated in a generic way, mainly in comparative studies, such as in comparison with healthy peers, with normative samples or the use of coping strategies during health and illness. Six documents are Dutch, one of which is a review article. In total, four documents are based on reviews.

In more than half of the documents (n=38) the family perspective is used as framework of the study. Related aspects are coping strategies of the parents, coping patterns of the family or maternal perceptions of children's illness behaviour and attributions of this behaviour to chronic illness. Again, about half of the studies investigate specific disease-related or chronic illness-related coping strategies. In this respect, coping with the treatment of childhood cancer was interpreted as disease-related coping. In other comparative studies coping is used in a generic way, such as coping strategies within the family or family coping. No review article was found; all documents are based on empirical studies, or theoretical discussions (n=3). Four studies are Dutch.

► go to page 85 (Volume 1) and 147 (Volume 2) to find abstracts on coping.

Self care and compliance

From the 58 documents found on these themes, 34 could be classified as studies carried out from the patient perspective. Self care (or illness management, self management or health behaviour) often involves a kind of adherence, flexible or more strict. About half of the documents in this sub classification appeared to address topics relating more or less purely to drug adherence (or medication compliance), including two review articles and one

Dutch empirical study. The remaining articles are based on (not Dutch) studies investigating the broader concept of illness management behaviour, management strategies, or self care practices.

In about 40% (24 studies), compliance and self care has been investigated from the family perspective. In these studies the role of the family is central to the illness management or therapy adherence in their chronically ill children. For example, how parents cope with the challenges of childhood chronic illness, or what family characteristics facilitate and provide optimal home care. In most of the documents, the broader concept of illness management is investigated, only six documents address the concept of compliance or adherence more strictly. All abstracts are based on empirical studies, one of which is a Dutch study.

► go to page 107 (Volume 1) and 168 (Volume 2) to find abstracts on self care and compliance.

Health care service

In total, 56 documents (11%) could be classified into the health care service theme. 24 Documents are based on studies from the patient perspective, whereas 31 have used the family perspective as starting point. One study was found on measurement. To start with the *patient perspective*, about half of the documents address health care needs: special health care needs, needs perceptions and information needs. In addition, quality of care is investigated in nine documents. Related topics are: doctor-patient relationships, patient satisfaction, perceptions of care, satisfaction with received health care and experience with home care. Health service utilisation is subject of research in a few documents, e.g. use of physician consultation or consult frequency. Five documents are based on reviews; seven documents (of which one review article) are Dutch studies.

The same division was found in documents on health care service from the *family perspective* (n=31): in half of the articles health care needs are investigated. In these articles, the need for information, follow-up needs and the need for influence on care, for example involvement in home therapy, are addressed. In nine studies the quality of care was investigated, i.e. satisfaction with health care services and parents' perceptions of quality of care. Utilisation of health care was subject of research in 8 studies. Related topics are: hospital admission, rehospitalisation patterns and provision of care. In one document, the access to healthcare has been investigated. Four

documents are based on a review of the literature. Three documents (based on empirical studies) are Dutch.

One study on *measurement* of care needs was found: a German study to assess the validity of the 'self care' and 'mobility' scales of the Pediatric Evaluation of Disability Inventory (PEDI).

► go to page 117 (Volume 1) and 195 (Volume 2) to find abstracts on topics on health care service.

g Conclusion

This bibliography gives an overview of scientific studies on the daily functioning, self-management and health care needs and utilisation of chronically ill children and adolescents; it concerns studies that used the perspective of the child or adolescent with a chronic illness, or their family members. In total, 503 documents published between January 1995 and April 2003 could be included, covering a broad range of subjects relating to quality of life, social participation, coping, self care, compliance and health care service. The contribution of Dutch studies appeared to be nearly 13%, mainly covering quality of life and social participation topics.

Almost two thirds of the documents were published after the year 2000. It is, therefore, obvious that from a scientific point of view, the attention on daily life and health care issues from the perspective of chronically ill children and adolescents, or that of their family, has recently increased. In addition, the family perspective appears to be an important starting-point in studies into younger populations: ample 40% of the included studies investigated the impact of a chronic illness on the family system, or took the family system into account when measuring the impact of a chronic illness on children or adolescents. Especially in relation to coping and health care, relatively many studies have been carried out within a family perspective. Also, in quality of life studies, the family perspective was used in almost half of the studies.

As far as the type of chronic illness is concerned, a majority of the included documents (80%) focus on a particular chronic disease, leaving 20% of the documents dealing with more than one chronic illness or with chronic illnesses in general. Frequently discussed diseases are diabetes, asthma, cancer, epilepsy, cystic fibrosis and rheumatoid arthritis. Furthermore, half of the included documents deal with aspects of quality of life. Also, much scientific attention is focused on self-management topics (25%), such as coping and self care or compliance. Relatively little attention, so far, has been paid to social participation and health care issues: 14% and 11% of the

included documents focus on these subjects respectively. Social participation generally refers to (a combination of) topics relating to school performance, peer relationships, employment, romantic relationships or leisure activities. Studies on health care service mainly discuss needs and wishes; relatively little is known about health care utilisation.

Finally, 10% of the documents appeared to be based on review studies. Reviews were found within each category of the main classification. So far, however, no review has been conducted on self-management studies using a family perspective, on coping, on self care or on compliance. This is in contrast with empirical studies on coping in which the family perspective is more often used than the patient perspective.

In sum, scientific research on topics of this bibliography increased in the last few years. Much attention is paid on quality of life topics, whereas relatively few studies focus on social participation and health care service, in particular with regard to health care utilization. Reviews are needed in the field of self-management, especially on those studies that have used a family perspective.

h Arrangement of the bibliography and users guide

This bibliography consists of two volumes, divided in the periods 1995 – 1999 (Volume 1) and 2000 – 2003 (Volume 2). According to our schematic arrangement, the abstracts are classified into four main subjects: quality of life, social participation, self management and health care. Each paragraph is further divided into a patient perspective and a family perspective. In addition, the paragraph on self management covers the concepts of coping, and of self care and compliance, in separate subparagraphs. Furthermore, as documents on the measurement of quality of life, social participation and health care were included as well, separate subparagraphs have been integrated in the related paragraphs. Finally, this bibliography contains an authors index as well as a subject index. These indexes can be found at the back of Volume 2.

All documents are available in the NIVEL library. Abstracts from periodicals to which the NIVEL library has a subscription do not have a number. Those articles from periodicals to which the NIVEL library is not subscribed have C-numbers. Additionally, books have B-numbers and reports have R-numbers. These numbers correspond with the numbering of the NIVEL library.

Notes

- ⁱ Patterson, JM. (1998). Chronic illness in children and the impact on families. In: Chilman CS, Nuwally EW & Cox FM (Eds.). *Chronic illness and disability: families in trouble series* (vol. 2 (pp. 69-107)). Newbury Park, CA: Sage.
- ⁱⁱ Definition derived from: Lorig KR. Chronic disease self-management: A model for tertiary prevention. *American Behavioral Scientist*, 1996; 39: 676-683. See also: Lorig KR, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter Ph, Gonzales VM, Laurent DD & Holamn HR. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. A randomized trial. *Medical Care*, 1999; 37: 5-14.
- ⁱⁱⁱ This bibliography has been conducted in two phases. The reasons for exclusion concern the second phase, relating to documents which have been published between January 2000 – April 2003 (47% of the total number of hits, i.e. included and excluded documents together).

Abstracts

1 Quality of life

1.1 *Quality of life from the patient's perspective*

Admi H. Growing up with a chronic health condition: a model of an ordinary lifestyle. *Qualitative Health Research*, 1996; 6(2): p.163-183
NIVEL: C 6381

The aim of this descriptive, exploratory study was to gain insight into how young people experience growing up with cystic fibrosis (CF). The retrospective, longitudinal, life-history method was used to generate grounded theory from 60 accounts by 21 informants (10 with CF and 11 of their family members). Data from in-depth interviews were analysed using constant comparative method. An ordinary lifestyle model emerged. Youngsters with CF maintained a dynamic balance between their own perceptions of the disease, others' perceptions of them, and the influence of contextual factors. The disease was found to be of little centrality to their psychosocial lives, and their illness perception followed developmental changes. Managing disease-related information was related to the perceived ability of the listeners to deal with the information and the situational context. The model was compared with competing models, and implications for health care practice and research are discussed.

Language: English

Keywords: Cystic fibrosis / Adolescents / Young adults / Quality of life / Social adjustment / Explanatory models

Alderman EM, Lauby JL, Coupey SM. Problem behaviors in inner-city adolescents with chronic illness. *Journal of Developmental and Behavioural Pediatrics*, 1995; 16(5): p.339-344
NIVEL: C 6384

The aim of this study was to examine the prevalence of behavioural problems like sexual activity, substance use, delinquency, and school failure in adolescents with chronic diseases. A clinical hospital-based sample of 217 inner-city 14 to 17 year olds with a variety of serious, chronic medical illnesses was studied and compared with a group of 121 similar-aged,

healthy friends with no known chronic illnesses living in the same community. No differences were found between groups in substance use, delinquency, percent who had ever had sexual intercourse, or mean age at first intercourse. There was a significant interaction effect of chronic illness and gender on age at first intercourse ($p = .015$); boys without chronic illness initiated sexual intercourse at a younger age than their girlfriends without illness. Contrary to expectations, significantly more of the healthy friends had repeated a grade in school than had those with chronic illness ($p = .002$). Results are discussed in terms of the interrelationships of chronic illness, gender, and environment on problem behaviours.

Language: English

Keywords: Chronic diseases, general / Adolescents / Behaviour problems

Boice MM. Chronic illness in adolescence. *Adolescence*, 1998; 33(132): p.929-939
NIVEL: C 6392

The aim of this review is to give an overview of the literature on chronically ill adolescents. Social issues, like family relations and coping strategies, psychological issues, like psychological stress, emotional problems and mental disorders, and cognitive issues, like cognition disorders and academic problems, are discussed.

Language: English

Keywords: Chronic diseases, general / Adolescents / Family relations / Coping / Psychosocial problems / Cognition disorders / Reviews

Burke P, Elliott M. Depression in pediatric chronic illness: a diathesis-stress model. *Psychosomatics*, 1999; 40(1): p.5-17
NIVEL: C 6396

The aim of this review is to give an overview of studies on depression in pediatric chronic illness. It is suggested that a diathesis-stress model can be a fruitful heuristic that would incorporate illness characteristics and attributes of the child and environmental effects in an overall framework to guide future research and treatment.

Language: English

Keywords: Chronic diseases, general / Depression / Psychological stress / Explanatory models / Reviews

Bussing R, Aro H. Youth with chronic conditions and their transition to adulthood: findings from a Finnish cohort study. *Archives of Pediatrics & Adolescent Medicine*, 1996; 150(2): p.181-186
NIVEL: C 6398

The aim of this study was to explore the effect of chronic health conditions in adolescence on eventual transitional paths and young adult functioning in a cohort of Finnish youths. A survey was carried out in school at age 16 followed by a postal questionnaire at age 22. Youths who had reported persistent chronic conditions at ages 16 and 22 were compared with peers without chronic health conditions, using two-way analysis of variance for continuous outcomes and logistic regression models for dichotomous outcomes, adjusting for socioeconomic differences. Main outcome measures were health status, chronic conditions, personal characteristics (including self esteem), health behaviour, education, family background, personal relations, and depression. Adolescents with chronic health conditions attained levels of psychosocial well-being, education, and marriage or dating as young adults similar to their peers without chronic conditions. Most of them experienced a successful transition to adulthood. Females with chronic conditions were more likely than women without chronic conditions to have moved away from their family of origin and to be living with a spouse or steady partner. These findings also suggest that males with chronic conditions from white-collar family backgrounds may be at increased risk for symptoms of depression in early adulthood. Youths with chronic conditions had similar rates of nicotine and alcohol consumption as their healthy peers. These findings suggest that in this cohort, most adolescents with common chronic conditions had a successful transition to adulthood.

Language: English

Keywords: Chronic diseases, general / Adolescents / Young adults / Quality of life / Health status / Academic achievement / Peer relations

Chaney JM, Mullins LL, Uretsky DL, Pace TM, Werden D, Hartman VL. An experimental examination of learned helplessness in older adolescents and young adults with long-standing asthma. *Journal of Pediatric Psychology*, 1999; 24(3): p.259-270
NIVEL: C 6400

The objective of this study was to examine the effects of experimentally induced learned helplessness in older adolescents and young adults with long-standing asthma. Thirty-nine participants (18-24 years of age) with

histories of long-standing asthma (AS) and an age-matched healthy cohort (HC) (N = 94) received either contingent or noncontingent feedback on an experimental task. Participants' anagram-solving performance was assessed following the experimental procedure. Participants also completed a measure of depression and pretest-posttest measures of mood, expectancy, and attributions related to experimental task performance. The AS participants demonstrated significantly greater problem-solving deficits following response-noncontingent feedback, compared to the HC group. Further, whereas both AS and HC participants made more internal performance attributions when given response-contingent feedback, only AS participants demonstrated a pattern of increased internal attributions (i.e., self-focus) following response-noncontingent failure. In addition, 21% of AS participants met DSM-IV criteria for major depression, compared to only 5% of the HC group. It can be concluded that individuals with long-standing asthma may be at increased risk for depression and for learned helplessness deficits, specifically impaired problem solving, in response to environmental noncontingency. Results are discussed in terms of both learned helplessness theory and perseverative self-focus conceptualizations of depression. The implications for both short- and long-term management of pediatric asthma are also discussed.

Language: English

Keywords: Asthma / Adolescents / Young adults / Depression / Risk factors / Coping

Coniglio SJ, Blackman JA. Developmental outcome of leukemia.

Topics in Early Childhood Special Education, 1995; 15(1): p.19-31

NIVEL: C 6406

The aim of this review is to present the results of studies on developmental issues concerning pre-school children who are treated for acute lymphoblastic leukaemia. Studies are categorised according to outcome measures used: (a) IQ or scholastic achievement tests, (b) neuropsychological performance tests, (c) memory or attention tests, and (d) psychosocial evaluation measurements. In each of these categories, evidence exists that preschool children treated for leukaemia are at high risk for developmental difficulties. Suggestions are offered for developmental surveillance and educational interventions.

Language: English

Keywords: Leukaemia / Pre-school children / Cognition disorders / Psychosocial problems / Developmental disorders / Reviews

Dorchy H, Olinger S. Bien-être des diabétiques insulino-dépendants: évaluation chez 100 adolescents et adultes jeunes en fonction de leur contrôle métabolique. (The well-being of diabetic and insulin-dependent adolescents and young adults in relation to their metabolism control.)

La Presse Médicale, 1997; 26(30): p.1420-1424

NIVEL: C 6416

The purpose of this study was to evaluate the well-being of diabetic adolescents and young adults in relationship with their glycated hemoglobin (HbA1c) levels and other characteristics. A total of 100 unselected subjects (73 men and 44 women), with a mean age of 21 years (14-38) and a mean diabetes duration of 12 years (0-26), were included in the study over a 3 month period. Mean age at onset of diabetes was 10 years. Twenty-five percent of the patients were of Moroccan origin. All the patients were autonomous for self-management and treatment. Their socioeconomic status was not different from that of the normal population. The mean annual HbA1c level in the 100 diabetic patients was 7.3 (4.7-11.7). Well-being was measured using a questionnaire developed by a working group of the World Health Organisation, International Diabetes Federation and St Vincent Declaration. The questionnaire included 4 subscales labelled depression, anxiety, energy and positive well-being. The measurement of all 4 subscales involved 22 items and allowed an estimation of general well-being. General well-being in women was not as good as in men due to a greater tendency toward depression. Well-being was better in patients with a professional activity than in the others. Patients age, duration of diabetes, number of insulin injections, frequency of home blood glucose monitoring, presence of 1 or 2 subclinical complications, had no effect on well-being. On the other hand, well-being was negatively correlated with the HbA1c levels: higher the HbA1c, higher the anxiety and the depression, and lower the energy and the positive well-being. Well-being was mainly associated with HbA1c levels; it improved with better glucemic control.

Language: French

Keywords: Diabetes mellitus / Adolescents / Young adults / Quality of life / Health status

Drotar D, Agle DP, Eckle CL, Thompson PA. Impact of repressive personality style on the measurement of psychological distress in children and adolescents with chronic illness: an example from hemophilia. *Journal of Pediatric Psychology*, 1996; 21(2): p.283-293

NIVEL: C 6419

The aim of this study was to describe the impact of the repressive personality style on the measurement of psychological distress among children and adolescents with haemophilia. Two groups were compared on parent and self-report measures of anxiety and depression: a nondefensive group (n = 34) with low distress; and a highly defensive group (n = 26) who were identified as having a repressive personality style and who also reported low distress. Consistent with hypotheses, highly defensive children reported comparable levels of anxiety and lower levels of depression than nondefensive children. On the other hand, mothers of highly defensive children and adolescents described them as more distressed than mothers of nondefensive (self-assured) children. Findings underscore the importance of including data from other informants (e.g., parents, teachers, or peers) to avoid misleading findings based on self-reports of anxiety and depression obtained from highly defensive children.

Language: English

Keywords: Haemophilia / Psychological stress / Personality / Anxiety / Depression / Questionnaires

Faro B. The effects of diabetes on adolescents' quality of life. *Pediatric Nursing*, 1999; 25(3): p.247-253, 286, 267-269
NIVEL: C 6424

The purpose of this study was to assess the impact of diabetes on overall quality of life (QOL) in adolescents. A pilot study was conducted in which 23 adolescents (12-16 years old) participated. The impact of diabetes on daily life, satisfaction with life, and common worries and frustrations were explored through the Diabetes Quality of Life for Youth scale (DQOLY) and semistructured interviews. The four major themes that emerged from the interviews were (a) restrictions, (b) differentness, (c) negative emotion, and (d) adaptation. Adolescents reported being most bothered by dietary restrictions, including the regimentation/scheduling of eating and its social ramifications. Adolescents in this study worried the most about the future and, in particular, complications. Older adolescents worried less, had lower Diabetes Impact scores, and had better Quality of Life scores on the DQOLY. The theme of adaptation and the negative emotion theme were both expressed most often by participants who had had diabetes for a longer period of time.

Language: English

Keywords: Diabetes mellitus / Adolescents / Quality of life / Psychological stress

Frank RG, Thayer JF, Hagglund KJ, Vieth AZ, Schopp LH, Beck NC, Kashani JH, Goldstein DE, Cassidy JT, Clay DL, Chaney JM, Hewett JE, Johnson JC. Trajectories of adaptation in pediatric chronic illness: the importance of the individual. *Journal of Consulting and Clinical Psychology*, 1998; 66(3): p.521-532
NIVEL: C 6428

The aim of this study was to examine individual difference and group difference models of adaptation in children with chronic illness. The adaptation of 27 children with juvenile rheumatoid arthritis (JRA) and 40 children with insulin-dependent diabetes mellitus (IDDM) was tracked for 18 months from diagnosis. A control group of 62 healthy children was followed over the same time period. Clustering procedures indicated that child and family adaptation could be described by a number of distinct adaptation trajectories, independent of diagnostic group membership. In contrast, parental adaptation trajectory was associated with diagnostic group membership and control over disease activity for the JRA group and with diagnostic group membership for healthy controls. The observation of common patterns across trajectory sets, as well as the finding that trajectories were differentially related to a number of variables of interest, support the use of trajectories to represent adaptation to chronic disease.

Language: English

Keywords: Rheumatoid arthritis / Diabetes mellitus / Coping / Parents / Family relations / Behaviour problems / Health status

Fukunishi I, Kudo H. Psychiatric problems of pediatric end-stage renal failure. *General Hospital Psychiatry*, 1995; 17(1): p.32-36
NIVEL: C 6431

The aim of this study was to examine psychological problems in children with end-stage renal disease (ESRD). A sample of 53 children with end-stage renal disease (26 children on continuous ambulatory peritoneal dialysis and 27 children with kidney transplants) was compared to a matched sample of 27 healthy children. Seventeen of the children on dialysis (65.4%) exhibited separation anxiety disorder, which was associated with the family psychological environment. After receiving kidney transplantation, school maladjustment continued, and adjustment disorder was seen in eight children (29.6%). The adjustment disorder was related to poor relationships with peers at school.

Language: English

Keywords: Kidney disease / Kidney transplantation / Mental disorders / School absenteeism / Peer relations

Gardiner P. Social and psychological implications of diabetes mellitus for a group of adolescents. *Practical Diabetes International*, 1997; 14(2): p.43-46
NIVEL: C 6433

The aim of this study was to examine the attitudes of young adults with diabetes towards their illness. The adolescents' own views were explored, using a questionnaire. Unlike previous studies, attitudes proved generally positive: 97.5% felt normal or only slightly different from non-diabetics. This correlated with how long they had had diabetes and their view of their diabetes control; 55% perceived control as excellent or good, and this related to frequency of blood-monitoring. Only seven individuals thought their families were overprotective. The data suggested a series of stages of acceptance, with a period of rejection sometimes occurring one to five years after diagnosis. Ten individuals (25%) found injections trying and claimed monitoring limited spontaneity. Twelve adolescents described weight problems; these were related to gender. Twelve monitored less than once daily and 11 frequently consumed unsuitable foods. Only 14 had considered future health prospects. Thirty two would prefer to attend specialist adolescent clinics.

Language: English

Keywords: Diabetes mellitus / Adolescents / Young adults / Attitude / Self esteem / Patient compliance / Family relations / Self care

Ginsburg AJ, Klonoff EA, Russo DC. Psychological and behavioral sequelae in children with chronic disease: an interactional model. In: Caddy GR, Byrne DG (eds). *Behavioral Medicine. International perspectives*. Volume 3. Norwood, New Jersey: Ablex Publishing Corporation, 1995: p.237-260
NIVEL: C 6436

In reviewing the psychological literature on chronic childhood illness, two distinct and dichotomous approaches appear. Historically, the literature focused on the identification of personality traits and psychiatric characteristics of a child and his or her family that presumably predisposed that child to illness. In contrast, more recent studies have utilised an interactional or biopsychosocial model to explain the impact of chronic

illness on children and families. Rather than focusing on identifying a psychiatric abnormality, this model assumes that the child with chronic illness has the potential to develop normally. Failure to do so is the result of specific, learned, maladaptive behaviours, as opposed to personality traits, that impact subsequent developmental tasks. In this book chapter, an attempt is made to outline the potential impact of this interactional model. First, a brief review attempts to address some of the weaknesses in the traditional “psychosomatic model”. Following this, the authors address the empirical support for an interactional and biopsychosocial model of chronic disease in children. In addition, they review data to support their contentions that, beyond limitations imposed directly by the disease itself, there exists no a priori basis on which to rule out developmental normalcy in children with chronic disease. Finally, the implications for treatment and research that derive from this interactional model are addressed.

Language: English

Keywords: Chronic diseases, general / Mental disorders / Psychological stress / Family relations / Explanatory models / Reviews

Kater AP, Heijboer H, Peters M, Vogels T, Prins MH, Heymans HSA. Kwaliteit van leven bij kinderen met sikkelcelziekte in Amsterdam. (Quality of life in children with sickle cell disease in Amsterdam.) *Nederlands Tijdschrift voor Geneeskunde*, 1999; 143(41): p.2049-2053

This study was aimed at exploring the differences in quality of life between children with sickle cell disease and healthy children from ethnic minorities. Quality of life was measured in children with sickle cell disease between the ages of 5 and 15 years who were under treatment in the Emma Kinderziekenhuis AMC, the Children Hospital, at Amsterdam. Questionnaires were used to be filled in either by the parents of children from 5 to 11 years, or by the children between 8 and 15 years of age. 45 Questionnaires were filled in. The results were compared with those of the healthy control group from ethnic minorities. Children with sickle cell disease and their parents scored significantly lower in the subscales regarding physical ability, mobility and independent functioning and in the subscale on the occurrence of negative moods. The subscales on the cognitive functioning, school results, social functioning and the occurrence of positive moods did show no significant differences. Concluded was that sickle cell disease in children causes reduced physical ability and may cause children to feel less happy in life; also, children with this disease feel that

they cannot function as independently as their healthy peers from ethnic minorities. Deterioration in the cognitive and social aspects of their quality of life has not been found.

Language: Dutch

Keywords: Sickle cell disease / Quality of life / Ethnic minorities / Health status / Psychosocial problems / Academic achievement / Daily life activities

Kokkonen J, Vainionpää L, Winqvist S. Physical and psychosocial outcome for young adults with treated malignancy. *Pediatric Hematology and Oncology*, 1997; 14(3): p.223-232

NIVEL: C 6458

The aim of this study was to examine the physical, neurological, neuropsychological, social, and psychiatric circumstances of young adults who had survived a malignant disease during childhood. A group of 27 (10 females, 17 males) patients at the ages of 16-26 years participated in this study. Twenty survivors had had leukaemia and the rest different solid tumours. Only a third (31%) of the subjects were considered to be without any clinically significant physical health problems or functional symptoms, musculoskeletal and endocrinological disorders being the most common. In the neuropsychological test panel including verbal and performance IQ the survivors had significantly lower scores. Early onset of the disease and receiving radiotherapy correlated with impaired test results most significantly, especially on memory functions. One in five of the survivors reported having suffered from reading and writing problems that interfered with success in school and the subjects of the study group had progressed to high school less often than control subjects. The social indices indicated delayed development of sexuality and separation from parents. Overt mental problems appearing at a one-off interview were the same as in the control group. In conclusion, up to two thirds of the childhood cancer survivors as young adults still have physical or neuropsychological health problems and half showed delayed psychosexual maturation. This magnitude of various disorders indicates a long-term but individually oriented follow-up of this small group with the opportunity of physical, social, or psychological management of their main problem.

Language: English

Keywords: Cancer / Leukaemia / Young adults / Health status / Cognition disorders / Academic achievement / Sexual development

Kokkonen J, Kokkonen E-R. Psychological and somatic symptoms in young adults with chronic physical diseases. *Psychotherapy and Psychosomatics*, 1995; 64(2); p.94-101
NIVEL: C 6459

The purpose of this study was to examine whether a long-term physical illness since childhood increases the risk of experiencing psychological and somatic symptoms. A group of 487 patients aged 20-25 years was interviewed and the findings were compared to 211 controls. Both somatic ($\chi^2 = 9.11$, d.f. = 6, $p < 0.001$) and psychological ($\chi^2 = 11.0$, d.f. = 6, $p < 0.001$) symptom indexes varied significantly between the patient groups. Female sex, family conflicts during childhood, poor scholastic performance and depressive mental disorders were especially observed to be significant risk factors related to an excessive occurrence of these symptoms. The results suggest that a disabling disease lasting from childhood until adulthood is complicated by a significant incidence of both psychological and somatic symptoms.

Language: English

Keywords: Chronic diseases, general / Young adults / Psychosomatic problems / Risk factors

Kyngäs H, Barlow J. Diabetes: an adolescent's perspective. *Journal of Advanced Nursing*, 1995; 22(2): p.941-947

The aim of this study was to investigate how adolescents with insulin dependent diabetes mellitus (IDDM) give meaning to and perceive the impact of their illness. An exploratory study was conducted in which 51 Finnish adolescents aged between 13 and 17 participated. Interview data were examined using continuous comparative analysis. The personal meaning of IDDM was described using the following categories: a habit; a little devil; a nightmare; stress; prison; death; and hell. A core concept to emerge was that of control. Young people felt IDDM controlled, or limited, their freedom and independence. Two main themes emerged in terms of the impact of IDDM in the lives of adolescents: a threat to life's equilibrium and a healthy lifestyle. Diabetes was viewed as a threat to physical, psychological and social well being which disrupted the balance of life. In contrast, the other main category, a healthy lifestyle, revolved around the notion that having IDDM offered a unique opportunity to live a healthy life. The results provided a useful insight into the personal meaning of IDDM and

serve to raise awareness of the problems and difficulties experienced by adolescents with this condition.

Language: English

Keywords: Diabetes mellitus / Adolescents / Quality of life / Sick role / Health behaviour

Leung SS, Steinbeck KS, Morris SL, Kohn MR, Towns SJ, Bennett DL. Chronic illness perception in adolescence: implications for the doctor-patient relationship. *Journal of Pediatrics and Child Health*, 1997; 33(2): p.107-112
NIVEL: C 6464

The aim of this study was to describe the interrelationship of chronic illness severity as perceived by adolescents with both psychosocial well-being and objective measures of illness severity and additionally to compare the adolescents' perception of illness severity with how their physicians believe that the adolescents perceive their illness severity. The psychological well-being of 48 adolescents with either cystic fibrosis (CF) or insulin dependent diabetes mellitus (IDDM) was measured by four standardised questionnaires. The adolescents' perception of severity of illness was measured using an original instrument (PSCI), and this measure was compared to their physicians' estimates of how the adolescents perceived the severity of their illness and clinical illness. There were 24 patients in both the CF and IDDM groups. Both groups were found to function well psychosocially; although, there were more patients with low self image compared to normative values. Depression and low self image were associated with a greater adolescent perception of illness severity. For both chronic illness groups, physicians' assessment of assumed adolescent perception of disease severity correlated with clinical indices of disease severity and was higher than the perception of illness severity reported by the adolescents. For adolescents with CF, but not with IDDM, perception of severity of chronic illness correlated with clinical indices. For adolescents with chronic illness, their perception of illness severity is an important indicator of psychosocial well-being. Physicians do not accurately infer their patients' perception of illness severity.

Language: English

Keywords: Cystic fibrosis / Diabetes mellitus / Adolescents / Sick role / Health status / Psychosocial problems / Doctor-patient relations

Mastroyannopoulou K, Sclare I, Baker A, Mowat AP. Psychological effects of liver disease and transplantation. *European Journal of Pediatrics*, 1998; 157(10): p.856-860
NIVEL: C 6468

The aim of this study was to investigate the psychological adjustment in children with liver disease. Three groups of children, aged 6-15 years, participated: ten had undergone a liver transplant (Gp1), 15 had ongoing chronic liver disease (Gp2) and 15 were healthy controls (Gp3). Children who had had a transplant appeared well adjusted and thought of themselves as healthy rather than ill, although areas of vulnerability were present, for example increased anxiety. No differences emerged in terms of coping with common or illness-related problems or understanding of the causes of illness and use of medication. Gps 1 and 2 showed higher levels of understanding of the functions of the liver but less understanding of illness prevention when compared to their healthy peers. Gp2 experienced less control over their health when compared to the other two groups. Gp1 rated themselves as more "healthy" than Gp2 but less so than Gp3. Children with chronic liver disease are able to communicate how they deal with the stresses of the condition. Though well adjusted in many ways, those who have had a transplant still show areas of psychological vulnerability which need to be addressed in clinical practice.

Language: English

Keywords: Liver disease / Liver transplantation / Quality of life / Psychological stress / Coping

Mullins LL, Chaney JM, Pace TM, Hartman VL. Illness uncertainty, attributional style, and psychological adjustment in older adolescents and young adults with asthma. *Journal of Pediatric Psychology*, 1997; 22(6): p.871-880
NIVEL : C 6472

The purpose of this study was to examine the psychological adjustment in a college sample of older adolescents and young adults (n = 49) with histories of childhood asthma. A substantial number of subjects evidenced clinically significant levels of overall distress. In addition, greater perceived asthma uncertainty and increased stable attributions for negative events were significantly associated with poorer psychological adjustment after controlling for demographic and disease variables. Further analyses revealed a moderating influence of uncertainty on attribution-adjustment

relationships. These findings provide initial support for a cognitive diathesis-stress view of adjustment in long-standing asthma. Results also support a growing body of evidence suggesting that the focus of efforts to enhance adjustment to asthma needs to be expanded beyond childhood and early adolescence.

Language: English

Keywords: Asthma / Adolescents / Young adults / Psychosocial problems / Psychological stress / Coping

O'Halloran CM, Altmaier EM. Awareness of death among children: does a life-threatening illness alter the process of discovery? *Journal of Counseling & Development*, 1996; 74(3): p.259-262

NIVEL: C 6474

The aim of this review is to present studies on death awareness among children who are healthy, chronically ill, and terminally ill. The results of the studies suggest that children with life-threatening diseases demonstrate increased understanding of death compared with children who are healthy or chronically ill. In particular, children with terminal illness, especially during the end stage of their disease, show an advanced understanding of the death concepts of irreversibility and finality. In contrast, healthy and chronically ill children appear to require certain age, cognitive development level, or intelligence thresholds to understand these concepts. Possible explanations for these findings are discussed. The implications for death awareness research for counsellors are used as a base for suggesting counselling strategies.

Language: English

Keywords: Chronic diseases, general / Terminal illness / Death / Attitude / Reviews

Patterson J, Blum RW. Risk and resilience among children and youth with disabilities. *Archives of Pediatrics and Adolescent Medicine*, 1996; 150(7): p.692-698

NIVEL: C 6478

The aim of this review is to present the results of studies on risk and protective factors as applied to children with chronic and disabling conditions so as to assist the health care professional in developing clinical strategies and interventions. Both risk and protective factors can be identified at multiple levels: the condition, the child, the family, and the

community. Conditions that are invisible have remitting-relenting courses, and where the prognosis is uncertain, these conditions are associated with the greatest emotional problems. Males with chronic conditions appear to have more emotional sequelae than do females. Likewise, personality characteristics of sociability and flexibility and physical characteristics of attractiveness are protective. Families with clear boundaries and a capacity to balance competing family needs, maintain flexibility, and ascribe positive meanings to life events all are protective. As increasing numbers of children with chronic conditions survive through adolescence to adulthood, the creation of environments where children can optimally develop becomes ever more pressing. It is evident that a range of factors, many amenable to interventions, can influence outcomes for these young people.

Language: English

Keywords: Chronic diseases, general / Psychosocial problems / Risk factors / Reviews

Roberts CS, Severinsen C, Carraway C, Clark D, Freeman M, Daniel P. Life changes and problems experienced by young adults with cancer.

Journal of Psychosocial Oncology, 1997; 15(1): p.15-25

NIVEL: C 6482

The aims of this study were: 1) to describe specific problems reported by young adult cancer patients, 2) to assess the life changes associated with the cancer, and 3) to examine the patients' well-being. Forty-six young adult cancer patients aged 22 to 35 years were surveyed regarding life changes and specific problems they had experienced. The majority of respondents were female, college educated, and married. Although nearly three-fourths of the respondents had completed treatment and were free of symptoms, they rated anxiety about their health and recurrence of their disease as their most stressful problems. Most were worried about their children's future and risk of cancer. Other concerns were physical and financial problems and changes in their life goals. The respondents' scores on the Brief Symptom Inventory showed a moderate elevation of psychological symptoms compared with test norms. The authors conclude that young cancer patients, who have little experience with poor health and confrontation with mortality, may need more psychosocial intervention to deal with existential concerns regarding themselves and their children.

Language: English

Keywords: Cancer / Young adults / Survivors / Psychological stress / Quality of life

Rydström I, Dalheim Englund A, Sandman P. Being a child with asthma. *Pediatric Nursing*, 1999; 25(6): p.589-590, 593-596, 616
NIVEL: C 6486

The purpose of this study was to explore the subjective experiences of children with asthma. Unstructured interviews were conducted with 14 children with asthma in Sweden. The data were analysed using a phenomenological hermeneutic method. The results showed that the children strived to live normal lives. Sometimes they felt that they were participants in everyday life; other times they felt like outsiders. As participants, they felt confident in their own knowledge, in other people's wish to help, and that medicine would help. As outsiders, they felt deprived, guilty, lonely, anxious, and fearful. Results were interpreted from an ecosophic as well as an existential perspective.

Language: English

Keywords: Asthma / Sick role / Coping / Quality of life

Schuttinga-Helder J, Tuinstra J, Groothoff JW, Post D. Zelfwaardering, chronische aandoeningen en de invloed van sociaal-economische status bij jongeren. (Self esteem, chronic diseases and socioeconomic influences in adolescents.) *Tijdschrift voor Jeugdgezondheidszorg*, 1996; 28(1): p.8-12
NIVEL: C 6491

This article describes a study into the relationship between chronic diseases, self esteem and socioeconomic status in adolescents from the provinces of Groningen, Friesland, Drenthe and Overijssel. Data have been collected at schools from 2000 adolescents, who have filled in a selfreport questionnaire. Self esteem of adolescents with chronic diseases turn out to be significantly lower than that of adolescents without chronic diseases. However, this only applies to boys, whereas girls are not affected in this respect by their chronic diseases. Girls turn out to have significantly lower self esteem than boys. An explanation for this difference cannot be found in literature. Socioeconomic status, divided in accordance with the education of the mother, show to be related to self esteem, i.e. higher education of the mother means higher self esteem of the child. This is true for both adolescents with chronic diseases and adolescents without chronic diseases, whether they are boys or girls. The educational level of the father does not show any relation to the self esteem of the child. The prevalence of chronic diseases in this study is striking, as 38% of the studied adolescents report to suffer from one or more chronic

diseases. This is a high percentage compared to other studies. It could be concluded that the percentage of adolescents with chronic diseases is higher in the north of the Netherlands than in the south, but this conclusion would be too hasty based on this study.

Language: Dutch

Keywords: Chronic diseases, general / Adolescents / Self esteem / Socioeconomic factors / Sex differences

Stawski M, Auerbach JG, Barasch M, Lerner Y, Zimin R, Miller MS. Behavioral problems of adolescents with chronic physical illness: a comparison of parent-report and self-report measures. *European Child and Adolescent Psychiatry*, 1995; 4(1): p.14-20
NIVEL: C 6505

The aim of this study was to examine the extent of behaviour problems in chronically ill adolescents. A comparison was made between parent-reported and self-reported behavioural symptomatology using the Child Behavior Checklist (CBCL) and the Youth Self-Report (YSR). Hundred-three outpatients, aged 11-16 years, suffering from cystic fibrosis (CF), asthma, or haematological/oncological conditions were assessed. Healthy adolescents and adolescents referred for psychiatric assessment comprised the comparison groups. Parent- and self-reports were significantly positively correlated in each group (all chronically ill children $r = .22$; Healthy group $r = .27$; psychiatric group $r = .50$), but the correlations were particularly low (and non-significant) in younger adolescents with haematological/oncological conditions or HCF., pointing to the need for physicians to include parents' and adolescents' viewpoints in their assessments of these adolescents' psychosocial state. The mean number of parent-reported and self-reported behaviour problems in the illness groups was no different from that of the Healthy group but significantly lower than that of the psychiatric group.

Language: English

Keywords: Cystic fibrosis / Asthma / Cancer / Adolescents / Behaviour problems

Storkebaum S. Psychische Belastungen bei angeborenen Herzfehlern. (Psychological burdens on patients with congenital heart diseases.) *Herz*, 1999; 24(6): p.476-483
NIVEL: C 6507

This article addresses the psychosocial problems of adults and young adults with congenital heart diseases. Psychosomatic chronification should be added to the chronic somatic illness, success in school education, job and survival have psychic impacts. Depression, neuroticisms and problematic relationships load a burden on patients and their environment as well as on doctors and nurses.

Language: German

Keywords: Congenital heart defects / Adolescents / Young adults / Psychosocial problems / Family relations / Coping

Stuber ML, Kazak AE, Meeske K, Barakat L. Is posttraumatic stress a viable model for understanding responses to childhood cancer? *Child and Adolescent Psychiatric Clinics of North America*, 1998; 7(1): p.169-182
NIVEL: C 6508

This article addresses the evidence for the utility of a trauma model for understanding the long-term impact of childhood cancer on survivors and their parents, and discusses the theoretical and practical implications of the model. Case material is presented to illustrate the types of symptoms that children and parents report. The pivotal role of parents in shaping the child's experience is discussed. Besides, data from recent studies are examined.

Language: English

Keywords: Cancer / Survivors / Parents / Posttraumatic stress symptoms / Explanatory models

Stuber ML, Christakis DA, Houskamp B, Kazak AE. Posttrauma symptoms in childhood leukemia survivors and their parents. *Psychosomatics*, 1996; 37(3): p.254-261
NIVEL: C 7947

The aim of this study was to examine the extent of posttraumatic stress symptoms in children who survived leukaemia. A self-report measure of posttraumatic stress (the Posttraumatic Stress Disorder Reaction Index) was used to evaluate 64 paediatric leukaemia survivors age 7-19 years and their parents (mothers n=63, fathers n=42). Based upon normative data for the Reaction Index, 12.5% of the survivors, 39.7% of the mothers, and 33.3% of the fathers reported symptoms consistent with a severe level of posttraumatic stress. The data indicate that a substantial subset of paediatric cancer survivors and their parents experience severe symptoms that can be

understood within a posttraumatic stress model. The data are discussed with regard to paediatric follow-up care for cancer survivors, as well as in terms of preventive steps that could be taken to lessen the traumatic aspects of paediatric cancer treatment.

Language: English

Keywords: Leukaemia / Survivors / Parents / Posttraumatic stress symptoms

Stuber ML, Houskamp B. Stress and pediatric medical technology.

In: Pfeffer CR (ed.) *Severe stress and mental disturbance in children.*

Washington: American Psychiatric Press, 1996: p.249-275

NIVEL: C 6509

The past decades have brought great advances in the technology of paediatric care. However, there are several major drawbacks to most of these technological rescues of dying children. Apart from the financial costs, there are significant physical and psychological costs associated with these new treatments. Much of this impact can be understood under the general heading of stress. These acute stressors and the resulting stress responses are a major focus of this article. In addition, the authors examine the long-term impact for survivors and their families.

Language: English

Keywords: Chronic diseases, general / Survivors / Medical technology / Psychological stress / Coping / Family

Tansella-Zimmermann C. Psychosocial factors and chronic illness in childhood. *European Psychiatry*, 1995; 10(6): p.297-305

NIVEL: C 6527

The aim of this review is to summarise recent research findings on the relationship between illness factors, individual and family functioning, coping strategies, and psychosocial adjustment in chronically ill children. The findings are presented within the framework of three complementary theoretical models: the family developmental approach, the psychosocial typology of illnesses, and the process model of stress and coping. These models are useful to a better understanding of the complex interactions between illness, family and coping and offer to the professionals engaged in the care of chronically sick children guidelines for assessment and the development of intervention programs. The review starts with examining the

impact of chronic illness on the psychosocial adjustment of the sick child, his/her siblings and parents. Then, psychosocial stressors and risk factors in terms of illness and family related characteristics are discussed. Coping resources and strategies are presented which have been shown to be related to child and parental adjustment; and finally, successful intervention programs are described.

Language: English

Keywords: Chronic diseases, general / Family relations / Coping / Psychosocial problems / Risk factors / Reviews

Tong EM, Sparacino PS, Messias DK, Foote D, Chesla CA, Gilliss CL. Growing up with congenital heart disease: the dilemmas of adolescents and young adults. *Cardiology in the Young*, 1998; 8(3): p.303-309

NIVEL: C 6514

The aim of this study was to explore the subjective experiences and dilemmas of adolescents with congenital heart disease during the transition from adolescence to young adulthood. The authors interviewed a convenience sample of 9 adolescents and young adults, using a semistructured protocol. Using analytic procedures inherent in Grounded Theory methodology, seven themes were identified: the dilemma of normality; dilemmas in disclosure; dilemmas in strategies for management of illness; the challenge of social integration versus social isolation; the challenge of dependence versus independence; the challenge of uncertainty; and strategies for coping. An understanding of these experiences by health professionals can be beneficial in helping this clinical population as they grow up and face the challenges of an uncertain, yet promising, future.

Language: English

Keywords: Congenital heart defects / Adolescents / Young adults / Social participation / Coping

Utens EM, Versluis - Den Bieman HJ, Verhulst FC, Meijboom FJ, Erdman RA, Hess J. Psychopathology in young adults with congenital heart disease. *European Heart Journal*, 1998; 19(4): p.647-651

NIVEL: C 6516

The aim of this study was to assess the occurrence of a wide range of behavioural and emotional problems in young adults long-term (> 9 years)

after they had undergone surgical correction for congenital heart disease in infancy and childhood. The problem scores on the Young Adult Self-Report of 166 young adults, aged 19-25 years, with congenital heart disease were compared with those of subjects of similar age from the general population. On most Young Adult Self-Report scales no differences were found between the mean problem scores of the congenital heart disease adults and reference peers. On only two Young Adult Self-Report scales (i.e. Somatic Complaints and Strange) and the total problem score were significant though small differences found between the mean problem scores of the congenital heart disease adults and reference peers. Also, no significant relationship was found between cardiac diagnosis and problem behaviours in congenital heart disease adults. No relationship was found between IQ scores and problem behaviours in congenital heart disease adults. Overall, it can be concluded that the results of the congenital heart disease adults were not unfavourable, since the differences in mean (total) problem scores between the congenital heart disease sample and reference group were small and limited to only two specific problem areas.

Language: English

Keywords: Congenital heart defects / Young adults / Behaviour problems / Psychosocial problems / Intelligence

Utens EMWJ, Verhulst FC, Erdman RAM, Meijboom FJ, Duivenvoorden HJ, Hess J. Psychosociaal functioneren van jeugdigen en jong-volwassenen 9 jaar en langer na operatieve behandeling van een aangeboren hartafwijking op de kinderleeftijd. (Psychosocial behaviour of children and young adults nine years or more after surgical treatment of congenital heart diseases.) *Nederlands Tijdschrift voor Geneeskunde*, 1996; 140(21): p.1126-1130

Aim of this study was to gain insight into the psychosocial behaviour of children and young adults who had undergone surgical treatment of their congenital heart disease at least 9 years ago. Psychosocial behaviour has been registered by using questionnaires and by tests on behaviour, emotional, intellectual and social coping and by interviews conducted by a psychologist. The study involved 498 children and young adults. Data were compared to those of the reference groups. Young patients showed significantly more behaviour problems and emotional problems than their healthy peers. Young adults, however, scored better in emotional coping than their peers. Their social behaviour was, generally speaking, good. No significant differences in emotional behaviour have been found between

several groups with cardiac diagnosis. Young children and their parents need extra psychosocial help after heart surgery.

Language: Dutch

Keywords: Congenital heart defects / Adolescents / Young adults / Behaviour problems / Psychosocial problems / Intelligence

Weekes DP. Adolescents growing up chronically ill: a life-span developmental view. *Family and Community Health*, 1995; 17(4): p.22-34
NIVEL: C 7795

This article focuses on the life-span period of adolescence, which encompasses the period beginning at 11 or 12 and ending around 19 to 21 years of age, with respect to chronically ill youngsters. The life-span developmental perspective is identified as a particularly useful theoretical approach for viewing this period in the life cycle. This article includes a general overview of the life-span developmental perspective, application of the life-span perspective to adolescent development, application of the perspective to adolescents growing up chronically ill, and discussion of the research and practice implications inherent in viewing chronically ill adolescents from a life-span developmental perspective.

Language: English

Keywords: Chronic diseases, general / Adolescents / Child development / Quality of life / Explanatory models

Zani B, Di Palma A, Vullo C. Psychosocial aspects of chronic illness in adolescents with thalassaemia major. *Journal of Adolescence*, 1995; 18(4): p.387-402
NIVEL: C 6526

The aim of this study was to investigate the impact of a chronic illness, i.e. thalassaemia major, on the psychological functioning and social behaviour of adolescent patients. Ninety thalasseemics and 100 healthy subjects of comparable age, sex and geographical background completed an ad hoc questionnaire designed to analyse the network of social relationships (family, friends, partner), the degree of social integration, different aspects of self-concept and the coping strategies used by adolescents when facing stressful situations. The results showed that thalassaemic adolescents have normal psychological and social development, score even better than their healthy peers in tests concerning self esteem and in self-description, and use

of functional coping strategies. The study would seem to support the hypothesis that chronic illness does not necessarily imply psychopathologies, but can strengthen adolescents' resources, contrary to the traditional stereotype view of the chronic patient as one with a poor psychological and social profile.

Language: English

Keywords: Thalassaemia / Adolescents / Social participation / Peer relations / Coping

1.2 Quality of life from the family's perspective

Banner LM, Mackie EJ, Hill JW. Family relationships in survivors of childhood cancer: resource or restraint? *Patient Education and Counseling*, 1996; 28(2): p.191-199

The aim of this review is to discuss studies on the developmental task of cancer survivors with regard to the transition from adolescence to adulthood, and the mediating influence of family relationships. Theories, concepts and findings relevant to this specific focus are considered in relation to whether these relationships may prove a resource or a restraint in this process. Potential aspects of family relationships that may be of interest to research are discussed, and clinical implications drawn.

Language: English

Keywords: Cancer / Survivors / Adolescents / Young adults / Quality of life / Family relations / Reviews

Barakat LP, Kazak AE, Meadows AT, Casey R, Meeske K, Stuber ML. Families surviving childhood cancer: a comparison of posttraumatic stress symptoms with families of healthy children. *Journal of Pediatric Psychology*, 1997; 22(6): p.843-859
NIVEL: C 6388

The aim of this study was to compare posttraumatic stress symptoms in survivors of childhood cancer and their parents with those of healthy children and their parents who responded to child-related stressors. A sample of 309 children, aged 8-20 years, participated in this study. The relationships of child demographic, cancer and treatment, and family and social support factors with posttraumatic stress symptoms were analysed also. Results indicate that mothers and fathers of childhood cancer survivors showed significantly higher levels of posttraumatic stress symptoms than comparison

parents. The survivors themselves did not differ from their healthy counterparts. Past perceived life threat and family and social support resources contributed to posttraumatic stress symptoms in survivors and their parents. Survivor mother and child and survivor father and child symptoms were associated. Implications for the long-term functioning of families of survivors and suggestions for preventive interventions are discussed.

Language: English

Keywords: Cancer / Posttraumatic stress symptoms / Parents / Social support

Barbarin OA, Sargent JR, Sahler OJZ, Carpenter PJ, Copeland DR, Dolgin MJ, Mulhern RK, Roghmann KJ, Zeltzer LK. Sibling adaptation to childhood cancer collaborative study: parental views of pre- and postdiagnosis adjustment of siblings of children with cancer.

Journal of Psychosocial Oncology, 1997; 15(3): p.1-14

NIVEL: C 6389

The aim of this study was to examine sibling emotional and social adjustment to childhood cancer, as seen by their parents. In open-ended interviews, parents of 254 siblings of children with cancer evaluated the pre- and postdiagnosis adjustment of their children. One-fourth of the siblings were asymptomatic both before and after the diagnosis. Behaviour and emotional problems were the most frequently reported problems arising after the diagnosis. Before the diagnosis, less than 12 percent of the siblings had either behavioural or affective symptoms, whereas 26 percent had such symptoms after the diagnosis. Type of maladjustment was unrelated to sex, birth order, or severity of the patient's illness. On the positive side, parents also reported favourable changes because of the illness in sibling's maturity, supportiveness, and independence. These positive effects were more likely to occur among adolescent and first-born siblings and when the patient's prognosis was poorer.

Language: English

Keywords: Cancer / Siblings / Behaviour problems / Psychosocial problems / Coping

Brown-Elliott KA, Barbarin OA. Gender differences in parenting a child with cancer. *Social Work in Health Care*, 1996; 22(4): p.53-71

NIVEL: C 6395

The aim of this study was to investigate the perceptions of parents of children diagnosed with cancer about their role in the illness situation. A sample of 124 parents participated in this study. The study found that mothers and fathers differ in their experience of and response to parenting a child with cancer. These differences appear to reflect traditional parenting roles characterised by a gender-based division of labour. Sex-role socialisation theory is discussed as an explanatory model of the parenting experience. Practice recommendations are offered to medical social workers and other health care professionals concerned with the long-term psychosocial adjustment of parents with chronically ill children.

Language: English

Keywords: Cancer / Parent-child relations / Sex differences

Canning RD, Harris ES, Kelleher KJ. Factors predicting distress among caregivers to children with chronic medical conditions. *Journal of Pediatric Psychology*, 1996; 21(5): p.735-749
NIVEL: C 6399

The aim of this study was to explore informant differences and to assess the importance of sociodemographic factors, child health status characteristics, and caregiver burden to variability in psychological symptoms among caregivers to 116 children with chronic medical conditions. Important informant effects were found. Caregiver-reported, but not physician-reported, burden was an important predictor. Severity of illness, whether rated by physician or caregiver, had little predictive effect whereas child impairment predicted greater distress, independent of sociodemographics. Lower family income and female child sex predicted caregiver distress independent of other variables. Even among families with higher income, those with the lowest income report much higher distress. Results are discussed in terms of the importance of informant choice and the use of sociodemographics as primary rather than control variables in studies of the families of chronically ill children.

Language: English

Keywords: Chronic diseases, general / Parents / Psychological stress / Socioeconomic factors

Cohn- Kirschenbaum J. An empirical study of parents' reaction to the diagnosis of congenital heart disease in infants. *Social Work in Health Care*, 1996; 23(2): p.67-79

NIVEL: C 6405

The aim of this study was to test the hypothesis that parents of newborn infants diagnosed with congenital heart disease experience more negative feelings of sadness, anger, fear and guilt than parents of normal newborns. Questionnaires rating feeling according to several scales of words describing emotions were administered to parents of both normal and heart problem infants. Results of the study suggest that parents of such infants were indeed more fearful than parents of normal infants. The data also indicate that all parents experience sadness, anger and fear, but parents of normal infants experience less anger and sadness. Many implications for social work practice, education and research are indicated as a result of this study.

Language: English

Keywords: Congenital heart defects / Infants / Parents / Quality of life

Derouin D, Jessee PO. Impact of a chronic illness in childhood: siblings' perceptions. *Issues in Comprehensive Pediatric Nursing*, 1996; 19(2): p.135-147

NIVEL: C 6409

The aim of this study was to examine siblings' perceptions of family disruption when a brother or sister had cystic fibrosis (CF) or asthma. Data were gathered by phone interviews and questionnaires. Phone interviews were conducted with siblings of chronically ill children and open-ended questions were employed focusing on the impact of the illness on the sibling and the family unit. Along the interview, siblings also completed a separate self esteem measure. Assessments of family functioning and demographic variables were obtained through parental questionnaires. Only the sibling interview data are addressed in this article. Fifteen families from the two illness groups participated. There were 6 male and 9 female respondents, with a mean age of 10.1 years. The average age of the well sibling was slightly older than the average age of the chronically ill child. For siblings of both disease groups, positive outcomes included strengthening some family relationships, achieving more personal independence, and experiencing satisfaction in seeing improvement in the ill child. Negative outcomes included worrying about the brother's or sister's illness, being jealous of the attention paid to the ill child, and the restriction of family events. Appropriate family interventions are suggested, as well as feedback as to the efficacy of phone interviews with school-age children.

Language: English

Keywords: Cystic fibrosis / Asthma / Siblings / Family relations / Self esteem

Diseth TH, Emblem R, Vandvik IH. Adolescents with anorectal malformations and their families: examples of hidden psychosocial trauma. *Family Systems Medicine*, 1995; 13(2): p.215-231
NIVEL: C 6410

The aim of this study was to investigate physical and mental health and psychosocial issues in adolescents with corrected anorectal malformations. Thirty-three adolescents and their families were examined by means of semistructured interviews and questionnaires. Seventy percent of the adolescents had persistent, impaired faecal control and 73% had flatus incontinence. The study revealed a high frequency of mental (58%) and psychosocial problems (73%) in the adolescents. Moderate to severe chronic family difficulties were reported in 55% of the families. There were significant correlations between treatment variables, somatic variables, mental and psychosocial outcome of the adolescents, and parental and family variables. The presence of chronic family difficulties was the strongest predictor (55%) of psychosocial outcome for the adolescents, together with the mother's warmth and criticism, and the adolescents' faecal continence function, all of which explained 71% of the variance in outcome. Anorectal anomalies represent underappreciated, persistent, and hidden psychosocial traumas both for the children and their families. The findings illustrate the need for further studies of the medical and psychosocial implications of treatment procedures. Optimal treatment requires somatic, psychological, and family-related care, and follow-up.

Language: English

Keywords: Anorectal malformations / Adolescents / Mental disorders / Psychosocial problems / Family relations

Dolgin MJ, Phipps S. Reciprocal influences in family adjustment to childhood cancer. In: Baider L, Cooper CL, Kaplan De-Nour A (eds). *Cancer and the family*. Chichester: John Wiley & Sons, 1996: p.73-92
NIVEL: C 6413

The authors of this book chapter argue that central to the understanding of family functioning in general, and of family adjustment to stressful life events in particular, is a perspective which recognises that changes affecting one element of the family system in turn influence other elements of that

system. Family adjustment to childhood cancer provides a model for examining such reciprocal influences within the family system insofar as events centring around the child-patient may have profound impact on the lives of parents and siblings, and to the extent that the adaptation of patients, siblings and parents is influenced by global family resources, characteristics and interactional patterns. Some of the models which provide a framework for understanding reciprocal influences in the family's response to cancer, are briefly reviewed. In addition, attention is paid to psychosocial adjustment within the family, the influence of the family on children's developmental adaptation, the reciprocity of parent and child adjustment, parenting behaviour, treatment-related distress and compliance with therapeutic regimens.

Language: English

Keywords: Cancer / Family relations / Psychological stress / Coping / Patient compliance / Explanatory models

Dongen-Melman JEWM van. *On surviving childhood cancer: late psychosocial consequences for patients, parents and siblings.* Rotterdam: Sophia Kinderziekenhuis, 1995
NIVEL: B 4918

This thesis is aimed at gaining an insight into the late psychosocial effects of childhood cancer on the entire family. A measuring instrument has been developed in order to measure psychosocial functioning of the parents. A questionnaire for the ex-patients and their brothers and sisters has been translated and validated. Not only the effects on the social functioning of the parents have been assessed: the demographic, personal-situational characteristics and illness-related risk factors were also taken into account. Research was carried out into functioning at school, the presence or absence of learning difficulties, and the psychosocial problems of ex-patients. A group of brothers and sisters were also included in this research and they were compared to their peers.

Language: English

Keywords: Cancer / Parents / Siblings / Psychosocial problems / Coping / Academic achievement / Questionnaires

Dongen-Melman JEWM van, Pruyn JFA, Groot A de, Koot HM, Hählen K, Verhulst FC. *Late psychosocial consequences for parents of*

children who survived cancer. *Journal of Pediatric Psychology*, 1995; 20(5): p.567-586
NIVEL: C 6415

The aim of this study was to investigate the psychosocial sequelae in parents of children who survived cancer. A sample of 133 parents participated. Questionnaires developed to measure the specific impact of the disease were used. Childhood cancer had distinct and persistent late psychosocial effects on parents of survivors. Uncertainty and loneliness were the most reported problems. Demographic and situational characteristics such as being a mother, low SES, no religious affiliation, chronic disease in a family member other than the child surviving cancer, and concurrent stresses increased the risk of reporting late problems. Treatment itself had little or no effect on reported problems. However, when treatment led to long-term sequelae in the child, a significant and specific effect on parental problems was observed. No decline of problems over time was found, which has implications for patient care.

Language: English

Keywords: Cancer / Survivors / Parents / Psychosocial problems / Risk factors

Drotar D, Agle DP, Eckle L, Thompson PA. Correlates of psychological distress among mothers of children and adolescents with hemophilia and HIV infection. *Journal of Pediatric Psychology*, 1997; 22(1): p.1-14
NIVEL: C 6418

The aim of this study was to evaluate the correlates of psychological distress in a multisite study of two groups: (a) mothers of HIV-positive children and adolescents with haemophilia (n=91), and (b) mothers of HIV-negative children and adolescents with haemophilia (n=92). Socioeconomic status, quality of family relationship support, and frequency of negative life events accounted for significant variance in Total Mood Disturbance (psychological distress) as measured by the Profile of Mood States in the overall sample. Severity of haemophilia was unrelated to distress. A significant interaction between HIV status and frequency of stressful life events indicated that this variable related more strongly to distress among mothers of HIV-infected children and adolescents with haemophilia than among mothers of HIV-negative children with haemophilia. Findings suggest that the presence of HIV infection in their children and adolescents may heighten the impact of

negative life events on the psychological distress experienced by these mothers.

Language: English

Keywords: Hiv / Haemophilia / Mothers / Psychological stress / Coping / Family relations

Drotar D. Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: what have we learned? what do we need to know? *Journal of Pediatric Psychology*, 1997; 22(2): p.149-165
NIVEL: C 6417

The purpose of this review is to present the results of studies concerning the relationship of parent and family functioning to the psychological adjustment of children with chronic health conditions. More adaptive family relationships and parental psychological adjustment were associated with positive psychological adjustment while less adaptive family relationships (e.g., greater conflict and maternal psychological distress) consistently predicted problematic adjustment. Conclusions were limited by small, site-specific samples, reliance on self report measures generally obtained from one parent, and general measures. Research progress would be enhanced by (a) more representative data sets; (b) process oriented, illness specific, and clinically relevant measures; (c) prospective analyses that clarify specific causal pathways between family functioning and children's adjustment; and (d) tests of interventions that modify risk and/or resistance factors.

Language: English

Keywords: Chronic diseases, general / Parents / Family relations / Coping / Mental disorders / Reviews

Eiser C, Berrenberg JL. Assessing the impact of chronic disease on the relationship between parents and their adolescents. *Journal of Psychosomatic Research*, 1995; 39(2): p.109-114
NIVEL: C 6420

The authors suggest that paediatric chronic disease poses many challenges for parents, the child, and their relationship together, especially during adolescence, when relations are being negotiated and redefined. The discussion of ways in which family relationships are affected by chronic or life-threatening disease is limited by a number of assumptions, usually based

on anecdote or general clinical observations. The authors address the negative impact of these assumptions and discuss the research that is available about parent-adolescent relationships in the presence of chronic disease.

Language: English

Keywords: Chronic diseases, general / Adolescents / Parent-child relations

Fanos JH. *Sibling loss*. Mahwah, New Jersey: Lawrence Erlbaum Associates, 1996
NIVEL: B 4934

The aim of this study was to examine the consequences on adults of growing up with a sibling who was chronically ill and ultimately died before adulthood. Seventy-five adults were interviewed who were between 18 and 45 years old (mean 30 years) at the time of the study. During their childhood, adolescence, or adulthood, when the interviewees were between 4 and 36 years of age (mean 17 years), they had lost a sibling to cystic fibrosis.

Language: English

Keywords: Cystic fibrosis / Death / Grief / Siblings / Family relations / Coping / Mental disorders

Fentner S, Seiffge-Krenke I. Die Rolle des Vaters in der familiären Kommunikation: Befunde einer Längsschnittstudie an gesunden und chronisch kranken Jugendlichen. (The role of the father in family communication: outcome of a longitudinal study of healthy and chronically ill adolescents.) *Praxis der Kinderpsychologie und Kinderpsychiatrie*, 1997; 46(5): p.354-370
NIVEL: C 6425

The aim of this study was to analyse communication processes in families of chronically ill adolescents. Fifty-five families caring for adolescents with diabetes were compared with families of healthy adolescents. Dimensions of individuality and connectedness in family discourse were analysed. Results showed an atmosphere of consensus in families with chronically ill adolescents, as well as a tendency to discuss fewer options than in families with healthy adolescents. Fathers in particular rarely disagreed and gave only indirect suggestions. In contrast, families with a healthy adolescent showed more vivid discussion and more individuality. Over time, fathers in all

families emphasised increased separateness with their adolescents, irrespective of the gender of the child.

Language: German

Keywords: Diabetes mellitus / Adolescents / Family relations / Communication

Floyd FJ, Gallagher EM. Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, 1997; 46(4): p.359-371
NIVEL: C 6426

The aim of this study was to examine the effects of disability, child behaviour problems, family status and child age on parental stress and caregiving demands and the use of support services by families of school-aged children with disabilities. Data were obtained from mothers and fathers of children (n=231) with mental retardation (MR) or chronic illness (CI), and a nondisabled behaviour-problems sample. Mothers identified fewer behaviour problems in children with MR and more in children with CI than did teachers. The presence of significant behaviour problems was more important than disability type in determining most forms of parental stress, and predicted mental health services use. MR group parents worried most about providing ongoing care into adulthood. Single mothers were not more stressed, but used more services than two-parent families. The results call for a wider array of community and family support services that target children with disabilities who have behaviour problems.

Language: English

Keywords: Chronic diseases, general / Mental retardation / Behaviour problems / Parents / Psychological stress / Health care utilisation

Hulstijn-Dirkmaat GM. Chronic renal failure in children: psychological implications for development and family. Nijmegen: Quikprint, 1995
NIVEL: B 4919

Progress in the medical treatment of children with chronic renal failure may have led to better life expectancy and a better quality of life, but far-reaching kidney function replacing techniques turn out to have a profound impact on young children, in particular, and on the mental coping ability of the children and their family. Key issue of this thesis is the assessment of the mental impact of terminal renal failure on children. The effect of terminal renal failure and kidney transplant, especially the cognitive development, has been

investigated in four studies. In addition, a study has been conducted into the impact of a dialysis treatment on the family.

Language: English

Keywords: Kidney disease / Kidney transplantation / Cognitive development / Family / Psychological stress

Ievers CE, Drotar D. Family and parental functioning in cystic fibrosis. *Journal of Developmental and Behavioral Pediatrics*, 1996; 17(1): p.48-55
NIVEL: C 6445

This article reviews 31 articles describing studies on functioning of families and/or parents of children with cystic fibrosis (CF), compared to families of healthy children, pinpointing factors that predict quality of adjustment, or evaluating interventions designed to improve functioning. Commonly cited concerns included the difficulty of the treatment regimen, the terminal nature of CF, and the disruption of intrafamilial relationships. Parents of children with CF experienced greater stress and burdens than parents of healthy children, yet parenting behaviour and family functioning were quite similar in CF and healthy control groups. Higher levels of distress, an avoidant coping style, and low levels of family support were associated with poor psychological adjustment. Recommendations for future research include: using multiple informants; using detailed, illness-specific measures and conceptual frameworks; and conducting studies of individual variation and interventions. Practitioners might consider performing periodic updates of how the family is managing as a whole.

Language: English

Keywords: Cystic fibrosis / Family / Parent-child relations / Psychosocial problems / Coping / Social support / Reviews

Ireys HT, Silver EJ. Perception of the impact of a child's chronic illness: does it predict maternal mental health? *Journal of Developmental and Behavioral Pediatrics*, 1996; 17(2): p.77-83
NIVEL: C 6446

The aim of this study was to investigate the effects of demographic factors, parameters of health conditions, service use variables, and perception of family impact of illness on the mental health of mothers of children with chronic health conditions. A longitudinal study was conducted in which 169 mothers of children with diverse chronic illnesses participated. Bivariate

analyses indicated that baseline assessments of demographic factors, condition parameters, and service use were (1) generally unrelated to maternal mental health at 1 year and (2) modestly related to maternal perception of the condition's impact 1 year later. Perceived impact and maternal mental health themselves were moderately related. Multivariate analyses indicated that the need to watch for changes in the child's condition, the presence of communication or speech problems, and the number of hospitalisations in the previous year predicted maternal perceptions of the impact of the condition 1 year later. Mothers perception of impact had a direct effect on mothers' mental health after accounting for condition parameters. Results suggest that condition parameters and service use can affect maternal mental health through mothers' perceptions of the impact of the condition on family life. Implications for interventions to prevent maternal mental health problems are discussed.

Language: English

Keywords: Chronic diseases, general / Mothers / Mental disorders / Family relations / Health status / Health care utilisation

Kazak AE, Christakis DA. The intense stress of childhood cancer: a systems perspective. In: Pfeffer CR (ed). *Severe stress and mental disturbance in children*. Washington: American Psychiatric Press, 1996: p.277-304
NIVEL: C 6450

In this book chapter the stressors associated with the diagnosis and treatment of cancer for children and their families are discussed. The effects of these stressors transcend the boundary of the family and include interactions with medical and educational systems. The orientation is guided by family systems and social ecological theories. The authors discuss stressful aspects of paediatric cancer across these systems.

Language: English

Keywords: Cancer / Psychological stress / Family / Explanatory models

Kirk S. Families' experiences of caring at home for a technology-dependent child: a review of the literature. *Child: Care, Health and Development*, 1998; 24(2): p.101-114
NIVEL: C 6452

The aim of this review is to present an overview of studies that have examined the experiences of families caring for a technology-dependent child at home. The social, emotional and financial impact on families and their perspectives on the services supporting them at home is described. The article concludes by identifying areas where further research is needed.

Language: English

Keywords: Chronic diseases, general / Parents / Home care / Coping / Family relations / Reviews

Labbé EE. Emotional states and perceived family functioning of caregivers of chronically ill children. *Psychological Reports*, 1996; 79(3 Pt 2), p.1233-1234
NIVEL: C 6461

The aim of this study was to examine the emotional status and perception of family functioning of primary caregivers of children with Batters disease. Thirty-two caregivers of children with Batters disease were compared to 11 primary caregivers of children with chronic and less severe medical illnesses. The former caregivers were significantly more depressed, anxious, perceived their families as less cohesive and reported greater negative effects on their schedule and health than the latter group.

Language: English

Keywords: Batters disease / Terminal illness / Parents / Coping / Family relations / Mental disorders

Lesar S, Maldonado YA. The impact of children with HIV infection on the family system. *Families in Society: the Journal of Contemporary Human Services*, 1997; 78(3): p.272-279
NIVEL: C 6463

The purpose of this study was to examine the effects of HIV infection on the family system. A sample of 48 caregivers of HIV-exposed children was involved in this study. Respondents completed the Impact on Family Scale as part of their participation in the study. Results showed that the psychological burden of the illness was significantly related to the child's HIV status. Financial burden, social and familial impact differed as a function of the child's and caregiver's HIV status. The impact of HIV infection differed as a function of the caregiver relationship. Implications of the findings for service delivery are discussed.

Language: English

Keywords: Hiv / Family relations / Psychological stress / Coping

Manne SL, Lesanics D, Meyers P, Wollner N, Steinherz P, Redd W. Predictors of depressive symptomatology among parents of newly diagnosed children with cancer. *Journal of Pediatric Psychology*, 1995; 20(4): p.491-510
NIVEL: C 6467

The purpose of this study was to examine predictors of depressive symptoms among 59 parents providing primary care to children newly diagnosed with cancer. Parents were studied for a 3-month period. The parent providing primary care to the child during medical treatment completed measures of depressive symptoms, endorsement of family routines, family functioning, amount of assistance from the spouse in providing care to the child, child behaviour problems, as well as measures of the severity of the child's treatment regimen. A strong relationship was found between child behaviour problems and parent depressive symptomatology. Although disease-related factors such as the child's functional impairment played a role in the parent's depressive symptoms, results revealed that the child's behaviour problems were most strongly associated with parent depressive symptoms and that family cohesiveness also had a contributory role in the maintenance of parent depressive symptoms.

Language: English

Keywords: Cancer / Parents / Depression / Behaviour problems / Family relations / Risk factors

Mastroyannopoulou K, Stallard P, Lewis M, Lenton S. The impact of childhood non-malignant life-threatening illness on parents: gender differences and predictors of parental adjustment. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 1997; 38(7): p.823-829
NIVEL: C 6469

The aim of this study was to explore differences between mothers and fathers with a child with a life-threatening illness with respect to mental health, family functioning, employment, relationships, coping style, and perceptions of prognosis. The mentioned factors were assessed in 93 mothers and 78 fathers of children with a life-threatening non-malignant condition. Results indicated high levels of psychological distress, significant effects on employment and relationships, and a family environment characterized by

low expressiveness, cohesion, and high conflict. Differences between mothers and fathers were found on a number of variables. Length of time since diagnosis, level of family cohesion, and sex of parents significantly predicted parental mental health.

Language: English

Keywords: Chronic diseases, general / Parents / Sex differences / Psychological stress / Family relations / Employment / Coping

Mescon JAW. Parents, teachers and medical personnel: helping children with chronic illness. *Early Child Development and Care*, 1995; 111: p.107-129
NIVEL: C 6471

The aim of this review is to present studies concerning the influences of childhood chronic illness on psychosocial and cognitive development, using both Eriksonian and Piagetian theoretical frames of reference. Family and child stress and coping with medical crises and manifestations of illness are explored. Recommendations are provided to enhance parent and professional communication and educational interventions with ill children.

Language: English

Keywords: Chronic diseases, general / Cognitive development / Social development / Coping / Psychological stress / Reviews

Ostroff J, Steinglass P. Psychosocial adaptation following treatment: a family systems perspective on childhood cancer survivorship. In: Baider L, Cooper CL en Kaplan De-Nour A (eds). *Cancer and the family*. Chichester: John Wiley & Sons, 1996: p.129-147.
NIVEL: C 6475

As the population of cancer survivors increases, a new phase of coping with cancer emerges - an off-treatment survivorship phase encompassing a distinct set of psychosocial issues. In this book chapter the authors review the major issues faced by childhood cancer survivors and describe potential patient, family and medical team factors associated with differential adequacy of psychosocial adaptation to childhood cancer survivorship. In addition, they describe a family-oriented intervention designed to help facilitate a more successful transition of adolescent cancer patients and their families from the active treatment phase to the off-treatment phase. This

intervention represents a direct clinical extension of the family systems concepts described in the second section of the chapter.

Language: English

Keywords: Cancer / Survivors / Coping / Family relations

Phipps S, Mulhern RK. Family cohesion and expressiveness promote resilience to the stress of pediatric bone marrow transplant: a preliminary report. *Journal of Developmental and Behavioral Pediatrics*, 1995; 16(4): p.257-263
NIVEL: C 6479

The aim of this study was to assess the effect of perceived family environment as a determinant of adjustment in children undergoing bone marrow transplant (BMT). A prospective, longitudinal study was conducted. Measures of patients' social competence, behaviour problems, and self esteem, along with perceived family conflict, cohesion, and expressiveness, were obtained before hospital admission for BMT and again in the period 6 to 12 months post-BMT. Significant declines were observed in post-BMT social competence and overall self-concept. Before BMT, perceptions of family conflict showed a moderate inverse correlation with patient adjustment, whereas family cohesion and expressiveness were unrelated or were weakly related with adjustment measures. In contrast, all pre-BMT family environment variables were highly predictive of adjustment post-BMT. Using a cross-lagged correlational approach, it was determined that perceived family cohesion and expressiveness act as protective factors, promoting resilience to the stresses of BMT, whereas family conflict acts directly as a risk factor that adversely affects adjustment regardless of stress level.

Language: English

Keywords: Leukaemia / Bone marrow transplantation / Family relations / Behaviour problems / Psychological stress / Coping

Sargent JR, Sahler OJZ, Roghmann KJ, Mulhern RK, Barbarian OA, Carpenter PJ, Copeland DR, Dolgin MJ, Zeltzer LK. Sibling adaptation to childhood cancer collaborative study: siblings' perceptions of the cancer experience. *Journal of Pediatric Psychology*, 1995; 20(2): p.151-164
NIVEL: C 6487

The aim of this study was to investigate thoughts and feelings about effects of cancer on self and family in siblings of children with cancer. Structured interviews were conducted with 254 siblings (aged 4-28 yrs). They indicated distress about family separations and disruptions, lack of attention, focus of family on the ill child, negative feelings in themselves and family members, cancer treatments and their effects, and fear of death. Siblings also reported becoming more compassionate, families becoming closer, and having experiences they otherwise would not have had. Age and gender differences in responses indicated distinctive perceptions of and vulnerability to the cancer experience. Older siblings were more likely to report positive effects than younger siblings, suggesting that level of maturity can moderate the stress of an ill child within the family.

Language: English

Keywords: Cancer / Siblings / Coping / Psychological stress

Sawyer M, Antoniou G, Toogood I, Rice M. Childhood cancer: a two-year prospective study of the psychological adjustment of children and parents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 1997; 36(12): p.1736-1743
NIVEL: C 6488

The aim of this study was to follow prospectively the psychological adjustment of young children, parents, and families during the first two years after the children's diagnosis of cancer. Children aged 2 to 5 years with cancer diagnoses and their parents and families (n=38) were assessed immediately after diagnosis, 1 year after diagnosis, and 2 years after diagnosis. At each assessment, the psychological assessment of the children and their families was compared with the adjustment of a cohort of children and families in the general community (n=39). Children with cancer and their parents experienced significantly more emotional distress than children and parents in the community during the period immediately after diagnosis. However, the number of problems experienced by the children with cancer and their parents declined during the first year after the children's diagnosis and stabilised at a level comparable with that found among children and parents in the general community. Although the results are consistent with reports that suggest that in the longer term the prevalence of psychological problems among children with cancer is similar to that found among children in the general community, they also highlight the considerable distress experienced by children and parents during the period immediately after the children's diagnosis.

Language: English

Keywords: Cancer / Pre-school children / Parents / Family relations / Psychosocial problems / Behaviour problems / Psychological stress

Scholte I, Zuuren FJ van. Leren leven met de bloedstollingsziekte trombocytopathie: een kwalitatief onderzoek bij ouders van kinderen met deze aandoening en bij volwassen patiënten. (Coping with thrombocytopathy: A qualitative investigation directed at parents of children with this dysfunctional blood coagulation, and at adult patients.) *Gedrag & Gezondheid*, 1998; 26(4): p.165-176

Thrombocytopathy is a dysfunction in the blood platelets, preventing their coagulation in case of bleeding. Without adequate measures, an internal or external haemorrhage can take a fatal course. Therefore, the possibility of a bleeding constitutes a continuous threat for patients with this disorder. In this study open interviews were held to investigate the psychosocial consequences of thrombocytopathy for parents of young patients (n=8) as well as for adult patients (n=10). The most important aspect of the disorder that emerged was the unpredictability of the threat. Parents try to find a balance, in their behaviour as well as in their cognitions, between exercising control over potentially dangerous events and their need of freedom of movement. Furthermore, they make use of relativism and social comparison. It was also possible to trace some person-related variables of interest, and to describe the role of the social environment. Theoretically the findings can easily be placed within the 'stress and coping' model of Lazarus and Folkman (1984) and the uncertainty-concept.

Language: Dutch

Keywords: Thrombocytopathy / Parents / Psychosocial problems / Coping

Seiffge-Krenke I. "One body for two": the problem of boundaries between chronically ill adolescents and their mothers. In: Solnit AJ, Neubauer PB, Abrams S, Scott Dowling A (eds). *The psychoanalytic study of the child*. Yale University Press, 1997: p.340-355
NIVEL: C 6493

In this book chapter the problem of boundaries between chronically ill adolescents and their mothers is reviewed from psychoanalytic and developmental perspectives. In general, the transition to adulthood encompasses several processes that are especially important for chronically ill adolescents, including the differentiation and fusion of self and others, the

integration of the mature genitals into the body concept, and the acceptance of a defective body. In particular, the constant vigilance over and care of the body prescribed for adolescents afflicted with diabetes, as well as the necessity of repeatedly injuring their bodies by injecting insulin, have no correlate in normal development. A case study is presented, which is derived from a longitudinal study on diabetic and healthy adolescents and their families, to illustrate the difficulties of balancing the need for boundaries and the wish for fusion and merger.

Language: English

Keywords: Diabetes mellitus / Adolescents / Parent-child relations / Child development

Sheeran T, Marvin RS, Pianta RC. Mothers' resolution of their child's diagnosis and self-reported measures of parenting stress, marital relations, and social support. *Journal of Pediatric Psychology*, 1997; 22(2): p.197-212
NIVEL: C 6495

The purpose of this study was to investigate the relation between maternal resolution/nonresolution of a child's diagnosis of chronic medical condition to self-reported measures of parenting stress, marital quality, and social support. Mothers were administered the Reaction to Diagnosis Interview, and classified as Resolved/Unresolved with respect to the child's diagnosis. Mothers also completed the Parenting Stress Index, Dyadic Adjustment Scale (DAS), Support Functions Scale, and Family Support Scale. Fathers completed the DAS. Maternal resolution vs. nonresolution of diagnosis was related to parenting stress, husband marital satisfaction, and level and helpfulness of social support. Resolution of diagnosis was not related to need for support. Specific subclassifications of Resolved and Unresolved also were differentially related to level and helpfulness of social support. Findings suggest that resolution/nonresolution of diagnosis has implications not only for individual functioning and child-parent interactions, as found in previous research, but also for other intimate familial relationships and social ecology.

Language: English

Keywords: Cerebral palsy / Epilepsy / Mothers / Psychological stress / Coping / Social support / Marital relationship

Silver-Johnson E, Stein REK, Dadds MR. Moderating effects of family structure on the relationship between physical and mental health in urban children with chronic illness. *Journal of Pediatric Psychology*, 1996; 21(1): p.43-56
NIVEL: C 6496

The aim of this study was to examine whether certain family structures modify the relationship between psychological adjustment and severity of physical illness, as measured by an index of functional status, among children with chronic illness. A sample of 352 families was divided into five types: two biological parents (n=149), mother plus another adult relative (n=47), mother plus unrelated spouse or partner (n=23), and mother alone (n=133). Correlations between children's functional status and adjustment were higher in the mother plus unrelated partner and mother alone families, and lower when mother lived with either the biological father or another adult relative. Children in the mother plus unrelated partner group also tended to have poorer overall adjustment than other children. Results are discussed in terms of family structure, childhood illness and adjustment, and the possible mechanisms that interrelate these variables.

Language: English

Keywords: Chronic diseases, general / Family relations / Family environment / Health status / Mental disorders

Silver-Johnson E, Bauman LJ, Ireys HR. Relationships with self-esteem and efficacy to psychological distress in mothers of children with chronic physical illnesses. *Health Psychology*, 1995; 14(4): p.333-340
NIVEL: C 6497

The purpose of this study was to examine the relationships of children's illness-related functional limitations and 2 maternal psychological resources, self esteem and efficacy, to symptoms of psychological distress in mothers of chronically ill children. Subjects were 365 urban mothers of 5-9 year old children with diverse chronic illnesses. Multiple regression controlling for sociodemographic variables indicated that presence of functional limitations in the child and lower resources each were associated with higher maternal scores on a psychological symptom scale. Self esteem had a main effect on maternal distress; however, a significant Efficacy-Functional Status interaction term suggested that mothers experienced greater distress when their children had illness-related functional limitations and maternal efficacy was low. Interventions aimed at enhancing maternal psychological resources

may reduce the likelihood of distress in mothers of children with chronic illness.

Language: English

Keywords: Chronic diseases, general / Mothers / Self esteem / Psychological stress

Sloper P, While D. Risk factors in the adjustment of siblings of children with cancer. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 1996; 37(5): p.597-607
NIVEL: C 6499

The purpose of this study was to examine the psychological adjustment of 99 siblings of children with cancer. At 6 months post-diagnosis, 24 siblings had scores in the borderline of clinical range on parent- and teacher-completed measures of behavioural adjustment and were reported to have shown negative changes in behaviour since diagnosis. The results of logistic regression analysis indicated that problems in adjustment were related to the degree of disruption of family life occasioned by the illness, the resources available to the family to cope with the effects of such disruption on siblings and siblings' perception of negative interpersonal effects on their lives.

Language: English

Keywords: Cancer / Siblings / Psychological stress / Coping / Behaviour problems

Sparacino PS, Tong EM, Messias DK, Foote D, Chesla CA, Gilliss CL. The dilemmas of parents of adolescents and young adults with congenital heart disease. *Heart & Lung*, 1997; 26(3): p.187-195
NIVEL: C 6502

The purpose of this qualitative pilot study was to provide a better understanding of parents' experiences as their children with congenital heart disease mature through adolescence and young adulthood. Subjects were eight parents whose children were patients of the paediatric cardiology service of a large university medical center. Each parent was separately interviewed with use of a semistructured interview guide. The study has identified seven themes: the dilemmas of normality, disclosure dilemmas, the challenge of uncertainty, illness management dilemmas and strategies, social integration versus social isolation, the impact of illness on the family, and coping with which parents have struggled throughout their adolescent's and young adult's life. It was not possible to determine whether the

experiences described by these parents are unique. It is concluded that parents experience distress, as outlined in the seven themes. They need assistance to determine what is "normal" for their child and how to monitor their child's health and safety. Further research is needed to develop specific interventions.

Language: English

Keywords: Congenital heart defects / Adolescents / Young adults / Parents / Psychological stress / Coping

Stuber ML. Stress responses to pediatric cancer: a family phenomenon.

Family Systems Medicine, 1995; 13(2): p.163-172

NIVEL: C 6510

The aim of this review is to present the research that suggests that cancer diagnosis, the life-threat it poses, and the aggressive treatment that is now employed, are experienced as traumatic by many children, and even more by their parents. Additionally, there appears to be a significant interaction between the responses of the paediatric patients and their parents. These findings have important clinical implications for those who provide care for these families. The traditional advice offered to families that have survived childhood cancer has been to go out and live a normal life. Traumatized parents, haunted by reminders or memories, have responded by avoiding discussions of the cancer experience. This has left children uninformed about aspects of their health and without an outlet to process their own memories or feelings about what happened as they mature. Suggestions are made for clinical interventions based on these new data.

Language: English

Keywords: Cancer / Survivors / Psychological stress / Parents / Parent-child relations / Posttraumatic stress symptoms / Reviews

Wallander JL, Varni JW. Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 1998; 39(1): p.29-46

NIVEL: C 6521

The aim of this review is to present the results of studies conducted primarily over the past 5-8 years on the psychosocial effects of paediatric chronic physical disorders on children and their families. A large body of studies show that both children and their mothers, as groups, are at increased risk for

psychosocial adjustment problems compared to peers, but that there is considerable individual variation in outcome. Since the last review on this topic (Eiser, 1990a), many studies have been conducted to identify risk and resistance factors associated with differences in adjustment among these children and their mothers. Improvements are noted in the theoretical basis for this work, programmatic nature of some of the research, and efforts at producing clinically relevant information. Evaluations of interventions, however, are lagging. Critical issues and future directions regarding developmental approaches, theory, method, measurement, and intervention are discussed.

Language: English

Keywords: Chronic diseases, general / Family / Psychosocial problems / Coping / Risk factors / Reviews

Williams PD. Siblings and pediatric chronic illness: a review of the literature. *International Journal of Nursing Studies*, 1997; 34(4): p.312-323
NIVEL: C 6524

The aim of this review is to present the results of studies published between 1970 and 1995 to identify the extent and nature of risks to siblings of chronically ill children, and the factors that may increase or lower the risks. A considerable amount of research is available in this area within the United States, but is relatively understudied elsewhere. About 60% of the studies reported an increase in sibling risk, while 30% reported no risk; and 10% had positive and negative outcomes. Interventions need to focus on the entire family system.

Language: English

Keywords: Chronic diseases, general / Siblings / Psychosocial problems / Risk factors / Reviews

1.3 Questionnaires and measures on quality of life

Bennett-Johnson S, Rodrigue JR. Health-related disorders. In: Mash EJ, Terdal LG (eds). *Assessment of child disorders*. New York: The Guilford Press, 1997: p.481-519
NIVEL: C 6391

In this book chapter the behavioural assessment of psychological aspects of chronic illness in children is discussed. Topics include current assessment

models, diagnostic classification, general patient and family functioning and disease-specific functioning (pain, knowledge about the illness and adherence).

Language: English

Keywords: Chronic diseases, general / Assessment / Family relations / Social adjustment / Quality of life

Bruil J. *Development of a quality of life instrument for children with a chronic illness.* Leiden: Universiteit Leiden, 1999
NIVEL: B 4802

This thesis describes how the questionnaire on the quality of life - the "HOE GAAT HET?" (How Are You, HAY) - has been developed. This questionnaire has been designed especially for children with a chronic illness, who are 7 to 13 years old. First, in a pilot study, the feasibility, validity and reliability were studied. Next, in the main study, validity and reliability of the HAY were tested both on a large group of children with a chronic illness (n=577) and on a group of healthy children (n=418). The HAY turned out to be a valid and reliable instrument.

Language: English

Keywords: Chronic diseases, general / Quality of life / Questionnaires

Dongen-Melman JEW van, Groot A de, Hählen K, Verhulst FC. *Commentary: Potential pitfalls of using illness-specific measures.* *Journal of Pediatric Psychology*, 1996; 21(1), p.103-106
NIVEL: C 6414

This book chapter addresses problems with using an illness-specific measure of psychological functioning before adequate reliability and validity studies have been completed and describes a study of the Deasy-Spinetta Behavioral Questionnaire (DSBQ) to measure school-related behaviour in children with cancer. Results raised questions about the validity of the data using the standard testing procedure (teacher rating of a child with cancer vs a typical child selected by the teacher), and the authors consequently examined the behavioural status of the control child vs 74 children surviving cancer and 70 other control children. Results suggest that reported differences on the DSBQ may reflect artificial differences as a result of the testing procedure, because the teacher selected an "ideal child," who had lower total problem scores than those of other controls, rather than a typical child.

Recommendations for future psychometric research on the DSBQ are discussed.

Language: English

Keywords: Cancer / Psychosocial problems / School / Questionnaires

Harris EM, Canning RD, Kelleher KJ. A comparison of measures of adjustment, symptoms, and impairment among children with chronic medical conditions. *Journal of the American Academy of Child and Adolescent Psychiatry*, 1996; 35(8): p.1025-1032

NIVEL: C 6439

The aim of this study was to examine the validity of 3 instruments used to measure emotional and behavioural problems among children with chronic illness. The Personal Adjustment and Role Skills Scale (PARS), Child Behavior Checklist (CBCL), and Columbia Impairment Scale (CIS) were compared with each other and with structured interview derived psychiatric diagnoses in 116 chronically ill children, aged 9 to 18 years. Three cutoff scores were used for each measure. The measures had good concurrent validity despite only moderate agreement with each other. Their criterion validity was only fair: levels of sensitivity were fair at low cutoffs to high at standard and high cutoffs; specificity and positive predictive values rose from moderate at low cutoffs to high at standard and high cutoffs. The agreement between the scales and a mental disorder diagnosis was only moderate at any of the cutoff points. Each of these measures has significant limitations. Both the CBCL and the PARS III appear to measure similar constructs but are likely to underidentify medically ill children with comorbid psychiatric problems. Consideration of global functioning across domains, with a measure such as the CIS, might provide an alternative approach to behavioural and symptom checklists in the assessment and management of children with chronic conditions.

Language: English

Keywords: Chronic diseases, general / Behaviour problems / Mental disorders / Questionnaires

Kazak AE, Stuber ML, Barakat LP, Meeske K. Assessing posttraumatic stress related to medical illness and treatment: the impact of Traumatic Stressors Interview Schedule (ITSIS). *Families, Systems & Health*, 1996; 14(3): p.365-380

NIVEL: C 6449

The aim of this study was to develop a semi-structured interview that assesses children and parents for posttraumatic stress symptoms after a child's illness. The interview, the Impact of Traumatic Stressors Interview Schedule, is described with regard to its theoretical development. The authors also provide preliminary data on ITSSIS and outline plans for continuing to assess its reliability and validity as a screening and outcome measure in behavioural health sciences research.

Language: English

Keywords: Cancer / Chronic diseases, general / Parents / Posttraumatic stress symptoms / Assessment

Koopman HM, Theunissen NCM, Vogels TGC, Zwinderman KAH, Verloove-Vanhorick SP, Wit JM. Health related quality of life of children with a chronic illness: parent versus child report. *Gedrag & Gezondheid*, 1999; 27(1-2): p.118-124

The purpose of this study was to evaluate the agreement between child and parent reports on children's Health Related Quality of Life (HRQoL). A sample of 416 Dutch children (8 to 15 years) with a chronic disease was involved in this study. Both children and their parents completed a 56 item questionnaire with seven eight-item scales: physical complaints, motor functioning, autonomy, cognitive and social functioning, positive and negative emotions. The correlations between child and parent reports varied from -.10 to .99 amongst the various chronic conditions. Children reported lower HRQoL on the physical complaints, motor functioning and positive emotions scales. Parents reported lower HRQoL on the social, and negative emotions scales. The child and the parent provide different information on HRQoL. Knowledge of both judgements seem necessary in the care of children with a chronic illness and their parents.

Language: English

Keywords: Chronic diseases, general / Quality of life / Parents / Questionnaires

**Scholte EM, Douma M. Validiteit en betrouwbaarheid van de VSPTS. (Validity and reliability of the VSPTS). *Kind en Adolescent*, 1999; 20(1): p.22-43
NIVEL: C 6490**

Validity and reliability of the behaviour scales and personality scales of the "Vragenlijst Sociale en Pedagogische Situatie" (VSPTS, Questionnaire Social

and Pedagogical Situation) have been tested on 250 adolescents in residential centers for physically handicapped and chronically ill young people. The scales that have been scored by group leaders show to be satisfactory internally consistent and the judgement of different people turned out to be reliable in comparison. The concept validity of the behaviour scales was covered by the comparable scales of the CBCL. The CBCL division of “young people with and without clinical problems” could well be predicted by the VSPS scales. The VSPS not only studies behavioural development aspects and emotional development aspects, but also several personal characteristics; this could be regarded to create additional value compared to the CBCL.

Language: Dutch

Keywords: Chronic diseases, general / Adolescents / Psychosocial problems / Behaviour problems / Questionnaires

Spieth LE, Harris CV. Assessment of health-related quality of life in children and adolescents: an integrative review. *Journal of Pediatric Psychology*, 1996; 21(2): p.175-193
NIVEL: C 6503

The aim of this review is to present and integrate the medical and psychological literature on the assessment of health-related quality of life (QOL) in paediatric populations. Definitions of QOL and the utility, health status, battery, and modular approaches to QOL assessment are presented. Measures currently available for use with children and adolescents were evaluated with respect to psychometric properties, QOL domains included, targeted age range, mode of administration, number of items, and time period assessed. The need to address methodological issues and practical barriers so as to encourage the inclusion of QOL outcomes in future clinical trials and other research is discussed.

Language: English

Keywords: Chronic diseases, general / Quality of life / Questionnaires / Reviews

2 Social Participation

2.1 Social participation from the patient's perspective

Bawden HN, Stokes A, Camfield CS, Camfield PR, Salisbury S. Peer relationships problems in children with Tourette's disorder or diabetes

mellitus. *Journal of Child Psychology and Psychiatry*, 1998; 39(5): p.663-668
NIVEL: C 6390

The purpose of this study was to get insight into the peer relationships, social skills, self esteem, parental psychopathology, and family functioning of children with Tourette's disorder. A sample of children with Tourette's disorder was compared with a chronic disease control group of children with diabetes mellitus. Children with Tourette's disorder had poorer peer relationships than their classmates and were more likely to have more extreme scores reflecting increased risk of peer relationship problems than children with diabetes mellitus, but did not report self esteem problems or social skills deficits. Measures of peer relationships were not related to severity or duration of tics. Children with Tourette's disorder and Attention Deficit Hyperactivity Disorder were at increased risk for poor peer relationships. The psychosocial problems of children with Tourette's disorder do not appear to be the generic result of having a chronic disease.

Language: English

Keywords: Tourette syndrome / Diabetes mellitus / Peer relations / Self esteem / Social adjustment

Bergers J, Nijhuis F, Janssen M, Horst F van der. Employment careers of young Type I diabetic patients in the Netherlands. *Journal of Occupational and Environmental Medicine*, 1999; 41(11): p.1005-1010
NIVEL: C 6534

The aim of this study was to examine the factors that influence the employment careers of young adults with diabetes. Diabetic patients, aged 20 to 34 years, were studied using a mail questionnaire. The study included all members of the Dutch Diabetic Association in that age group. A total of 5987 questionnaires were mailed: 4300 completed questionnaires were returned, giving a response rate of about 72%. The focus was on problems type I diabetic patients face in the labour market: entry into the labour market, conditions at work, and (premature) exit from the labour market owing to health problems. This study carefully distinguished between employability and employment. Results showed that having diabetes did not decrease the chance of entry into the labour market for the subjects, although some types of jobs are still unavailable for diabetic patients. There was no higher unemployment in the study population than in the general population.

Although there were problems faced by patients in the work situation, they were generally limited to a small group.

Language: English

Keywords: Diabetes mellitus / Young adults / Employment

Choquet M, Du Pasquier-Fediaevsky L, Manfredi R. Sexual behavior among adolescents reporting chronic conditions: a French national survey. *Journal of Adolescent Health*, 1997; 20(1): p.62-67

NIVEL: C 6401

The purpose of this study was to compare sexual behaviour in adolescents with a physical handicap or a chronic illness (HCI, n = 604) to a healthy group (HG, n = 7,332). Data drawn from a French national health survey carried out among 7,936 adolescents (mean age = 16.2 years) were used. A self-report questionnaire concerning health behaviour, sexual behaviour, and chronic illness was used in 136 public secondary schools. HCI and HG groups were compared on reported sexual behaviour as well as on information (on sexuality, AIDS, and pregnancy) given by the parents. Logistic regression was performed for boys and girls to explore the relationship of health status (HCI or HG) to sexual intercourse, adjusted for sociodemographic variables. Fifty-two percent of HCI boys and 38% of HCI girls reported sexual intercourse (vs. 42% of HG boys and 28% of HG girls). The HCI girls reported more often than HG girls changing partners, pregnancy, and use of oral contraceptives. The HCI boys reported more often than HG boys receiving information on sexuality from their parents. It can be concluded that French HCI adolescents are at high risk for pregnancy and sexually transmitted diseases (STD).

Language: English

Keywords: Chronic diseases, general / Adolescents / Sexual behaviour / Sexual education

Dawkins JL. Bullying, physical disability and the paediatric patient. *Developmental Medicine and Child Neurology*, 1996; 38(7): p.603-612

NIVEL: C 6408

The aim of this study was to compare the rates and types of bullying in two groups of paediatric patients: those attending the Child Development Center with conditions affecting their appearance or gait and a control group of those attending a general paediatric outpatient clinic with conditions not associated with visible abnormality. The children completed Olweus' self

report bullying questionnaire anonymously. Using logistic regression analysis, the most important variables found to increase a child's chance of being bullied were having fewer friends, being alone at playtime, being male and requiring extra help in school. Significantly more of the group from the Child Development Centre were bullied during the term. However, there was no indication that the children attending the Child Development Centre with a visible disability were more likely to be victims than the control group once these four factors were taken into account.

Language: English

Keywords: Chronic diseases, general / Bullying / Peer relations

Dolgin MJ, Somer E, Buchvald E, Zaizov R. Quality of life in adult survivors of childhood cancer. *Social Work in Health Care*, 1999; 28(4): p.31-43
NIVEL: C 6535

The purpose of this study was to assess the long-term adjustment and quality of life of adult survivors of childhood cancer in the domains of educational achievement, employment status, military service, family status, health, and psychological well-being. Sixty-four adult survivors of childhood cancer participated. Subjects had been diagnosed with cancer prior to age 18, were three years or more off therapy with no evidence of disease, and over 18 years old at the time of the study. Data from structured interviews were compared to responses on similar items from a control group with no history of serious illness during childhood, matched for age, sex, and parental education levels. Results indicated an overall pattern of integration into the social mainstream, with similar objective levels of achievement for survivors and controls for most measures of education, employment, significant relationships, and psychological well-being. Results also indicated certain areas of disadvantage, such as military recruitment difficulties, lower income levels, and higher rates of workplace rejection. Significantly, almost 50% of the survivors reported subjective feelings that their illness experience had impaired their achievement in several domains. Quality of life is considered an important outcome parameter in terms of clinical decision making as well as in guiding preventive and supportive intervention efforts.

Language: English

Keywords: Cancer / Survivors / Young adults / Academic achievement / Social participation / Employment / Peer relations / Quality of life

Ellerton ML, Stewart MJ, Ritchie JA, Hirth AM. Social support in children with a chronic condition. *Canadian Journal of Nursing Research*, 1996; 28(4): p.15-36
NIVEL: C 6423

The purpose of this study used was to investigate social support in children with a chronic condition and how children use social support in coping with everyday demands and demands related to their condition. A descriptive exploratory design was used. Participants comprised 62 school-aged children (16 with diabetes, 16 with cystic fibrosis, 15 with spina bifida, and 15 with no chronic illness). Data were collected about their social support networks, the support functions provided by the networks, and their satisfaction with support. The children also described the social support they received and their use of social support as a coping strategy in specific stressful situations. The healthy children had the largest support networks overall and the largest peer networks. Children with spina bifida had the smallest networks overall and the smallest number of peers in their networks. Healthy children reported more support overall than the children in the illness groups. Both the healthy children and the children with a chronic condition described academic issues as the main source of everyday stress. Children with a chronic condition identified restriction due to illness as the key illness-related stressor. Children with a chronic condition reported more stress and more support seeking in everyday stressful situations than in illness situations. The results will guide the design of a future social support intervention for children with a chronic condition.

Language: English

Keywords: Diabetes mellitus / Cystic fibrosis / Spina bifida / Social support / Coping / Psychological stress

Herwaarden MA van, Berge M ten, Prakken ABJ, Sinnema G, Kuis W, Net J van der. De gevolgen van polyarticulaire juveniele chronische artritis in het dagelijks leven. (Effects of polyarticular juvenile chronic arthritis in daily life.) *Nederlands Tijdschrift voor Geneeskunde*, 1997; 141(4): p.192-196

This study was aimed at gaining an insight into the effects of polyarticular juvenile chronic arthritis, or JCA, on the functioning and the quality of life of children. Patients with polyarticular JCA who were to return within half a year for polyclinical checkups were asked to take part in the study. Twenty-three children were checked on the disease. The diseases was assumed to be

active when the blood showed signs of inflammation. Functional impairment was studied by assessing joint swelling, joint pain and mobility limitations and deviations on X-rays of the wrists. Functional limitations were studied by using questionnaires with questions on the limitations patients encounter in daily life. Handicaps were studied using questionnaires with questions on pain, well-being, behaviour and fear. Six out of 22 patients were in the active phase of the diseases, as was concluded based on laboratory data. All patients suffered, on the whole, from either pain or swollen joints, or both. 21 Out of 22 patients showed X-ray deviations on both radio-carpale joints. 3 Out of 17 children had not suffered any pain in the previous week and 1 out of 16 children did not feel hampered by his illness in daily life activities. At school, these children were less active than their healthy peers and they did not perform as well as their healthy peers. Social life was limited for the girls and many of them showed internalising behaviour. The patients did not differ from their healthy peers in feelings of fear and their behaviour. Only 6 patients turned out to be in the active phase of the illness; nevertheless, the whole group of patients showed deviations in all aspects of the illness, in joint problems, functional limitations and handicaps, To gain insight into the effects on the functioning of these children and their quality of life, the issue has to be studied from different points of view. Additionally, custom-made treatment can be started, based on the results of this research.

Language: Dutch

Keywords: Rheumatoid arthritis / Quality of life / Activities of daily living / Pain / Anxiety / Academic achievement / Psychosocial problems

Holaday B, Swan JH, Turner-Henson A. Images of the neighbourhood and activity patterns of chronically ill schoolage children. *Environment and Behavior*, 1997; 29(3): p.348-373
NIVEL: C 6443

The aim of this study was to examine the perceptions of chronically ill school-age children and their parents of their immediate social and physical environment. Three hundred and sixty-five chronically ill children (ages 10 through 12) were interviewed about their neighbourhood. The children described aspects of their neighbourhood that they liked and disliked, and their activity patterns alone and with peers. The parents also evaluated neighbourhood safety. Regression analysis was used to identify parent-and-child-reported items that may have influenced images of neighbourhood safety. The findings demonstrate that chronically ill children's activity patterns in their neighbourhoods are influenced by child factors (perception

of the neighbourhood and its safety, gender, type of illness) and by parental factors (perception of neighbourhood safety, income, home ownership). The findings also suggest that the patterns of interaction of chronically ill children with their neighbourhood may be a source of developmental risk.

Language: English

Keywords: Chronic diseases, general / Home environment / Safety / Leisure

Houx L, Jongma J. Meldpunt “ Ervaringen van jongeren met een handicap of chronische ziekte en werk”. (Experiences of disabled young people or young people with a chronic illness and work.) Utrecht: Jopla, Gehandicaptenraad, 1999
NIVEL: R 9924

This small scale study was started as a result of a new law in the Netherlands, the “wet op de (Re)integratie van Arbeidsgehandicapten (REA, reintegration of people incapacitated for work)”, in 1998. The law was meant to stimulate employers to employ disabled people or people with a chronic illness. It was not clear whether this law improved the facilities for young people on the labour market. To gain insight into this question, young people were invited to speak about their experiences by telephone. A total of 33 youngsters responded and they were interviewed by means of a questionnaire. Eleven out of the 33 respondents earned money out of labour, five of whom had found their job by employment mediation. Thirteen respondents in total had taken part in an employment mediation route. Nine respondents thought to have received sufficient support and judged the quality of the support as satisfactory to good. Six respondents were offered extra training and were examined on their abilities for the job market. Six respondents had had to wait. Four respondents had had results by job mediation. The authors concluded that it is difficult to involve youngsters with a handicap or chronic illness in job mediation and that, in the end, only few of these youngsters succeed in finding a job on the regular job market. The authors conclude with a list of recommendations to improve this situation.

Language: Dutch

Keywords: Chronic diseases, general / Adolescents / Young adults / Employment / Vocational rehabilitation

Huizen RS van, Visser EM, Vros EM, Wisse SC. Pesten: een extra handicap. Een exploratief onderzoek naar de beleving van pesten bij

lichamelijk gehandicapte en /of chronisch zieke kinderen in de leeftijd van 10 tot 15 jaar. (Bullying: an extra handicap. An exploratory study into the experiences with bullying of physically handicapped children and chronically ill children aged 10 to 15 years.) Utrecht: Universiteit Utrecht, Wetenschapswinkel Sociale Wetenschappen, 1998
NIVEL: R 9906

Prestudies of the JOPLA, a platform for youngsters with a handicap or chronic illness, showed that many of these youngsters are bullied. Bullying turned out to be the reason to leave regular education and visit a special school. This study was set up to explore to what extent, in what way and why these youngsters are bullied. Children aged 10 to 15 years (n=38), who frequented regular school education, or had moved to a special school after one or two years of regular education were studied. The answers on the questionnaire showed that they were bullied more often than children without handicaps or chronic illnesses, i.e. 10.8% vs 2.2%. They blamed it on their handicap or chronic illness. Children who had moved to a special school did not indicate that they had decided to do so for being bullied, but because they were not satisfied with the school. However, they had been bullied significantly more often at their previous school than the respondents who were frequenting regular school education. Bullying, the way the school handles bullying and encounters handicapped children appears to be related.

Language: Dutch

Keywords: Chronic diseases, general / Bullying

Ipsa Facto. Tussen vraag en aanbod: Onderzoek naar wenselijkheden en mogelijkheid van loopbaanbegeleiding voor chronisch zieke jongeren. (Between offer and demand: study into the desirability and possibility of career mediation for chronically ill young adults.) Houten: Ipsa Facto, 1991
NIVEL: C 6539

This publication reports on the results of several sub-studies into the social problems of chronically ill young adults at school, during their study and at work. The problems young people encounter during their school period, when choosing a profession and when looking for work have been collected. Additionally, the question whether young people would like to receive help and guidance in making choices and what kind of help and guidance they need was explored. The researchers looked into the question whether the available help and guidance is sufficient. Based on a discrepancy they

discovered between offer and demand, they suggested to experiment with mediation for the children at school, in their careers and in finding work.

Language: Dutch

Keywords: Chronic diseases, general / Adolescents / Young adults / School / Vocational education / Employment / Needs assessment

Jacobson AM, Hauser ST, Cole C, Willett JB, Wolfsdorf JI, Dvorak T, Wolpert H, Herman L, Groot M de. Social relationships with young adults with insulin-dependent diabetes mellitus: ten-year follow-up of an onset cohort. *Diabetic Medicine*, 1997; 14(1): p.73-79

NIVEL: C 6447

The aim of this study was to examine aspects of close peer relationships of young adults with diabetes mellitus (IDDM). A longitudinal study was conducted in which a cohort of children and adolescents with IDDM (n = 57) and an age-matched group of children and adolescents who were originally recruited after an acute illness, accident, or injury (n = 54) were followed for 10 years. Now aged 19-26 years, these two groups were compared in terms of their friendship patterns, dating and love experiences, and sense of loneliness. All subjects in both groups had at least one friend. However, the IDDM group reported fewer friendships overall. The difference was accounted for by the number of less intimate friends. The two groups had similar frequencies of current romantic partners (IDDM = 63%; comparison group = 64%). While dating attitude and dating assertiveness did not differ between groups, some differences were found in terms of experiences of a primary love relationship. IDDM patients experienced less trust and sense of intimate friendship in these love relationships. No differences in loneliness were found. The preponderance of these findings indicate that the two groups had similar patterns and experiences of close peer relationships. Thus, the study does not suggest that IDDM leads to serious problems in forming social relationships for these patients during the transition to young adulthood. On the other hand, the IDDM patients' lower level of trust and intimacy within love relationships are consistent with other findings from this study suggesting specific areas of lowered self worth that appear in social relationships.

Language: English

Keywords: Diabetes mellitus / Young adults / Peer relations / Friendship

Kokkonen J, Kokkonen E-R, Saukkonen A-L, Pennanen P. Psychosocial outcome of young adults with epilepsy in childhood. *Journal of Neurology, Neurosurgery, and Psychiatry*, 1997; 62(3): p.265-268
NIVEL: C 6457

The aim of this study was to evaluate social maturation and psychiatric morbidity in young adults treated for epilepsy during their childhood. Eighty one young adults (43 women, 38 men, mean age 22.3 years) with epilepsy during their childhood were interviewed about their social development and psychiatric symptoms. The results were compared with those from 211 randomly selected controls (106 women, 105 men, mean age 23.2 years). Compared with the controls the patients had more often not succeeded in passing the normal comprehensive school (20% v 2%) or had left school at the secondary level (53% v 46%) and remained without any vocational education (27% v 11%). There was no significant difference in the employment status of those with work between the patients and the controls. The patients were significantly more often labelled with poor social maturation and dependent lifestyle factors such as living with their parents. However, risk analysis showed that neither the disease itself nor antiepileptic medication were significant predisposing factors for poor social adjustment but low or borderline mental capacity or learning disabilities relating to epilepsy were. Psychiatric morbidity was similar in both groups. The social handicap found in a certain group of young adults with epilepsy during childhood is largely associated with neurological and cognitive impairments other than epilepsy itself. With the present mode of treatment epilepsy itself does not seem to disturb adolescent social and psychological development.

Language: English

Keywords: Epilepsy / Young adults / Mental disorders / Social development / Academic achievement / Employment

Kokkonen J. The social effects in adult life of chronic physical illness since childhood. *European Journal of Pediatrics*, 1995; 154(8): p.676-681
NIVEL: C 6537

The aim of this study was to examine the social outcome in patients with juvenile onset chronic physical disorders. An unselected group of 487 patients (222 females, 265 males), aged 19-25 years, and an age-matched group of 202 physically healthy controls were involved in this study. The interview covered both comprehensive and vocational schooling, data on their employment status, relationship to parents and sexual development in

detail. The overall social maturation index showed poor social maturation in patients more often than in the controls. At the time of the study 23% of the patients and 11% of the controls had no vocational education or were not on their way to gaining it. Excluding those with a disability pension (10%), working experience, employment status and unemployment were fairly similar in both groups. Sexual development was delayed more often in the patients than in the controls and the patients were significantly more often unmarried and living in the same household as their parents. However, social and psychological factors accumulating in excess in the patient group were observed more significant than the physical disease to the delayed social maturation. It can be concluded that among patients with chronic physical disorders there is a minor group with delayed social maturation. Those at risk can easily be recognised even before adolescence in order to offer them and their parents support to achieve reasonable social development in early adulthood.

Language: English

Keywords: Chronic diseases, general / Young adults / Social participation / Vocational education / Employment / Sexual development

Lock J. Psychosexual development in adolescents with chronic medical illnesses. *Psychosomatics*, 1998; 39(4): p.340-349
NIVEL: C 6465

The aim of this review is to give an overview of studies on the psychosexual development in chronically ill adolescents, in order to assist clinicians working with medically ill adolescents with psychosexual issues. MEDLINE and PsychINFO database searches of English-language medical journal articles published between 1986 and 1997 for articles related to medical illness and psychosexual development in adolescence were done. The author found that little systematic research on the psychosexual implications of medical illnesses for adolescents has been undertaken, but existing studies suggest that psychosexual development is negatively affected by medical illness. A three-phase model of adolescent psychosexual development is presented, with specific psychosexual tasks associated with each phase. Impediments to progressing through adolescent psychosexual phases due to medical conditions are identified, and case examples are provided. The author concludes that clinicians working with adolescents with medical conditions should attend to the possibility of psychosexual impediments in these adolescents and use developmentally appropriate methods for assessing and treating these difficulties when they arise.

Language: English

Keywords: Chronic diseases, general / Adolescents / Sexual development / Explanatory models / Reviews

Nassau JH, Drotar D. Social competence among children with central nervous system-related chronic health conditions : a review. *Journal of Pediatric Psychology*, 1997; 22(6): p.771-793
NIVEL: C 6473

The aim of this review is to give an overview of empirical studies of social competence among children with central nervous system (CNS) related chronic health conditions. The overwhelming majority of studies evaluated social competence at the level of social adjustment; the domains of children's social performance and social skills were relatively neglected. Findings are criticised with respect to conceptualisation of social competence among children with CNS conditions and methodological considerations. Directions for future research include expanding the conceptualisation of social competence in this population to include social demands and competencies specific to children with CNS conditions and utilising explicit theoretical frameworks that allow for competing hypotheses to be tested.

Language: English

Keywords: Nervous system diseases / Epilepsy / Spina bifida / Cerebral palsy / Social adjustment / Social skills / Reviews

Scheffer N. *Stappen in de goede richting: stappenplan voor leerlingen met JCA in het reguliere onderwijs. (Steps in the right direction: a step-by-step scheme for pupils in regular education.)* Groningen: MO-A Pedagogiek, 1994
NIVEL: R 9903

Key question in this text is which problems and bottlenecks pupils with juvenile chronic arthritis encounter at school. Data on experiences of children with JCA and their parents have been collected. Possibilities to support them have been assessed. The study resulted in a step-by-step scheme for children and their parents as a guidance in finding their way in school education and in the social support systems.

Language: Dutch

Keywords: Rheumatoid arthritis / School

Sexson SB, Dingle AD. Medical problems that might present with academic difficulties. *Child and Adolescent Psychiatric Clinics of North America*, 1997; 6(3): p.509-522

NIVEL: C 6494

This article discusses the effects of chronic medical illnesses and their treatment on children's academic adaptation, both as primary effects (neurocognitive changes) and secondary effects (e.g. school absences, illness-induced stress, constraints on physical and social activities, and decreased expectations from family, school, and the health care team). Some common disease entities (e.g. asthma, cancer, haematologic disorders, HIV, aids, insulin-dependent diabetes mellitus, sensory impairment) and their treatment modalities are summarised along with more general concepts applicable to the evaluation of any child with a chronic illness who may be experiencing academic difficulties. Pertinent review articles regarding the specific illnesses are cited.

Language: English

Keywords: Asthma / Cancer / Hiv / Aids / Diabetes mellitus / Haematological diseases / School absenteeism / Academic achievement

Seiffge-Krenke I. The capacity to balance intimacy and conflict: differences in romantic relationships between healthy and diabetic adolescents. *New Directions for Child Development*, 1997; 78: p.53-67

NIVEL: C 6492

The aim of this study was to explore developmental changes in romantic relations of adolescents who differ in health status. Whereas healthy adolescents were increasingly able to balance both intimacy and conflict in their relationships with romantic partners, diabetic adolescents were unable to experience both positive and negative relationship qualities. Although this developmental delay was partly overcome, after four years some differences were still noticeable.

Language: English

Keywords: Diabetes mellitus / Adolescents / Peer relations / Sexual development

2.2 Social participation from the family's perspective

Banis S, Peer DR van, Suurmeijer ThPBM. Pedagogische onzekerheid en overbescherming bij ouders van kinderen met hemofilie: verklarende

factoren en gevolgen. (Pedagogical insecurity and over-protection in parents with children suffering from haemophilia: explanatory factors and consequences.) *Pedagogische Studiën*, 1999; 76(3): p.157-169
NIVEL: C 6387

This article discusses the pedagogical insecurity and over-protection in parents of children suffering from haemophilia. The following issues have been studied: (1) what are the effects of the clinical characteristics of children and the emotional reactions of the parents on the educational characteristics (2) is there a link to be drawn between the protective behaviour of the parents and the social participation of the children. One hundred and eight mothers of sons with haemophilia between the age of 0 to 12 years have been interviewed. The mothers' emotional reactions turned out to affect the pedagogical insecurity and over-protective behaviour more than the clinical characteristics of the sons. Additionally, a positive link has been established between the number of behavioural limitations the sons had to experience and negative encounter with peers.

Language: Dutch

Keywords: Haemophilia / Parent-child relations / Social participation

Loomis JW, Javornisky JG, Monahan JJ, Burke G, Lindsay A.
Relations between family environment and adjustment outcomes in young adults with spina bifida. *Developmental Medicine & Child Neurology*, 1997; 39(9): p.620-627
NIVEL: C 6466

The aim of this study was to explore the relations between family environment and employment, community mobility, residential independence and social activity in young adults with spina bifida. Thirty-two young adults with spina bifida completed a questionnaire (Family Environment Scale) assessing their perceptions of family social environment while growing up. Additionally, subjects responded to a structured interview addressing their current employment status, residential situation, level of community mobility, and extent of social activity. Multiple logistic regression analyses were used to assess the relation between family environment and adjustment as a young adult. With this limited sample, results indicated that perceived family environment explained variance in employment, community mobility, and social activity as an adult, even beyond that explained by lesion level and intelligence. Regression coefficients showed positive relations between perceived family

encouragement of independence and achievement and young adult outcomes. In contrast, perceived moral/religious emphasis of the family and degree of family involvement with intellectual/cultural activities evidenced negative relations with the measures of young adult adjustment.

Language: English

Keywords: Spina bifida / Young adults / Family relations / Employment / Social participation / Housing / Autonomy

Meyers MK, Lukemeijer A, Smeeding T. The cost of caring: childhood disability and poor families. *The Social Service Review*, 1998; 72(2):

p.209-233

NIVEL: C 6538

Children in poor families are at heightened risk for disabilities and chronic health problems, and care for these children can impose substantial costs on families and public programs. Although the prevalence and costs of disabilities among poor children have important policy implications, they have been largely overlooked in research on poverty and welfare and on the costs of childhood disabilities. The aim of this study was to examine the prevalence of childhood disabilities and chronic illness among welfare recipient families in California and the probability families caring for these children experience higher out-of-pocket costs and material hardship than do other similar families.

Language: English

Keywords: Chronic diseases, general / Socioeconomic factors

Schmidt C, Seiffge-Krenke I. Freundschaftsbeziehungen und familiäre Beziehungen aus der Sicht chronisch kranker und gesunder Jugendlicher: Unterschiede in den Beziehungsqualitäten und Veränderungen über die Zeit. (Perceptions of friendships and family relations in chronically ill and healthy adolescents: quality of relationships and change over time.) *Psychologie in Erziehung und Unterricht*, 1996; 43(2): p.155-168

NIVEL: C 6489

The aim of this study was to examine the development of peer relations and family relations in chronically ill and healthy adolescents. This study was part of a longitudinal project on coping with chronic illness in adolescence. Subjects were 91 male and female German school-age children and

adolescents (age at baseline = 12-16 years) with diabetes and 107 normal male and female German school-age children and adolescents (age at baseline = 12-16 years). Over a 4-year period, the subjects and their parents completed annual interviews and questionnaires assessing the adolescents' relationships with their families and peers. Changes in these parameters were determined with multivariate analysis of variance (MANOVA), and results from the 2 samples were compared. Marked differences in the development of friendships and the quality of the parent-adolescent relationship were found. The chronically ill adolescents described higher nurturance in their relationship to both parents, while they experienced less intimacy, affection and companionship in their friendships.

Language: German

Keywords: Diabetes mellitus / Adolescents / Parent-child relations / Friendship / Peer relations

Taanila A, Järvelin M-R, Kokkonen J. Cohesion and parents' social relations in families with a child with disability or chronic illness.

International Journal of Rehabilitation Research, 1999; 22(2): p.101-109
NIVEL: C 6511

The purpose of this study was to examine how a child's physical or intellectual disability or diabetes affects family cohesion, the parents' social life, work and leisure time activities, and whether there is any association between the parents' social relations and family cohesion. The parents of 89 children aged 12-17 years returned a questionnaire and were interviewed by a social worker. Family cohesion increased in all the groups by an average of 27%. The effect was smallest in the families of children with diabetes, whereas in the families with intellectual or physical disability family cohesion increased from 6 to 13 times more often compared to the families of children with diabetes. The increased family cohesion was not associated with the change in the parents' social relationships, work, career or leisure time activities; the importance of these activities did not decrease even though family cohesion increased. However, a child's chronic illness or disability affects the everyday life of the family, for instance 71% of the parents with diabetic children thought that the regularity of family life increased and about a half of the parents with physically or intellectually disabled children had to change their hobbies because of the child. In planning treatment and rehabilitation for a chronically ill or disabled child more attention should be paid to the whole family and its needs, not only to the child.

Language: English

Keywords: Diabetes mellitus / Mental retardation / Family relations / Parents / Social support / Employment / Leisure

Taanila A, Kokkonen J, Järvelin M-R. The long-term effects of children's early-onset disability on marital relationships. *Developmental Medicine and Child Neurology*, 1996; 38(7): p.567-577
NIVEL: C 6512

The aim of this study was to investigate the long-term effects of a child's chronic illness or severe physical or intellectual disability on parents and their marital relationship. The parents of 89 children with diabetes, mental retardation or a motor handicap, aged 14-17 years, were interviewed. The parents returned a questionnaire and a social worker interviewed them. One-fifth of the respondents had experienced the child's disability as contributing positively to the marital relationship. Twenty-five % reported impairment in some areas of the marital relationship, while only 7% felt that they had drawn apart from each other. A higher level of occupational education, insecurity at onset, heavy daily demands for care of the child, unequal distribution of tasks between the spouses and a lack of time for leisure activities were found to be risk factors for impaired marital satisfaction. Adequate information, a realistic notion of the illness or disability and practical advice for everyday life seemed to be the protective factors for the marital relationship.

Language: English

Keywords: Diabetes mellitus / Mental retardation / Motor disorders / Parents / Marital relationship

3 Self Management

3.1 Coping

3.1.1 Coping from the patient's perspective

Admi H "Nothing to hide and nothing to advertise". Managing disease-related information. *Western Journal of Nursing Research*, 1995; 17(5): p.484-501
NIVEL: C 6382

The aim of this study was to explore how adolescents and young adults with cystic fibrosis manage disease-related information through various developmental stages. The retrospective, longitudinal, life history method was used to generate a descriptive theory from accounts constructed with 21 informants: 10 adolescents and young adults with cystic fibrosis (CF) aged 16 to 25 years, and 11 of their significant family members. People chose a specific telling strategy according to the perceived ability of the audience to deal with the information and the situational context. Four strategies of managing disease-related information emerged: visibility, direct telling, silent telling, and concealment. The informants frequently chose information management strategies that enabled an ordinary style of living. These strategies neither reflect feelings of shame nor of pride, as it is suggested in the existing literature. Implications for theory, health care practice, and further research are discussed.

Language: English

Keywords: Cystic fibrosis / Adolescents / Young adults / Coping

Albaret MCh. L'Adolescent face au cancer: études du soi et des stratégies de coping. (The adolescent facing cancer: studies of the self and coping strategies.) *Neuropsychiatrie de l'enfance et de l'adolescence*, 1996; 44(6-7): p.240-247
NIVEL: C 6383

The aim of this study was to investigate the psychological impact of cancer on adolescents with regard to self representation and self esteem. A comparative study with 55 healthy and 33 ill adolescents was conducted. The main axis concerned the study of coping with the illness. Some sex-linked differences appeared in the results for the clinical population, girls being more weakened and utilising less coping strategies. Boys possess a direct emotional management which leads to problem-focalisation: the problem-focused coping is in close correlation with self esteem. It seems there is a differentiation in the resources and determinisms of coping facing emotional distress. In short, coping processes reflect a differential socialisation of emotions according to sex but also according to the social role and status.

Language: French

Keywords: Cancer / Adolescents / Self esteem / Coping

Boekaerts M, Röder I. Stress, coping, and adjustment in children with a chronic disease: a review of the literature. *Disability and Rehabilitation*, 1999; 21(7): p.311-337

The purpose of this review was give an overview of the literature on the consequences of having a chronic disease on the child's functioning in daily life. The body of literature is discussed in three parts: (1) the academic and psychosocial adjustment of chronically ill children, (2) the ways chronically ill children cope with disease-related stress and other stressors, and (3) the effectiveness of coping strategies. Children with a chronic disease do not show lower school performance despite higher absence rates. Their self-concept is similar to that of healthy children. However, they show more behaviour problems, especially internalising problems such as depression and social withdrawal. No evidence could be found for the claim that children with a chronic disease are more frequently confronted with stress than their healthy peers. Children with a chronic disease use a variety of coping strategies to deal with various disease-related and common stressors. The coping strategies they use in relation to common stressors appear to be similar to those of healthy children. It can be concluded that incidences of maladjustment vary across studies and different chronic diseases. Most studies on coping lack situational sensitivity, which makes it impossible to compare results. Findings on the effectiveness of these children's coping strategies are still scarce and inconclusive. Recommendations for future research on coping with chronic disease in childhood are given.

Language: English

Keywords: Chronic diseases, general / Quality of life / Academic achievement / Coping / Psychological stress / Reviews

Boyd JR, Hunsberger M. Chronically ill children coping with repeated hospitalizations: their perceptions and suggested interventions. *Journal of Pediatric Nursing*, 1998; 13(6): p.330-342
NIVEL: C 6394

The aim of this study was to explore how chronically ill children who are repeatedly hospitalised cope and how they feel others can assist them to cope with their recurrent hospital experiences. A qualitative research study with a grounded theory methodology was conducted. Six hospitalised children, ages 10 to 13 years, with various chronic conditions participated in an audiotaped interview, completed a drawing and kept a journal. The subjects identified their perceived stressors of hospitalisation; revealed their use of

both cognitive and behavioural coping strategies; described how hospital personnel, family, and friends enhanced their coping; and illustrated the impact of the hospital environment on their coping process. From comparison of the data, it is theorised that chronically ill children who are repeatedly hospitalised become adept at identifying and implementing a repertoire of coping strategies, accessing family and friends as resources in the coping process, developing patterns of coping with their parents, and utilising the hospital environment to promote coping. Their coping is enhanced by familiarity and knowledge and by the respect and patience of gentle, supportive, and competent health care professionals.

Language: English

Keywords: Chronic diseases, general / Hospitalisation / Coping / Social support

Christian BJ, d’Auria, JP. The child’s eye: memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing*, 1997; 12(1): p.3-12
NIVEL: C 7899

The aim of this study was to explore the ways adolescents with cystic fibrosis conceptualise their illness and related life events. A qualitative study was conducted, based on a grounded theory approach. A purposive sample of 20 adolescents (12-18 years of age) with cystic fibrosis were interviewed. Adolescents used three protective strategies for reducing a sense of difference with peers: (1) keeping secrets, (2) hiding visible differences, and (3) discovering a new baseline. “Good friends” were a critical source of support and decreased the importance of differences in their social world. Interventions should focus on strategies for dealing with difficult peer situations and the negative reactions of others.

Language: English

Keywords: Cystic fibrosis / Adolescents / Peer relations / Sick role / Coping

Doka KJ. The cruel paradox: children who are living with life-threatening illness. In: Corr CA, Corr DM (eds). *Handbook of childhood death and bereavement*. New York: Springer Publishing Company, 1996: p.89-105
NIVEL: C 6411

In this book chapter the ways in which children cope with life-threatening illnesses are explored. It begins by providing a general model of coping with

life-threatening illness, one that views life-threatening illness as a series of phases. In each of these phases, individuals have to cope with a unique set of tasks. The article further explores particular issues that arise as children struggle with life-threatening illnesses. Finally, the authors consider other children, siblings, and peers, who are affected by this struggle.

Language: English

Keywords: Chronic diseases, general / Coping / Parents / Siblings

Garrison WT. Coping with chronic medical illness: lessons from working with children and adolescents with diabetes mellitus. In: Pfeffer CR (ed). *Severe stress and mental disturbance in children*. Washington: American Psychiatric Press, 1996: p.307- 323
NIVEL: C 6434

This book chapter offers a review in which a number of empirical studies and conceptual ideas are presented that pertain to psychological factors in diabetes mellitus. Through this review it is hoped to derive lessons that serve to inform a broader conceptual understanding of stress and coping with chronic diseases during childhood.

Language: English

Keywords: Diabetes mellitus / Psychological stress / Coping / Mental disorders / Reviews

Gilbert MC. Coping with pediatric migraine. *Social Work in Health Care*, 1999; 28(3): p.21-38
NIVEL: C 6435

The purpose of this study was to explore the coping strategies which are used by children with paediatric migraine pain. An exploratory study was designed in which 8 children, aged 6-12 years, participated. The following three broad categories of coping and their subtypes emerged from the data: affective, cognitive, and problem-focused coping. Implications for practice, research, and education, particularly regarding the use of spirituality and prevention, are discussed.

Language: English

Keywords: Migraine / Pain / Coping

Grey M, Lipman T, Cameron ME, Thurber FW. Coping behaviors at diagnosis and in adjustment one year later in children with diabetes. *Nursing Research*, 1997; 46(6): p.312-317

The aim of this study was to determine the influence of coping behaviour used at diagnosis on metabolic control, psychosocial adjustment and self-perceived competence 1 year later. A total of 89 children (8 to 14 years of age; 48% male; 59% White) received follow-up quarterly from diabetes diagnosis to 1 year later. Findings indicated that, in general, although metabolic control worsened over the first year, psychosocial status and coping behaviours were stable. Boys had worse metabolic control than girls. Multiple regression analysis indicated that self-worth at 1 year postdiagnosis was associated with less use of spirituality (beta = .44), more use of humour (beta = .28), and more positive self care (beta = .28); and self-care was less likely to be positive in older children ($r = .32$). These variables accounted for 47% of the variance (39% adjusted) in general self worth when entry self worth was controlled. Poorer overall adjustment at 1 year postdiagnosis was associated with more use of avoidance behaviours (beta = .47) and poorer self care (beta = .71); and more use of avoidance was associated with older age. These variables accounted for 62% of the variance (58% adjusted) in adjustment when adjustment at diagnosis was controlled. Poorer metabolic control was associated with more use of avoidance (beta = .30) and female gender (beta = .39), and avoidance behaviours were more common in older children (beta = .12). This model predicted 33% of the variance (25% adjusted) in metabolic control 1 year after diagnosis.

Language: English

Keywords: Diabetes mellitus / Coping / Self care / Psychosocial problems

Kintner E. Adolescent process of coming to accept asthma: a phenomenological study. *Journal of Asthma*, 1997; 34(6): p.547-561
NIVEL: C 6451

The purpose of this study was to identify the essential structure of the process of acceptance of chronic illness by adolescents with asthma. Phenomenological design, method, and analysis within a life span developmental framework guided this study. The sample consisted of 6 adolescents diagnosed with asthma who were identified by health care professionals as verbalising and demonstrating acceptance of their chronic illness. The results have implications for diagnosing lack of acceptance and developing and testing interventions to facilitate acceptance.

Language: English

Keywords: Asthma / Adolescents / Coping

Kliwer W. Children's coping with chronic illness. In: Wolchik SA, Sandler JN (eds). *Handbook of children's coping. Linking theory and intervention*. New York: Plenum Press, 1997: p.275-300
NIVEL: C 6453

This book chapter offers a review of the research on the most prevalent chronic diseases experienced by children and adolescents, as well as diseases that are less common but present significant coping challenges. It begins by describing the extent of chronic illness in children and adolescents, then discusses the psychological impact of having a chronic condition. Models of children's adaptation to chronic illness are reviewed next, followed by a discussion of adaptive tasks and developmental issues faced by these children. A summary of interventions to facilitate adjustment and suggestions for future directions close out the article.

Language: English

Keywords: Chronic diseases, general / Coping / Psychosocial problems / Explanatory models

Phipps S, Fairclough D, Mulhern RK. Avoidant coping in children with cancer. *Journal of Pediatric Psychology*, 1995; 20(2): p.217-232
NIVEL: C 6480

The purpose of this study was to compare coping styles in children with cancer. A sample of children with cancer (n=66) and a normative control group of healthy children (n=414) participated. A newly designed instrument, the Children's Behavioral Style Scale (CBSS), was used. It was hypothesised that children in the oncology group would make greater use of an avoidant coping style (Blunting) than controls. Results confirmed the primary hypothesis: children with cancer endorsed greater use of blunting or avoidant coping than did healthy children. A new conceptual model of coping style was introduced utilising CBSS scores to identify children as Monitors, Blunters, Active or Passive copers. Using this model, a similar proportion of Active and Passive copers were found in both groups, while the shift towards Blunting in the oncology group was accentuated. Within the oncology group, a positive relationship between Blunting scores and time elapsed since diagnosis was observed, suggesting that the increased Blunting in children with cancer is a reactive phenomenon, at least partly a response

to the contingencies of cancer and its treatment. These findings may provide an alternative interpretation to previous reports of increased defensiveness and repression in children with cancer.

Language: English

Keywords: Cancer / Coping / Questionnaires

Pretzlik U. *Children coping with a serious illness: a study exploring coping and distress in children with leukaemia or aplastic anaemia.*

Amsterdam: SCO-Kohnstamm Instituut, 1997

NIVEL: B 4859

The six studies reported here were designed to describe the ways seriously ill children cope with their illness and treatment, and to explore factors (both individual and familial) which influence their coping. The choice of instruments and design was influenced by the Lazarus and Folkman transactional model of stress and coping (1984), especially their concept of coping. In the first study the Kidcope Checklist was adapted to a younger British sample. Validity and test-retest reliability were established. In the five hospital based studies 53 children (7-16 years) and their parents took part. All the children had leukaemia or aplastic anaemia. Children's coping was examined in detail by applying a variety of research methods, which included observation during a medical procedure, a questionnaire about children's perception of competence and self-worth and a semi-structured interview about their coping strategies. Parental coping and the social environment of the family were studied through Coping Health Inventory for Parents and the Family Environment Scale. Results show that the children's coping was significantly related to the context of the problem but much less to the individual differences. Children who rated themselves at interview as more distressed during the blood test were observed to show more distress behaviour. Children who were observed taking an active interest in the blood test displayed less distress behaviour and had higher self esteem than children who showed no interest in the procedure. Results from parents and the family are discussed with reference to the children's self-reported and observed coping. Some relationships were found between parents' coping with their child's illness, the social climate of the family and the children's way of coping.

Language: English

Keywords: Leukaemia / Anaemia / Coping / Self esteem / Psychological stress / Family relations / Questionnaires

Roth M. Körperbezogene Kontrollüberzeugungen bei gesunden und chronisch kranken Jugendlichen. (Body-related locus of control in healthy and chronically ill adolescents.) *Praxis der Kinderpsychologie und Kinderpsychiatrie*, 1999; 48(7): p.481-496
NIVEL: C 6483

The aim of this study was to analyse body-related locus of control beliefs in healthy and chronically ill adolescents. A second aim was to examine the influence of locus of control beliefs on psychosocial adaptation. A sample of asthmatic and diabetic adolescents and a sample of healthy adolescents aged 12 to 16 were examined using the KLC-questionnaire. The questionnaire measures the locus of control concerning health, appearance and physical ability. Regarding the structure of body-related locus of control beliefs, the results show no differences between healthy and chronically ill adolescents; but the ill adolescents show less external locus of control. In the sample of chronically ill adolescents the locus of control is independent of severity and duration of their illness. Significant correlations between external locus of control and psychosocial adaptation could only be found in healthy adolescents. The results are discussed based on illness-specific experiences and general characteristics of adolescent body image.

Language: German

Keywords: Asthma / Diabetes mellitus / Adolescents / Attitude / Psychosocial problems

Ryan-Wenger NA. Children, coping, and the stress of illness: a synthesis of research. *Journal of the Society of Pediatric Nurses*, 1996; 1(3): p.126-138
NIVEL: C 6485

The aim of this review is to synthesise and comment on 32 research articles published since 1980 on coping strategies used by children with chronic or acute illness, to identify gaps in the research base, and to provide direction for practice, future research, and theory development. Children's repertoire of coping strategies is the same during health and illness, although the frequency or effectiveness of some of the strategies is often different. Much more in-depth descriptive and longitudinal research is needed, particularly how, when, and why coping strategies are learned, retained, and later discarded. Research is needed to examine the relationship between coping and health outcomes, and on the effectiveness of nursing interventions designed to influence children's coping behaviour.

Language: English

Keywords: Chronic diseases, general / Coping / Psychological stress / Reviews

Woodgate RL. Adolescents' perspectives of chronic illness: "It's hard".

Journal of Pediatric Nursing, 1998; 13(4): p.210-223

NIVEL: C 6525

The aim of this study was to elicit detailed descriptions of adolescents' chronic illness experiences. An exploratory, qualitative study with tenets from grounded theory was used, guided by the philosophy of symbolic interactionism. Understanding the adolescents' experiences included exploring adolescents' perspectives of the following: (1) what it is like to have a chronic illness, and (2) how they deal with having a chronic illness. A sample of 23 adolescents, 13 to 16 years of age, and diagnosed with either diabetes, asthma, arthritis, Crohn's disease, or ulcerative colitis participated. Data collection involved the adolescents participating in open-ended interviews. The constant comparative method was used to analyse all data from the interviews. The findings revealed that having a chronic illness made life more difficult for the adolescents. Adolescents experience extra effort, restriction, pain, and additional worries because of having a chronic illness. However, adolescents also clearly had ways to help them deal with their illness. These strategies and recommendations for practice and future research are discussed.

Language: English

Keywords: Diabetes mellitus / Asthma / Rheumatoid arthritis / Crohn's disease / Ulcerative colitis / Adolescents / Sick role

3.1.2 Coping from the family's perspective

Bluebond-Langner M. *In the shadow of illness: parents and siblings of the chronically ill child*. Princeton, New Jersey: Princeton University Press, 1996

NIVEL: B 4888

The author presents an ethnography of the everyday lives of the families and the siblings of children who have cystic fibrosis. This is done in the form of accounts by members of nine different families, who are at different points in the progression of the disease. The major issues the parents face and the ways in which they deal with them over the course of the illness are discussed. The relationship between the strategies that parents adopt and the

well sibling's views of the disease and their sibling's condition are examined. The role of the parents strategies and the well sibling's views in how the siblings conduct their relationships with their parents and ill siblings are examined as well as how the well siblings and other members of the family perceive the well siblings' position in the family.

Language: English

Keywords: Cystic fibrosis / Siblings / Parents / Coping / Family relations

Bower AM, Hayes A. Mothering in families with and without a child with disability. *International Journal of Disability, Development and Education*, 1998; 45(3): p.313-322

NIVEL: C 6393

The aim of this study was to compare mothers' perceptions of their family life in three different family environments, those without a child with disability and those families who live with an intellectual or physical disability, respectively Down syndrome and spina bifida. All families had children in the middle childhood period, allowing the mothers to reflect on earlier experiences and changes in their family life. Mothers' psychological characteristics are explored in terms of the coping resources they utilise when meeting stressful life situations in their family and how their personal resilience and vulnerability is related to these individual coping resources.

Language: English

Keywords: Spina bifida / Mental retardation / Mothers / Coping / Family relations / Quality of life

Clark SM, Miles-Shandor M. Conflicting responses: the experiences of fathers of infants diagnosed with severe congenital heart disease. *Journal of the Society of Pediatric Nurses*, 1999; 4(1): p.7-14

NIVEL: C 6402

In this study the experiences of fathers of infants newly diagnosed with severe congenital heart disease were explored. Subjects were 8 fathers, aged 23-40 years, whose infants were hospitalised for severe congenital heart disease, were technology dependent at time of enrolment, and were expected to have serious chronic health problems at discharge. Involvement of fathers with their infants after birth is important for continued development of the father's role and for the infant's well-being. Semistructured interviews were conducted in the hospital and the home until the child reached 15 month

adjusted age. Findings indicate that fathers experience 4 interrelated conflicting reactions: the joy of seeing the child born and becoming a father, plus the sadness and loss associated with the baby's illness; the challenge of becoming attached while dealing with fears about the infant's vulnerability and potential death; the need to try to maintain control while feeling a loss of control; and the struggle to remain strong for others while hiding their intense emotions. Findings have implications for intervening with fathers during the early diagnostic phase of a serious illness, particularly serious congenital heart disease.

Language: English

Keywords: Congenital heart defects / Infants / Fathers / Parent-child relations / Psychological stress / Coping

Cohen MH. The stages of prediagnostic period in chronic, life-threatening childhood illness: a process analysis. *Research in Nursing & Health*, 1995; 18(1): p.39-48
NIVEL: C 6404

This article explicates a theory of family behaviour under conditions of sustained uncertainty brought about by the diagnosis of a chronic, life-threatening illness of a child. The procedures of the grounded theory method were used to collect and analyse data. The analysis illuminated a perceptual-interpretative-behavioural process that made visible the emergence and intensification of the uncertain period during the prediagnostic period. This process, which may consist of up to three stages, most frequently began with the parents' initial awareness of the child's illness cues and terminated with the diagnostic announcement. The stages were categorised as Lay Explanatory (I), Legitimizing (II), and Medical Diagnostic (III). The duration of stage III was found to be a significant factor in explaining the variation in parental response to the diagnosis.

Language: English

Keywords: Chronic diseases, general / Parents / Psychological stress / Coping / Explanatory models

Dadds MR, Stein REK, Silver-Johnson E. The role of maternal psychological adjustment in the measurement of children's functional status. *Journal of Pediatric Psychology*, 1995; 20(4): p.527-544
NIVEL: C 6407

The aim of this study was to explore how mothers interpret illness behaviour in their children to assess whether maternal psychological adjustment predicts maternal perceptions of children's behavioural limitations and attributions of these behaviours to chronic illness. Functional status ratings and attributions to illness by 365 mothers of 5- to 8-year-old children with chronic illnesses were associated with children's overall adjustment but not with mothers' own psychological distress. Illness attributions also were related to the child's medical visits and hospitalisations. Thus, mothers' illness attributions are related to her perceptions of the child's health and more general behavioural adjustment, but not to her own mental health. Results support the validity of the FS II(R) as a measure of functioning related to children's health status that is not influenced by maternal psychological adjustment.

Language: English

Keywords: Chronic diseases, general / Mothers / Behaviour problems / Psychosocial problems / Mental disorders / Health status

Eiser C, Havermans T, Eiser JR. Parents' attributions about childhood cancer: implications for relationships with medical staff. *Child: Care, Health and Development*, 1995; 21(1): p.31-42
NIVEL: C 6421

The aim of this study was to investigate family coping with treatment of childhood cancer in relation to attributions about cause and responsibility for onset of the disease. Interviews were conducted with 28 mothers and 23 fathers of 30 children with cancer. Coping strategies found to be helpful were assessed using the Coping Health Inventory for Parents. Fathers were more likely than mothers to accept that there was no known cause for the child's illness. Fathers who blamed doctors for failing to diagnose the condition found medical staff less helpful up to 2 years later. The theoretical importance of blaming others more than oneself is discussed, along with practical implications for services in paediatric oncology.

Language: English

Keywords: Cancer / Parents / Coping / Sex differences / Professional-family relations

Gibson CH. The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*, 1995; 21(6): p.1201-1210

The aim of this fieldwork study was to describe the process of empowerment as it pertains to mothers of chronically ill children. Following a theoretical analysis, empowerment was conceptualised as a social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems, and mobilise the necessary resources in order to feel in control of their own lives. Four components of the process of empowerment emerged: discovering reality, critical reflection, taking charge, and holding on. As a result of the study, empowerment was reconceptualised as largely a personal process in which individuals developed and employed the necessary knowledge, competence and confidence for making their voices heard. Participatory competence - the ability to be heard by those in power - was the outcome of this process. Although the unique finding in this study suggests that the process of empowerment was largely intrapersonal, there was a relational element in the process. Clearly, the intrapersonal and interpersonal processes of empowerment are intertwined.

Language: English

Keywords: Nervous system diseases / Mothers / Coping / Professional-family relations

Grootenhuis MA. *Coping with childhood cancer: strategies of parents and hospital staff*. Amsterdam: Universiteit van Amsterdam, 1996
NIVEL: R 9909

Key issues in this thesis are the emotional effects on parents of children with cancer, the way they are coping in the stressful situation and the relation between the emotional consequences and the way parents adapt to the illness. 163 Parents of 84 children were studied. The emotional consequences and the coping strategies of parents of children with a cancer in remission differed from those of parents of children with a cancer that was not in remission. This also turned out to be important in the decision to make use of alternative medicine. An additional coping strategy was found in attributing positive characteristics to the children by parents and hospital workers. A warning was directed towards hospital workers not to overestimate the children with respect to pain.

Language: English

Keywords: Cancer / Parents / Psychological stress / Coping

Gudmundsdottir M, Gilliss CL, Sparacino PSA, Tong EM, Messias DKH, Foote D. Congenital heart defects and parent-adolescent coping. *Families, Systems & Health*, 1996; 14(2): p.245-255
NIVEL: C 6437

The purpose of this study was to examine coping strategies of adolescents with congenital heart diseases and their parents, as they relate to each other. Single, separate interviews were conducted with eight parents and their adolescent children who have had surgical repairs. The interviews were transcribed and the data analysed, in pairs, using Grounded Theory procedures. The analysis of the data revealed two dyadic patterns of coping: (1) similar coping, which included the subcategories of mutual protection, being accepting of each other; dealing with the illness by normalising it, approaching the illness mechanically, and keeping the illness in its place; and (2) dissimilar coping, which included the single subcategory of a problematising and withdrawing mode of illness management.

Language: English

Keywords: Congenital heart defects / Adolescents / Coping / Parent-child relations

Hoekstra-Weebers J, Heuvel F, Klip EC, Bosveld HEP, Kamps WA. Social support and psychological distress of parents of pediatric cancer patients. In: Baider L, Cooper CL, Kaplan De - Nour A (eds). *Cancer and the family*. Chichester: John Wiley & Sons, 1996: p.93-107
NIVEL: C 6442

Little research has been done on the relation between psychological functioning of parents of children with cancer and the support they receive and their satisfaction with the support over time. A longitudinal study was carried out with 164 parents of 87 all newly diagnosed children with cancer. Four hypotheses were examined: 1. Following the diagnosis of cancer in their child, parents will need more support from their network. There will be more supportive interactions, as compared to a norm group, but satisfaction with support will remain the same. 2. Parents will benefit more from some types of support than from other types. 3. Parents who are psychologically distressed, will need more support than parents who are not distressed, both shortly after diagnosis and 6 months later. 4. With time, parental need for support will be more comparable to the level found in the norm group. It was found that only the parents who were psychologically distressed, received more support. Parents who did well psychologically, were more satisfied with support although they received as much support as the norm group.

Language: English

Keywords: Cancer / Parents / Psychological stress / Social support / Coping

Horn JD, Feldman HM, Ploof DL. Parent and professional perceptions about stress and coping strategies during a child's lengthy hospitalization. *Social Work in Health Care*, 1995; 21(1): p.107-127
NIVEL: C 6444

The aims of this study were (1) to explore the stressors and coping strategies of families whose children with chronic illness require lengthy hospitalisations and (2) to compare the reports of families on stress and coping strategies with those of health services professionals. A non-randomised sample of 13 families (13 mothers and 5 fathers) whose child with chronic illness was hospitalised for a minimum of 30 days and 11 professionals who worked with such children were interviewed in a semi-structured survey using open-ended questions. Key phrases from family interviews were organised into categories of family-reported stressors and coping strategies. Key phrases from professional interviews were categorised into family stressors and descriptions of challenging families. Families and professionals reported that personal emotions and communication problems were the most predominant stressors. Families relied on a wide range of coping strategies; securing information and obtaining support from hospital staff were most helpful. Professionals stated that emotionally reactive families were the greatest challenge to them. Professionals serving chronically ill children and their families were found to be sensitive to the stressors facing these families. Professionals described challenges that related to family coping strategies.

Language: English

Keywords: Chronic diseases, general / Hospitalisation / Psychological stress / Family / Coping / Attitude

IpsO Facto. Allochtone chronisch zieke jongeren: een verkennende studie. (Chronically ill adolescents from ethnic minorities: an exploratory study.)
Houten: IpsO Facto, 1991
NIVEL: R 9910

This exploratory study depicts the problems chronically ill Moroccan and Turkish young adults encounter. The data have been collected by sending a questionnaire (n=34) and by interviewing (n=10) social workers who work with these young adults on a daily basis. They have the impression that

chronic illnesses are more widely spread and more serious due to the many consanguineous marriages, the lack of birth control in cases of apparent heredity, late discovery of the illness, non-compliance and bad housing and living conditions. They recognise the following characteristics of the problems: the ethnic culture allowing no room for adaptations in favour of one individual; the way people experience illness with a strong separation between ill and healthy people; the fact that the youngsters are more and more changing into Dutch people and the problems that may occur when the parents arrange marriage. The Dutch system of social assistance is aimed at the individual and tries to make the chronically ill adolescent independent, which clashes with the Turkish and Moroccan group culture that chooses to care for a child who is ill and who is not allowed to do anything for himself.

Language: Dutch

Keywords: Chronic diseases, general / Adolescents / Ethnic minorities / Sick role / Coping / Family relations

Knafelz K, Breitmayer B, Gallo A, Zoeller L. Family response to childhood chronic illness: description of management styles. *Journal of Pediatric Nursing*, 1996; 11(5): p.315-326
NIVEL: C 6454

The purpose of this study was to identify unique styles of family subjective response to childhood chronic illness. Drawing on principles of triangulation, the investigators collected data longitudinally from multiple family members (ill child, parents, well sibling) in 63 families using structured and unstructured data collection techniques. In all families there was a school-age child with a chronic illness. Five family management styles (FMSs) were identified. Each is made up of a distinct configuration of qualitative themes. Across the five FMSs, the configurations reflect differences in the following major aspects of the chronic illness experience: definition of the illness experience, management goals and approach, and illness consequences. The five FMSs (thriving, accommodating, enduring, struggling, and floundering) represent a continuum of difficulty families experience in managing a child's chronic illness. The FMSs also contribute to understanding the underlying processes associated with differing outcomes for families and their individual members when a child has a chronic illness.

Language: English

Keywords: Chronic diseases, general / School-age children / Family / Coping

Koch U, Härter M, Jakob U, Siegrist B. Parental reactions to cancer in their children. In: Baider L, Cooper CL, Kaplan De-Nour A (eds). *Cancer and the family*. Chichester: John Wiley & Sons, 1996: p.149-170
NIVEL: C 6455

This multi-centre study focuses on the stressors arising from the experience of having a child with cancer and the strategies adopted in coping with these stressors. The main subjects of the study were the following: stressors for the child or adolescent from the point of view of the parents: educational and professional development, time pressures, reactions to the illness and behavioural changes; stressors of the parents and stress reactions due to the illness of their child: emotional and physical complaints, restrictions on quality of life, effect on family life, time and financial pressures, effects on employment or profession; individual adaptation: personal and professional help, coping style, social support, practical help, emotional support, information, utilisation of psychosocial assistance and evaluation of the support received. The analysis is based on 473 mothers and 326 fathers from a total of 504 families.

Language: English

Keywords: Cancer / Psychological stress / Coping / Parents

Last BF, Grootenhuis MA. Emotions, coping and the need for support in families of children with cancer: a model for psychosocial care. *Patient Education and Counseling*, 1998; 33(2): p.169-179

The aims of this article are to outline a theoretical background of cognition and emotions in families of children with cancer, to discuss the process of coping and to present a conceptual framework for understanding children's and parental reactions to childhood cancer. In the case of childhood cancer, the personal threats are severe for both the child, the parents and other family members. For the child, there is the threat to physical integrity, safety, security, and above all, to life. For the parents, there is the threat of losing the child. However, a number of studies have shown that psychopathological disturbances are rarely found in children with cancer or their parents. It can be concluded from these studies that most children and parents use coping strategies that protect them from developing psychopathology. In organising support for families with a child with cancer, much can be learned from children's and parent's perceptions and reactions. When problems of adjustment arise, a thorough analysis of how children and parents perceive their situation, as well as an extensive analysis of their

coping efforts, is necessary to direct effective support actions. A psychosocial support model is proposed which can be helpful in interpreting these emotions and coping strategies.

Language: English

Keywords: Cancer / Parents / Coping / Explanatory models

Malone JA. Family adaptation: adult sons with long-term physical or mental illnesses. *Issues in Mental Health Nursing*, 1997; 18(4): p.351-363
NIVEL: C 6472

The aim of this descriptive study was to explore the coping strategies of families with an adult son with either a long-term physical or mental illness. Sixty-two family members with an outpatient adult son with a long-term physical (8 families) or mental (3 families) illness participated. Multiple methods and multiple family members' perspectives were used. Family members completed FILE, FIRM, FAM-III, FACESIII, the Progress Evaluation Scale, and the Nottingham Health Profile. Single-item indicators were based on Rolland's (1988) psychosocial typology of illness, Mishel's (1988) components of uncertainty of illness, and selected demographics. On most of the instruments and their subscales, there were few statistical differences. Family members often did not report the same diagnosis. Based on the qualitative data, families coped by "just working with it" or "trying to step back."

Language: English

Keywords: Chronic diseases, general / Young adults / Family / Coping

Meijer AM, Oppenheimer L. The excitation-adaptation model of pediatric chronic illness. *Family Process*, 1995; 34(4): p.441-454
NIVEL: C 6470

The aim of this study was to examine the value of the psychosomatic family model for the study of chronically ill children. Four conceptual problems arise in the discussion of this model: the unidirectional causality of the model, the function of the sick child for the family system; the pathology of the family characteristics; and the disease type. In this study the authors propose (a) that a distinction be made between uncontrolled and controlled forms of disease, and (b) that the family characteristics of "cohesion" and "adaptation" be examined in relation to the parental capacity for problem

solving and the acceptance or rejection of the child by the parents. Twenty families with a child suffering from controlled asthma were compared with 20 families with a child suffering from uncontrolled asthma. Contrary to the assumptions derived from the psychosomatic family model, the results show significantly more cohesion and structure in the group with a child suffering from controlled asthma. The findings of this study are integrated in a new model for the study of chronic childhood illness - the excitation-adaptation model. In this model two circular processes are emphasised involving (a) the progress of the illness and the way in which parents and child deal with medication and medical advice and (b) the factors influencing the therapy compliance on the part of the parents, the family and the child. By studying these factors in connection with the management of the illness, it should become clear whether family characteristics are adaptive or pathological.

Language: English

Keywords: Asthma / Family relations / Psychosomatic problems / Coping / Explanatory models

Parker M. Families caring for chronically ill children with tuberous sclerosis complex. *Family & Community*, 1996; 19(3): p.73-84
NIVEL: C 6476

OBJECTIVE: To document how families cope with the stresses of caring for a chronically ill child with tuberous sclerosis complex (TSC), a rare paediatric neurological disorder. Families caring for TSC children have some special needs as well as some needs which are common to all families caring for a chronically ill family member. **METHODS:** A pilot study was performed in which members of seven families were interviewed; twelve interviews were conducted (5 married couples and 2 married women). **RESULTS:** The results show that family members giving care to a child with TSC report difficulties providing care; lack of spontaneity in family life; feelings of guilt, ambiguity, and chronic grief; variable support from formal and informal sources; and a profound impact on all aspects of family life. Many families feel they face an endless stressful, unpredictable and potentially chaotic family life.

CONCLUSIONS: This research may present new insights for health care professionals. It is hoped that the discussion will raise their awareness about TSC and encourage them to offer more effective help to all families caring for chronically ill members.

Language: English

Keywords: Tuberous sclerosis / Psychosocial problems / Family relations / Coping

Patterson JM, Garwick AW, Bennett FC, Blum RW. Social support in families of children with chronic conditions: supportive and nonsupportive behaviors. *Journal of Developmental and Behavioral Pediatrics*, 1997; 18(6): p.383-391
NIVEL: C 6477

The aim of this study was to explore the amount of emotional, informational, and tangible social support received by parents of chronically ill children from the family, community, and service providers. Parents of 182 young children with a variety of chronic health conditions were questioned about these issues. They were also asked to describe nonsupportive or hurtful behaviours received from family or community members. Both mothers and fathers reported that family members provided the most emotional and tangible social support and service providers the most informational support. The amount of perceived support from all sources increased over time, but 78% of mothers and 60% of fathers reported at least one instance of nonsupport from these same sources, primarily from extended family members and health professionals. Health professionals are encouraged to show respect and to provide timely, accurate information in a sensitive manner to parents whose child has a chronic health condition and to assist parents in handling nonsupportive behaviours from family and friends.

Language: English

Keywords: Chronic diseases, general / Parents / Social support

Reay D, Bignold S, Ball SJ, Cribb A. "He had just a different way of showing it": gender dynamics in families coping with childhood cancer. *Journal of Gender Studies*, 1998; 7(1): p.39-52
NIVEL: C 6481

The purpose of this study was to examine gender differences within families with respect to coping with childhood cancer. Qualitative indepth interviews were conducted with mothers and fathers in thirty-five families in which a child has been diagnosed with cancer. Gendered patterns in which mothers and fathers deal differently with both emotions and emotional needs when their child has cancer were examined. It is argued that the gender dynamics which develop are the consequences of a complex mixture of external constraints and internal inclinations. The research found important commonalities in the ways in which women as a group and men as a group deal with child cancer. Fathers' tendencies to distance themselves emotionally from the illness resulted in a reluctance to talk, the playing

down of the impact of the diagnosis and an unrealistic, overly optimistic stance. In contrast, women's coping mechanisms involved a much more close-up emotional engagement with cancer in which some women became so immersed in their child's illness they felt they were drowning. The article concludes that the accommodations most couples reach when their child is seriously ill are inscribed in dominant representations of caring as women's work. In the process of dealing with childhood cancer the familial status quo is disrupted. The result is to increase already existing inequities in divisions of both practical and emotional labour between women and men.

Language: English

Keywords: Cancer / Parents / Coping / Sex differences

Williams HA. There are no free gifts!: social support and the need for reciprocity. *Human Organization*, 1995; 54(4): p.401-409
NIVEL: C 6523

This article presents findings from a larger study of 202 African American and white parents of children with cancer, focusing on social support, social networks, and coping. Most discussions of social support highlight affective support and its relationship to psychological outcomes. Rarely are charitable gifts to individuals mentioned in the literature. Although both affective and material support are discussed in this paper, the data focus primarily on the financial support that was given to the parents as a tangible form of social support. Using M. Sahlin's model of reciprocity, it is argued that the normal patterns of exchanges alter due to the pressing needs of providing support to those experiencing a crisis. It is proposed that an additional form of reciprocity operates where the support recipient returns the favour to a new person in need. Findings suggest that the need and desire to reciprocate is a generalised feeling that cuts across gender, race, and socioeconomic distinctions.

Language: English

Keywords: Cancer / Parents / Social support / Coping

3.2 *Self care and compliance*

3.2.1 *Self care from the patient's perspective*

Alvin P, Rey C, Frappier JY. Compliance thérapeutique chez l'adolescent malade chronique. (Therapeutic compliance in chronically ill adolescents.) *Archives de Pédiatrie*, 1995; 2(9): p.874-882
NIVEL: C 6385

The purpose of this review is to address a number of determinants of (non-) compliance in chronically ill adolescents. Possible determinants of adolescents' level of compliance may be divided into demographic factors, patient and family characteristics, aspects of the illness and treatment regimen, and quality of the patient-doctor relationship. Compliance should be viewed as a reflection of the experience of chronic illness as well as the expression of specific adolescent developmental issues. Practical guidelines are proposed.

Language: French

Keywords: Chronic diseases, general / Adolescents / Patient compliance / Reviews

Burroughs ThE, Harris ME, Pontious SL, Santiago JV. Research in social support in adolescents with IDDM: a critical review. *The Diabetes Indicator*, 1997; 23(4): p.438-448
NIVEL: C 6397

The aim of this review is to present the findings of 32 scientific studies that examined the relationship between social support and adherence/metabolic control in adolescents with insulin-dependent diabetes mellitus. Social support included qualitative family support characteristics, communication patterns, sibling and peer relationships, and regimen-specific support behaviours. The literature was examined in the context of adolescent development. Although the results of these studies were somewhat inconsistent, some general patterns emerged that are described and discussed in detail. Methodological limitations and suggestions for future research are provided.

Language: English

Keywords: Diabetes mellitus / Reviews / Adolescents / Social support / Patient compliance

Coates VE, Boore JRP. The influence of psychological factors on the self-management of insulin-dependent diabetes mellitus. *Journal of Advanced Nursing*, 1998; 27(3): p.528-537

The aim of this study was to investigate the influence of a number of psychological factors upon self-management among young adults with insulin-dependent diabetes mellitus. Health beliefs, perception of control and knowledge were assessed by scales and questionnaires and glycosylated haemoglobin results and clinic attendance records obtained for 263 patients. The results demonstrated that the sample members perceived that they were responsible for the control of their diabetes, that the benefits of following treatment were greater than any barriers and that they were knowledgeable about their diabetes. However, these factors were not predictive of the outcome variables of metabolic control or clinic attendance according to multiple regression analysis. Implications of these results for nursing practice and for future research are discussed.

Language: English

Keywords: Diabetes mellitus / Adolescents / Young adults / Self care / Patient compliance / Sick role

Creer ThL. Medication compliance in chronically-ill children. *Tijdschrift voor Kindergeneeskunde*, 1998; 66(4): p.142-145
NIVEL: C 8533

This article focuses on 3 aspects of problems in compliance of chronically ill children. First, a description of the behaviour is presented. This includes a synopsis of the prevalence of noncompliance, as well as question of what is the ideal goal to seek with respect to adherence. Second, factors correlated with noncompliance are enumerated and discussed. Barriers to adherence, particularly those associated with the management of chronic diseases, are described. Finally, a number of suggestions for improving compliance in the paediatric population are offered.

Language: English

Keywords: Chronic diseases, general / Patient compliance

Frey M. Behavioral correlates of health and illness in youths with chronic illness. *Applied Nursing Research*, 1996; 9(4): p.167-176
NIVEL: C 6429

The purpose of this study was to examine the relationships among general health behaviour, illness management behaviour, indicators of health (functional, physical/mental, and perceived health status) and indicators of illness (duration, control, and perception of severity) in 5 samples of youth with either insulin dependent diabetes mellitus (IDDM) or asthma. Descriptive data indicated that youths performed approximately 72% of the health and illness management behaviours recommended by health professionals. General health behaviour and illness management behaviour were significantly related ($r = .39$ to $.62$; $p < .05$). General health behaviour was more consistently related to indicators of health ($r = .37$ to $.62$; $p < .001$) than to indicators of illness. Illness management behaviour was not related to indicators of illness either. However, illness management behaviour was significantly related to higher perception of health status ($r = .35, .48$; $p < .001$). Interestingly, there were no relationships between health and illness indicators. These findings challenge nurses to address general health behaviour as well as illness management in practice and to raise questions as to whether illness management improves illness status or if illness status influences health status when health is viewed from a nursing perspective. Knowing the links between behaviour and relevant health and illness outcomes will facilitate identification and movement toward goals of improved health and may account for intervention failure.

Language: English

Keywords: Diabetes mellitus / Asthma / Self care / Health status / Coping / Sick role / Patient compliance

Hanna KM, Guthrie DW. Involvement in health behaviors among youth with diabetes. *The Diabetes Educator*, 1999; 25(2): p.211-219
NIVEL: C 6438

The purpose of this study was to examine involvement in a broad range of health behaviours among adolescents and young adults with diabetes. The sample consisted of 107 adolescents and young adults (12 to 24 years old) with Type 1 diabetes mellitus. Participants were asked to report involvement in health enhancing, health compromising, and diabetes mismanagement behaviours. The participants reported low levels of health compromising behaviours and high levels of health enhancing behaviours. Females reported significantly higher levels of diabetes mismanagement than males. Males in late adolescence (18 to 24 years) reported significantly higher levels of health compromising behaviours than males in early (12 to 14 years) and middle (15 to 17 years) adolescence. Females in late adolescence (18 to 24

years) reported significantly higher levels of health compromising behaviours than females in early adolescence (12 to 14 years). Diabetes educators who work with youth may want to assess all of these health behaviours, keeping in mind age and gender differences.

Language: English

Keywords: Diabetes mellitus / Adolescents / Young adults / Patient compliance / Health behaviour / Sex differences

Kokkonen J, Lautala P, Salmela P. The state of young adults with juvenile onset diabetes. *International Journal of Circumpolar Health*, 1997; 56(3): p.76-85
NIVEL: C 6456

The aim of this study was to investigate the physical and psychosocial health status, mode of coping with adult health care and medical treatment in 82 young adults (46 males, 36 females, average age 20.9 yr. and average disease duration 12.7 yr.) who had had diabetes since childhood. All but three of them made regular visits to a health care facility but only 27% monitored blood glucose reasonably well. Only eight percent had a HbA1 concentration within the optimal range, and half had an inappropriate level. Half of the subjects with high HbA1 in adolescence had managed to improve it since leaving the paediatric unit. The most common clinical findings were lipohypertrophy and depressed patellar and achillar reflexes. Up to 70% had background retinopathy and 10% proliferative retinopathy, while two thirds (62%) had depressed conduction velocity of the peroneal nerve. Clinically significant psychiatric problems were found in 17% of the patients, depression being the most prominent feature. Among the social characteristics, delayed social maturation and lack of vocational education were found to be more common than in age-matched controls. One in three exhibited a major overt physical problem and one in five a major psychosocial problem. In conclusion, whatever the health care follow-up unit attended by young adults with diabetes since childhood, the teams face health problems that differ totally from one individual to another. It is important at this transitional age to focus attention in a broad-minded manner on the many factors complicating diabetes or affecting good compliance with treatment.

Language: English

Keywords: Diabetes mellitus / Young adults / Health status / Patient compliance / Mental disorders / Psychosocial problems

Skinner TC, Hampson SE. Social support and personal models of diabetes in relation to self-care and well-being in adolescents with type 1 diabetes mellitus. *Journal of Adolescence*, 1998; 2(6): p.703-715

NIVEL: C 7762

The aim of this study was to examine the mediating influence of peer support and illness representations on the relationship between family support, self-management and well-being. Seventy-four participants (12-18-years old) with type 1 diabetes mellitus completed questionnaires assessing their self-management, depression, anxiety, perceived social support and personal models of diabetes. Perceived impact of diabetes, but not perceived seriousness, and peer support were significant predictors of depression. Family support was a significant predictor of all self-management measures. However, for dietary self-management this relationship was partially mediated by the perceived efficacy of treatment to control diabetes, but not efficacy of treatment to prevent complications.

Language: English

Keywords: Diabetes mellitus / Adolescents / Self care / Quality of life / Social support / Peer relations

Sciver MM van, d'Angelo EJ, Rappaport L, Woolf AD. Pediatric compliance and the roles of distinct treatment characteristics, treatment attitudes, and family stress: a preliminary report. *JDBP: Journal of Developmental and Behavioral Pediatrics*, 1995; 16(5): p.350-358

NIVEL: C 6515

The aim of this study was to examine compliance, treatment attitudes, and illness-related family stress in children with chronic illnesses. Three paediatric cohorts (n=75, ages 8 to 20 years) were involved: boys with haemophilia (n=31), sickle cell disease (n=22) or asthma (n=22). Between-group differences were found on compliance and treatment attitudes, with patients with sickle cell disease demonstrating greater treatment cooperation than their counterparts and boys with haemophilia expressing more positive outlooks on medical advice and about health outcomes. Positive treatment attitudes were associated with specific compliance behaviours for boys with haemophilia but not for other groups.

Language: English

Keywords: Haemophilia / Sickle cell disease / Asthma / Patient compliance / Psychological stress / Family

3.2.2 Self care from the family's perspective

Gallo AM, Knafl KA. Parents' reports of "tricks of the trade" for managing childhood chronic illness. *Journal of the Society of Pediatric Nurses*, 1998; 3(3): p.93-102
NIVEL: C 6432

The purpose of this study was to examine how parents cope with the challenges of childhood chronic illness. A qualitative, comparative, secondary analysis was carried out. Participants were 58 families (55 mothers, 44 fathers) with a school-age child (6-15 years old) with a chronic illness. Three approaches to illness management were identified: strict adherence, flexible adherence, and selective adherence. These approaches varied in the extent to which parents developed and relied on target management behaviours that concurred with or deviated from the treatment plan prescribed by healthcare providers. The three management approaches contribute to understanding the processes associated with differing interactions between healthcare professionals and parents when a child has a chronic illness.

Language: English

Keywords: Chronic diseases, general / Parents / Coping / Patient compliance

Hill SA. Taking charge and making do: childhood chronic illness in low-income black families. *Research in the Sociology of Health Care*, 1995; 12: p.141-156
NIVEL: C 6441

The purpose of this study was to explore family characteristics and resources which facilitate its ability to provide optimal home care for chronically-ill children. Interviews were conducted with 32 low-income African-American mothers of children with sickle cell disease. The results indicate that family caregiving is shaped by larger forces, such as race and class inequality and lack of access to quality medical care. These factors foster a discrepancy between patients and medical experts in their definitions of illness and appropriate responses to it, thus influencing the home caregiving strategies in low-income black families.

Language: English

Keywords: Sickle cell disease / Coping / Family relations / Socioeconomic factors

Kurnat EL, Moore- Murphy C. The impact of a chronic condition on the families of children with asthma. *Pediatric Nursing*, 1999; 25(3): p.288-292
NIVEL: C 6460

The aim of this descriptive study was to examine the needs and concerns of families of children with asthma. The Hymovich's Parent Perception Inventory (HPPI) was used in a small sample of 14 parents. The results show that parents had greatest concerns about time management, financial strain, and family relations. Important nursing interventions related to family management of asthma include assessing family perceptions and coping abilities; encouraging expression of feelings and concerns; educating the child and family about the disease and condition management; supporting positive coping behaviours; and securing resources to help families manage their child's condition.

Language: English

Keywords: Asthma / Parents / Family relations / Coping / Needs assessment / Nursing

Meijer AM. Psychische problemen, gezinsinvloeden en beheersbaarheid van astma bij kinderen. (Psychological problems, family influences and controllability of childhood asthma.) *Gedrag & Gezondheid*, 1996; 24(3): p.105-117

The purpose of this study was to examine which psychosocial variables enhance the controllability of asthma in children. It is argued that a distinction between controlled and uncontrolled asthma leads to a better insight into the role of psychosomatic variables than a distinction on the basis of the severity of the asthma. Previous studies were mainly concerned with research relating to psychological problems of asthmatic children and the influence of family factors and childrearing attitudes on children's asthma. After comparing different studies and quoting the arguments of some critics, the factors are described which are thought fundamental in psychological research concerning the health of asthmatic children. First, the authors propose that a distinction be made between the severity and the degree of controllability of asthma. Second, it is proposed that some family characteristics (cohesion, adaptation and the interactional problem solving capacity of the parents), and some psychological variables of the child (anxiety for instance) and the parents (psychopathology for instance) be examined. After studying these variables in connection with the management

of the illness it should become clear which factors are adaptive or maladaptive for the health of the child.

Language: Dutch

Keywords: Asthma / Mental disorders / Family relations / Health status

Middleton D. A discursive analysis of psychosocial issues: talk in a 'parent group' for families who have children with chronic renal failure.
Psychology & Health, 1996; 11(2): p.243-260

The aim of this study was to examine psychosocial issues faced by parents of children with chronic renal failure. A discursive approach was used, in which examples of talk within support groups for parents were analysed over a 32 month period at a Regional Paediatric Renal Unit within the UK National Health Service. All the parents were directly involved in management of home based peritoneal dialysis of their children. The analysis examines features of the organisation and content of parents' talk about what is commonplace in the management of the demands they face in the difficult circumstances of their child care. Common understandings within the groups are shown to be achieved through the parents' exploration of uncertainties in the care of their children. The value of qualitative analysis of health care talk in the evaluation of support groups for families involved in this form of paediatric care is also discussed.

Language: English

Keywords: Kidney disease / Parents / Social support / Home care

Prout A, Hayes L, Gelder L. Medicines and the maintenance of ordinariness in the household management of childhood asthma.
Sociology of Health & Illness, 1999; 21(2): p.137-162

The aim of this qualitative study was to explore the ways in which children with asthma and their parents construct a sense of ordinariness. The 'adaptation' perspective on chronic illness was used as a frame of reference. The management strategies of 9 families were examined. It is shown that household members did not generally regard asthma as a major problem. Regular medication, usually in the form of inhaled drugs, was their main response. Few other strategies were followed and little attention was paid to the non-medicinal preventive actions recommended in asthma management guidelines and educational material. Parents' and children's accounts suggest

that they were involved not only in managing a disease but also in maintaining a sense of their own ordinariness. Paradoxically, medicines, especially inhalers, were the main resource for accomplishing this goal because they supported the ordinariness of the child and the family far more readily than other preventive measures.

Language: English

Keywords: Asthma / Parents / Coping / Patient compliance

Spalding K, Mackeever P. Mothers' experiences caring for children with disabilities who require a gastrostomy tube. *Journal of Pediatric Nursing*, 1998; 13(4): p.234-243
NIVEL: C 6501

The aim of this qualitative study was to explore mothers' experiences of feeding children with severe disabilities by a gastrostomy tube. Twelve mothers each participated in one, open-ended, home interview. Mothers gave detailed accounts of their activities and the tremendous stress involved in feeding the children. They described spending enormous time and energy seeking confirmation of the feeding problem and devising extraordinary practices to ensure the child's survival before "giving in" to the gastrostomy tube. Following gastrostomy tube insertion, they initially felt relief and disappointment, before customising feeding and moving on. Mothers' suggestions for improving professional services are discussed along with implication for practice and research.

Language: English

Keywords: Chronic diseases, general / Mothers / Psychological stress / Feeding

Sterling YM, Jones-Corson L, Johnson DH, Bowen MR. Parents' resources and home management of the care of chronically ill infants. *Journal of the Society of Pediatric Nurses*, 1996; 1(3): p.103-109
NIVEL: C 6506

The purposes of this study were to identify the resources of parents or primary caretakers who manage chronically ill infants at home and to determine the psychometric properties of the Home Care Resources Inventory (HCRI), using a cross-sectional, descriptive design. Hundred parents or primary caretakers of chronically ill infants who were discharged from hospital at least 1 week participated. Ninety-three % of the sample

were mothers; infants' ages ranged from 1-22 months. The main outcome measures were the HCRI, the Spielberger State Trait Anxiety Inventory, and a demographic questionnaire. Parents reported strong resources in the area of support and inconsistent resources in the areas of coping, time, and respite. The HCRI has acceptable psychometric properties. It is concluded that identifying resources, especially personal time and respite, is essential for successful home management of chronically ill infants. The HCRI can be used to pinpoint areas that are strong or weak in the resource areas measured.

Language: English

Keywords: Chronic diseases, general / Infants / Parents / Coping / Social support / Home care / Questionnaires

Waissman R. Professional and lay people in the management of a chronic illness in children: the care performed by families compared to medical expertise. *Advances in Medical Sociology*, 1995; 6: p.159-182
NIVEL: C 6520

The aim of this ethnographic study was to analyse the different tasks considered in the framework of actions as “medical” work performed by families who are compelled to organise, in interaction with professionals, the implementation of care for their chronically ill child, suffering from end stage renal disease. The management actions for such a serious chronic illness encompasses material and technical aspects of work as well as emotional labour in the course of interaction between the ill child and the caretaker. It underlines the importance of the reactions of the affected child to the long term treatment, both technical and medical, which shape the relationships between the different actors. The impact of sophisticated technology such as dialysis techniques on the life of the child and the family bring the role of lay people and professionals into confrontation. Professionals such as nurses refuse to consider the care work especially the management of technical aspects performed by families as being of the same level of professionalism as their own work. The focus is on the opposing viewpoints which reflect on the meaning ascribed to the notion of “medical work” when it is carried out by lay people and perceived as informal, or when it is implemented by professionals.

Language: English

Keywords: Kidney disease / Home care / Parents / Professional-family relations

4 Health care service

4.1 Health care service from the patient's perspective

Ahmad WIU, Atkin K. Ethnicity and the caring for a disabled child: the case of children with sickle cell or thalassaemia. *The British Journal of Social Work*, 1996; 26(6): p.755-775
NIVEL: C 6522

While the rhetoric of special health needs of ethnic minority communities has been prevalent for three decades, the special needs of people with sickle cell anaemia and thalassaemia, have received little recognition. The aim of this review is to provide an overview of the social research literature on sickle cell disorders and thalassaemia major in the broader context of debates on childhood disability and chronic illness and on ethnicity, racism, and health care. Issues related to caregiving, coping, and hemoglobinopathy service provision are among those addressed. A proposed increased involvement of social services departments in work with children with disabilities is discussed.

Language: English

Keywords: Sickle cell disease / Thalassaemia / Ethnic minorities / Coping / Psychosocial problems / Quality of care / Reviews

Dunsmore J, Quine S. Information, support, and decision-making needs and preferences of adolescents with cancer: implications for health care professionals. *Journal of Psychosocial Oncology*, 1995; 13(4): p.39-56
NIVEL: C 6532

The aim of this study was to explore treatment experiences and preferences of a group of 51 Australian young people with cancer (27 males and 24 females aged 12-24 years). The focus was on identifying their information, support, and decision making needs and preferences to inform health professionals and thereby improve patients' treatment experiences. A 42-item self-administered questionnaire, including open- and closed-ended items, was developed to collect current and retrospective data. Responses to open-ended items were content-analysed. The young people wished to be more informed and involved in treatment decisions. Almost all of them (49) wanted to be informed about "bad news", such as treatment is ineffective, prognosis is poor, or death is imminent. Their preferences for involvement with health professionals, family, and peers in different contexts are

reported. The qualities of health professionals that facilitated communication, according to the young people, were the ability to listen, genuine concern, professional expertise, and honesty, whereas an impersonal manner, use of technical jargon, haste, and the generation gap hindered communication.

Language: English

Keywords: Cancer / Adolescents / Young adults / Needs assessment / Patient satisfaction

Fox C. The insulin-dependent patient: perceptions and preferences.

Diabetic Medicine, 1995; 12(4): p.344-348

NIVEL: C 6427

In this article, the perceptions and attitudes of adolescents and young adults with diabetes are discussed. Although patients realise that insulin is the missing hormone which keeps them alive and well, they do not regard it as a cure for diabetes because it may cause hypoglycaemia, it does not completely abolish the risk of long-term side effects, and it does not permit a life style equivalent to their prediabetic state. Clearly, though, insulin can improve quality of life and significantly reduce the risk of complications. Patients' perceptions of their illness and the available treatment have been explored by several means: letters written to a diabetes specialist nurse by children with diabetes, group discussion at a Young Adult Clinic and responses to questions at the annual Youth Diabetes Conference. Improvements in patient care will stem from physicians' awareness of patients' perceptions and from developments in insulin therapy.

Language: English

Keywords: Diabetes mellitus / Adolescents / Young adults / Sick role

Gruijters M, Planken M. Jongeren en diabetes: een doelgroepenonderzoek voor beleidsontwikkeling. (Young adults and diabetes: a target group study for policy making.) Utrecht: Universiteit Utrecht, 1998

NIVEL: R 9923

This study, commissioned by the Diabetes Vereniging Nederland, was aimed at gaining insight into the situation and information need of young people with diabetes. Information on how young people with diabetes experience their illness, what problems they encounter and how they cope was gathered

by a questionnaire (n=328) and by interviewing people (n=10). Additionally, the information need was studied of these young people and their opinion about the quality of care.

Language: Dutch

Keywords: Diabetes mellitus / Adolescents / Young adults / Needs assessment / Coping / Sick role / Patient satisfaction

Hosli EJ. Ziektebegrip bij kinderen: de ontwikkeling van het denken over ziekte. (Understanding illness: The development of children's thinking about illness) Amsterdam: Thesis, 1998
NIVEL: R 10406

This thesis consists of 3 studies which focus on what children know and are able to understand about illness. Different theoretical frameworks were used. The aim of the first study was to gain insight into the development of thinking about illness in individual children. The interviews suggested that experience has an important influence on the content and amount of knowledge. The second study focused on systematic age-related restrictions in the transfer of information. It was concluded that these restrictions have to be taken into account. The third study focused on the role of experiences in the development of thinking about illness. Four different 'thinking patterns' could be formulated, each of which characterised by a specific central concept and accompanied by specific missing knowledge. These findings have implications for clinical practice; in informing chronically ill children about their disease and treatment a central question has to be: 'what does a child need to know in order to handle the disease adequately?'

Language: Dutch

Keywords: Chronic diseases, general / Cognitive development / Needs assessment

Luft P, Koch LC. Transition of adolescents with chronic illness: overlooked needs and rehabilitation considerations. *Journal of Vocational Rehabilitation*, 1998; 10(3): p.205-217
NIVEL: C 8531

The aims of this article are: (1) to explore the overlooked needs of adolescents with chronic illness with respect to health, emotional, social and vocational issues; and (2) to recommend strategies for addressing those needs through an interdisciplinary approach to transition planning that promotes the autonomy of the adolescent.

Language: English

Keywords: Chronic diseases, general / Adolescents / Young adults / Vocational education / Needs assessment

Macnelts A, Musick B, Austin J, Dunn D, Creasy K Psychosocial care needs of children with new-onset seizures. *Journal of Neuroscience Nursing*, 1998; 30(3): p.161-165
NIVEL: C 7858

The purpose of this study was to examine the satisfaction of children with new-onset seizures with the received health care, their need for information and support and their seizure-related concerns and fears. The Child Report of Psychosocial Care Scale was used in a sample of 63 children (33 girls and 30 boys), aged 8-14 years. They completed the scale two times, 3 months and 6 months after their first seizure. Results indicated that children need the most nursing care in two areas: information related to the seizure condition, especially managing their condition, and support, in the form of talking to other children with seizures. The scale provides direction for tailored nursing interventions that will meet the specific needs of children with seizures for information and support.

Language: English

Keywords: Epilepsy / Patient satisfaction / Needs assessment / Social support

Woodgate RL. Health professionals caring for chronically ill adolescents: adolescents' perspectives. *Journal of the Society of Pediatric Nurses*, 1998; 3(2): p.57-68
NIVEL: C 6533

The purpose of this qualitative study, with tenets from grounded theory, was to describe chronically ill adolescents' perceptions of how health professionals can best care for chronically ill adolescents. Twenty-three adolescents, 13 to 16 years of age, who were diagnosed with either diabetes, asthma, arthritis, Crohn's disease, or ulcerative colitis participated in the study. From the analysis eight themes emerged: (1) treat me like a person; (2) try to understand; (3) don't treat me differently; (4) give me some encouragement; (5) don't force me; (6) give me options; (7) have a sense of humour; and (8) know what you are doing. It is concluded that health professionals need to adopt an overall approach described as careful manoeuvring when caring for adolescents with chronic illness. This approach involves the health professional having sound knowledge and the

ability to guide adolescents confidently and sensitively in the management of their illness.

Language: English

Keywords: Diabetes mellitus / Asthma / Rheumatoid arthritis / Crohn’s disease / Ulcerative colitis / Adolescents / Needs assessment / Quality of care

2.4.2 Health care from the family’s perspective

Arksey H, Sloper P. Disputed diagnoses: the cases of RSI and childhood cancer. *Social Science & Medicine*, 1999; 49(4): p.483-497

This article draws on evidence from studies of two quite different conditions, repetitive strain injury (RSI) and childhood cancer, to explore lay perspectives and empowerment in relation to obtaining a diagnosis. The findings of the studies are scrutinised in respect of four related areas of concern: how much lay views count, exercising choice, referral pathways and the withdrawal of thrust from medical practitioners. The evidence suggests that a substantial number of patients with RSI and parents of children with cancer felt their experiences and knowledge were disregarded by doctors in the diagnostic process. Denying the validity of an individual’s perceptions had implications for obtaining an accurate diagnosis, which could, in turn, make access to appropriate health care and treatment problematic. Their experiences led some people with RSI to show a general distrust of medicine; this was less the case for parents of children with cancer. A key issue is the need for additional training in two areas of the medical curriculum: communication skills and occupational health problems. The underlying problems of attitudes, especially giving weight to the informed views of lay people, is another matter that needs to be addressed.

Language: English

Keywords: Cancer / Parents / Professional-family relations / Quality of care

Atkin K, Ahmad WIU, Anionwu EN. Screening and counselling for sickle cell disorders and thalassaemia: the experience of parents and health professionals. *Social Science & Medicine*, 1998; 47(11): p.1639-1651

The aim of this study was to get insight into service provision with respect to screening and counselling to families caring for a child with a sickle cell disorder or thalassaemia. It explores the perspectives of parents, front-line

practitioners, managers and health commissioners. Poor quality of care, inadequate information and professionals' insensitivity were salient themes in parental accounts. The parents' experience also confirms the problems faced by minority ethnic people in having their welfare needs recognised, more generally. Although the focus is on genetic conditions affecting minority communities in the UK, the issues the authors address are at the heart of the 'new genetics'.

Language: English

Keywords: Sickle cell disease / Thalassemia / Parents / Needs assessment / Ethnic minorities

Auslander WF., Thompson SJ, Dreitzer D, Santiago JV. Mothers' satisfaction with medical care: perceptions of racism, family stress, and medical outcomes in children with diabetes. *Health and Social Work*, 1997; 22(3): p.190-199

The aims of this study were to identify sociodemographic, family, and community predictors of mothers' satisfaction with their children's medical care, based on an ecological framework, and to determine the extent to which satisfaction is associated with medical outcomes such as adherence to treatment and health status of children with diabetes. Although individual demographics have little influence on satisfaction, family and community stressors are significant predictors of mothers' satisfaction with medical care. Mothers who reported greater perceptions of racism and family stress were significantly less satisfied with their children's medical care those from less stressful environments. Mothers' satisfaction with medical care was significantly associated with adherence but was not significantly related to the children's health status.

Language: English

Keywords: Diabetes mellitus / Mothers / Satisfaction / Quality of care / Psychological stress / Ethnic minorities

Axtell SAM, Garwick AW, Patterson J. Unmet service needs of families of young children with chronic illnesses and disabilities. *Journal of Family and Economic Issues*, 1995; 16(4): p.395-411
NIVEL: C 6528

The aim of this study was to determine satisfaction and unmet needs of parents of children with special health care needs. Data about were collected

from 187 families with young children (under two years) who have chronic illnesses and disabilities. The purpose was to assess parents' satisfaction with services their families received, and to identify families' unmet service needs as well as the reasons for these unmet needs. Although families' ratings of the adequacy of services are relatively high, 28% of the families report unmet service needs. The unmet needs most often reported are occupational, physical, or speech therapy, respite care/child care, and special education. Lack of funding is the most common reason for unmet needs. Children with multiple impairments are at highest risk for unmet needs. Only 22% of unmet needs reported at the initial interview have been met by the time of the six-month follow-up. Increased coordination and monitoring of services across service sectors are indicated.

Language: English

Keywords: Chronic diseases, general / Parents / Satisfaction / Quality of care / Special education / Needs assessment

Baine S, Rosenbaum P, King S. Chronic childhood illnesses: what aspects of caregiving do parents value? *Child: Care, Health and Development*, 1995; 21(5): p.291-304
NIVEL: C 6531

The purpose of this study was to examine the values of parents of chronically ill children about a variety of aspects of care and services, assessing both the absolute and relative importance of 22 defined components of care (COCs). Respondents were 80/111 parents (72%) of children with diabetes mellitus and 45/56 parents (80%) of children with cystic fibrosis, followed at a regional university affiliated children's hospital. They completed a two-part mailed questionnaire, rating independently each COC, and then ranking all 22 COCs using a modified Q-sort technique. While the majority of COCs were judged as 'somewhat' or 'very' important by over 75% of respondents, there was also significant agreement between the two groups on their rankings of the COCs (Spearman rank coefficient $r = 0.92$, $P < 0.001$). The COCs ranked most highly by both groups were diagnosis, treatment, education/information, continuity/consistency, accessible and available care, evaluation of chronic illness, and parental involvement. Furthermore, the concordance between this combined medical illness group and a previously studied neurodevelopmental group was $r = 0.72$ ($P < 0.001$). These results are discussed in relation to the non-categorical approach to longstanding childhood illness and disability.

Implications for preventive mental health within the content and structure of health services are considered.

Language: English

Keywords: Diabetes mellitus / Cystic fibrosis / Parents / Needs assessment / Quality of care

Peterson JW, Sterling YM, Weekes DP. Access to health care: perspectives of African-American families with chronically ill children.

Family and Community Health, 1997; 19(4): p.64-77

NIVEL: C 6529

The aim of this study was to explore the needs and experiences of access to health care of a vulnerable group, African American families with children who have a chronic illness (asthma). An ethnographic approach was used. Primary caretakers of 7 families explained how they view asthma, the strategies they develop for caring for their child and how they experience of access to health care. These experiences fall into four categories: getting health care that is wanted, getting health care that is unwanted, not getting health care that is wanted, and not getting health care that is unwanted. Each category represents different implications for advocating health care for this vulnerable population.

Language: English

Keywords: Asthma / Parents / Ethnic minorities / Needs assessment

Petr CG, Allen RI. Family-centered professional behavior: frequency and importance to parents.

Journal of Emotional and Behavioral Disorders, 1997; 5(4): p.196-204

NIVEL: C 6530

The purpose of this study was to assess parents' perceptions of the importance and frequency of family-centred behaviours in health care provision for chronically ill children. A nationwide sample of caregivers of children with emotional and behavioural disorders, developmental disabilities, or chronic health problems completed the Family Centered Behavior Scale, a measurement of the construct of family-centred service delivery. The differences in ratings between caregivers of children with emotional and behavioural disorders (EBD) and parents of children with other disabilities on the frequency and importance of behaviours exhibited by professionals are described. Results indicate strong agreement between

the two groups on which behaviours they consider to be most important, but those behaviours are performed much less frequently, according to caregivers, by professionals serving children with EBD. These results indicate that more intensive training of service professionals and more research about the effectiveness of family-centred practices may be necessary if long-standing professional approaches to this population are to be reversed.

Language: English

Keywords: Chronic diseases, general / Mental disorders / Professional-family relations / Quality of care

Sloper P. Needs and responses of parents following the diagnosis of childhood cancer. *Child: Care, Health and Development*, 1996; 22(3): p.187-202
NIVEL: C 6500

The aim of this study was to examine parents' views of the effects of childhood cancer on family life at 6 months post-diagnosis, their satisfaction with services, and the support they needed and obtained. Ninety-eight families took part in the study which involved interviews with the main carer and self-report questionnaires completed by mothers and fathers. Levels of parental psychological distress were assessed, using the Malaise Inventory: 55% of mothers and 41% of fathers scored above the cut-off point held to indicate high levels of emotional distress. Relationships between scores on this measure and reported effects and support were investigated. Negative effects on parental employment, finance, and family relationships and lack of emotional support were associated with higher levels of distress. Parental concerns regarding delay in diagnosis and unmet needs for counselling were noted.

Language: English

Keywords: Cancer / Parents / Psychological stress / Family relations / Needs assessment

Temmink D, Hutten JBF, Zee J van der, Huyer Abu-Saad H. Dutch nurse clinics for children with asthma: views of professionals and parents. *Journal of Nursing Quality*, 1999; 14(1): p.63-71
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In the Netherlands, there are two kinds of nurse clinics for patients with asthma. Extramural nurse clinics are run under the sole responsibility of a home care organisation while transmural nurse clinics are run under the joint responsibility of a home care organisation and a hospital. The aim of this study was to get insight into the opinions of professionals and parents of asthmatic children about the care given at these clinics. It is concluded that organisational differences between the clinics do not influence parents' (positive) perceptions of the quality and continuity of care provided by the clinics.

Language: English

Keywords: Asthma / Parents / Home care / Quality of care

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