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Families' needs when a child is long term ill: A literature review with
reference to nursing research

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Abstract

This article reports a literature review which draws together findings targeting families' needs when a child is long-term ill. The databases PubMed and CINAHL were searched from 1999 to 2003 during February 2004. The search terms were child health care, family caregivers, and needs and combinations of these. The search was limited to articles published in English and the Scandinavian languages. The analysis entailed a series of comparisons across articles focusing on major areas of inquiry and patterns of results. Various levels of needs are described, based on individual, family, and social needs.

Key words: child, family care givers, literature review, long term illness, needs,

INTRODUCTION

Historically, professionals have been the major caregivers when a child was ill, and it is still assumed that they know how children think and feel about treatment and care (Beauchamp and Childress 2001). Children and young people in need of long term care are particularly vulnerable. Their future depends on their parents and family and the legal system, as well as on social welfare. (Winn Oakley 2002). Long-term or acute illness in childhood influences not only the child but also its entire family. Craft and Willadsen's (Craft and Willadsen 1992) definition of family is particularly useful for families of children with a long-term health condition: a social context consisting of at least two persons characterised by caring, mutual attachment, long-term commitment, and responsibility. Responsibilities include providing for individual growth, supportive relationships, the health of members and the family unit, and the maintenance of the system amidst constant individual, family, and societal change. In this definition, the family is more than the sum of its individuals and more than a system; the attributes holding it together – caring, mutual attachment, long-term commitment, and responsibility – must be present as well.

Family nursing systems combine knowledge about family and health with practice skills that simultaneously encompass multiple systems, including individual, family, and larger systems, in health and illness. The family health system proposes that the nursing perspective of family health should link family structure, function, and health variables (including both wellness and illness), and incorporate the psychosocial and contextual aspects of nursing, while viewing the family as a unit and considering individual health issues in the treatment of the family (Wright,

Watson et al. 1996). A synthesis of current research of families and chronic illness identified two major areas of inquiry; descriptive studies of how families respond to illness and explanatory studies of variables contributing to response to the chronic illness (Knafl and Gilliss 2002). However, in clinical practise it might be of great value to describe what recent research have shown to be the needs of the family when a child in the family have a long term illness.

AIM

The aim was to identify, via a literature review families' needs when a child in the family has a long-term illness.

METHODS

A literature search was undertaken using snowball sampling to identify papers within the area of families' needs when a child is ill. The two biggest electronic databases for nursing research PubMed and CINAHL were used in February 2004. The search terms child health care, family caregivers, and needs and combinations of these were used. Searching was limited to articles published in English, Swedish, Norwegian, and Danish during a five year period from 1999 to 2003 which comprised the research from the five latest years. The search resulted in 90 articles. See tables 1 and 2. Duplicated articles (n= 7) were excluded. Both authors read all identified articles independently and the relevance and appropriateness of each paper was judged by the purpose of the review. Thirty-six articles were found to be relevant for the purpose (Goodman 1993; Polit, Beck et al. 2001) Notes were taken while read and 12 new references were identified through citations. Three overview articles were included as they covered areas that were missing in the articles

identified in the literature review, for example cultural context and actual research. In total 48 articles were included in the review. Tables 3 and 4 show a description of the included articles. Of the 24 articles describing studies with a qualitative design, the data collection was performed using interviews (18), focus groups (3), observations (2), and case studies (1). The articles described children's morbidity in areas of hospitalisation, intensive care, child health care, home care, and psychiatry care. Children's morbidity was described from the viewpoints of specific illnesses such as: chronic illness, cancer, multiple congenital malformations, acquired brain damage, dialysis, spina bifida, urethro-vesical reflux, epilepsy, autism, behaviour disorders, HIV, and juvenile rheumatoid arthritis. Parents were mostly described as caregivers (including foster- and step-parents). However, in a few articles siblings, grandparents and older caregiving relatives were included.

Insert tables 1 - 4 about here

The articles were reviewed and analysed by both authors first independently and then jointly. A need can be defined in different ways. In our analysis we used the Finnish philosopher Georg Henrik von Wright's definition "A person needs such things that are bad for the person to be without" (von Wright 1982). The analysis was performed as a content analysis in different steps. First, each article was read by both authors. Second, each author scrutinized each article and identified major areas of inquiry and summarised the identified needs. In the next step series of comparisons across the major areas and patterns of results was performed jointly. Disagreements were solved by dialogue and final consensus among the two authors.

Concepts found to be important for families were chosen as headings in this presentation.

RESULTS

Families' needs when a child is ill were identified and categorised in four comprehensive areas including the child, the family, the society and the individual close relative. The four categories concerned the following needs:

- optimizing the child's health, recovery to health, and development
- support for the family to relieve the situation and help them to cope
- support to make the family maintain family functions and stability
- having personal needs satisfied.

Need to optimize the child's health, recovery to health, and development

Need for participation and cooperation

Parents see themselves as closely connected to their child and experience that their contributions to the child's care and treatment are of great importance for their child's recovery and development irrespective of the culture they live in (Shields 2001). Parents have a need to feel secure in the care of their child (Hallström, Runeson et al. 2002) and to convey security to their child (Kristensson-Hallström 1999; Hallström, Runeson et al. 2002; Young, Dixon-Woods et al. 2002). By this means that they will be able to be present or be able to participate in all situations their child is dealing with, including intensive care (Powers and Rubenstein 1999). Parents describe a need to participate in the child's care (Bragadottir 1999; Balling and McCubbin 2001; Shields and King 2001; Armstrong and Kerns 2002;

Hallström, Runeson et al. 2002; Lindstrand, Brodin et al. 2002), in planning of the child's care and habilitation (Sheilds 2001; Lindstrand, Brodin et al. 2002), and being able to participate in decisions concerning their child's care and treatment (Hallberg, Lindbladh et al. 2001; Sheilds 2001; Hallström, Runeson et al. 2002; Hallström, Runeson et al. 2002; Hodgkinson and Lester 2002; Lindstrand, Brodin et al. 2002). Parents will be seen as partners in care and they mean that by good co-operation between the parents and the staff the child's care can be customized for the child (Kristensson-Hallström 1999; Ramritu and Croft 1999; Marino and Marino 2000). To make sure that good co-operation will take place, parental and staff roles need to be elucidated and parents need to know who is responsible for the child's care (Kristensson-Hallström 1999; Walker 2001; Hallström, Runeson et al. 2002).

Need for communication

Good communication increases conditions for participating in care and information is a prerequisite to be able to participate in care and decisions (Polkki, Pietila et al. 2002). Good communication between parents and staff is important to parents irrespective of cultural context (Schaffer, Vaughn et al. 2000; Shields 2001; Irlam and Bruce 2002). Communication includes both getting information from staff and informing staff about the child and its condition (Hallström, Runeson et al. 2002). Parents have great need for information when their child is ill, the more serious and extensive the child's illness is, the greater is the need for information (Pyke-Grimm, Degner et al. 1999; Ramritu and Croft 1999; Aytch, Hammond et al. 2001; Balling and McCubbin 2001; Walker 2001; Yiu and Twinn 2001; Scharer 2002). Parents want information about the child's diagnosis, prognosis, medical complications and

side effects, risks, the child's treatment and tests, how they should take care of the child in the best possible way, how to deal with and cope with painful and other trying situations, and the strain the child's disease puts on the family (Pyke-Grimm, Degner et al. 1999; Rosenthal, Biesecker et al. 2001). Early information about the diagnosis decreases parental insecurity (Swallow and Jacoby 2001). The need for information is experienced as greater than the need for emotional support in cases of both physical and psychiatric illness (Pyke-Grimm, Degner et al. 1999; Scharer 2002).

Parents see themselves as experts on their child and want their opinions, experiences and knowledge to be asked for and used (Hallström, Runeson et al. 2002; Thomlinson 2002). They believe that they have superior knowledge about the child's development and needs, and using this knowledge the child's care may be optimized (Hallström, Runeson et al. 2002).

Need for control

Parents describe a great need to control or supervise the care of their child (Rose and Clark-Alexander 1999; Balling and McCubbin 2001; Hallström, Runeson et al. 2002; Thomlinson 2002; Young, Dixon-Woods et al. 2002; Sterling and Peterson 2003), partly to be able to ensure that everything goes right, partly to be able to protect their child and to question the care (Hallström, Runeson et al. 2002; Young, Dixon-Woods et al. 2002). It is especially important to have control over the information sharing as well as the supervision of technical care (Balling and McCubbin 2001). In cases of chronic illness parents sometimes feel that higher-quality care is given at home than in hospital, as parents have more time than nurses

and other staff at the hospital to nurse and to control the child's care (Balling and McCubbin 2001).

Need for competence

To be able to optimize the child's health, recovery, and development, parents believe it is of the utmost importance that the child is taken care of by competent staff, that staff have adequate education so that they can satisfy the needs and expectations children and parents have. Parents want their child and themselves to be taken care of in an individual way by professionals with the requisite knowledge and competence (Schaffer, Vaughn et al. 2000; Hallström, Runeson et al. 2002; Hodgkinson and Lester 2002; Sterling and Peterson 2003). Parents themselves experience heavy demands on their competence from themselves, their partner, the child, and the staff (Hallström, Runeson et al. 2002).

Need for support for the family to relieve the situation and help them to cope

Families have a need for support to keep the family together (Ramritu and Croft 1999; Johnson and Hastings 2001; Young, Dixon-Woods et al. 2002). This also means that the family has the possibility to get some relief in terms of taking care of the ill child (Hallström, Runeson et al. 2002). Support is needed from different sources, such as the following:

Need for support from family members

Families seek and receive support from other family members (Ramritu and Croft 1999; Rosenthal, Biesecker et al. 2001; Walker 2001; Cimete 2002; Hallström,

Runeson et al. 2002; Gerhardt, Vanatta et al. 2003). Grandmothers most commonly help with babysitting (Green 2001). Grandparents' own needs are seldom expressed as they consider that the family already has too great a burden (Ramritu and Croft 1999). Immigrant families seek and receive most support from closest members included in the nuclear family (Morse and Messimeri-Kianidis 2001).

Need for support from health care and social authorities

When parents and close relatives receive attention from professionals with the necessary knowledge and competence in medicine, nursing, child development, emotional support, and family circumstances they feel supported and their possibilities to satisfy their needs increase (Bragadottir 1999; Armstrong and Kerns 2002; Hodgkinson and Lester 2002; Scharer 2002; Sterling and Peterson 2003). However, some parents find themselves more capable of satisfying their own needs than staff think they are (Shields, Kristensson-Hallström et al. 2003).

Parents whose children have a genetic or acquired disease have needs for supervision (Yiu and Twinn 2001) and counselling to counteract and work upon the feelings of guilt that may occur (Ramritu and Croft 1999; Hodgkinson and Lester 2002; Thomlinson 2002). The family needs help to be able to prevent siblings and partners from being forgotten (Leavitt, Martinson et al. 1999; Johnson and Hastings 2001). Mothers in the families tend to focus on the ill child while siblings, partner, housework, and occupation are set aside. The mothers are often aware of the problem and reflect on what it might imply for the development of siblings (Young, Dixon-Woods et al. 2002). Regular psychosocial assessment of the families' total

needs (including siblings) is needed to enable adequate support (Leavitt, Martinson et al. 1999; Ramritu and Croft 1999; Wills 1999).

Need for support from friends, other parents, and religion

Meeting other parents in the same situation or friends can support parents in demanding situations (Ramritu and Croft 1999; Hallström, Runeson et al. 2002). Community support networks are found to be of great help to parents of children with traumatic brain injuries (Armstrong and Kerns 2002). Prayer and support in religion are reported to be of great support for African-American woman and close relatives in Australia, Turkey, and the USA (Ramritu and Croft 1999; Rose and Clark-Alexander 1999; Cimete 2002; Sterling and Peterson 2003).

Need for a supporting physical environment

Parents believe that the hospital environment is important for the child's recovery. They feel secure knowing that the child is closely monitored and that medical staff is easily accessible. Self-contained units at the hospital are useful for close relatives, especially if they live at a great distance from the hospital. Parents find it important to have physical arrangements to be able to stay with the child, including a place to sleep cook and spend some time with the rest of the family (Ramritu and Croft 1999).

Need for support to make the family maintain family functions and stability

Need for an overall social system

Social contributions when a child is long-term ill differ in various countries. The mother's ability to read and write influences the child's health in some countries (de Souza, Peterson et al. 1999) while in other countries the parents' verbal competence may influence their child's care (Hallström, Runeson et al. 2002). While parents in Western countries describe a need for compensation for lost income from work (Thyen, Kuhlthau et al. 1999) and economic compensation for increased costs (Cimete 2002; Mason and Linsk 2002), parents in developing countries describe needs to be able to keep their jobs while staying with their child during the hospitalisation and difficulties paying the child's hospital costs (Shields and King 2001).

Need for well-functioning organizations

There is a need for well functioning organizations in health care with good and well-established routines including short waiting times and good flowcharts (Ramritu and Croft 1999; Hallström, Runeson et al. 2002). Communication and flows between different care-giving bodies – between hospitals, between hospitals and primary care and home nursing, and between caregivers and health-care providers – has to be well-functioning otherwise times at hospital tend to be unnecessarily long (Noyes 2002). Parents feel that they need help to facilitate bureaucracy when contacting authorities (Cimete 2002).

Need for specific contributions from society

Parents consider that parental education about the child's normal development, regularly follow-up and the possibility to be included in networks with other families, increases their capacity to maintain family functions and stability

(Hallberg, Lindbladh et al. 2001). Follow-up programmes including regular meetings for small children and their parents tend to strengthen the parental role and to decrease the number of acute hospitalisations (Nelson 1999).

Parents whose children have diseases with special needs experience a need, for example, for sports and recreation opportunities for disabled children (Field and Oates 2001), access to remedial teaching (Rosenthal, Biesecker et al. 2001), a support team for parents with autistic children (Johnson and Hastings 2001) and support from social workers (Gordon, McKinley et al. 2003).

Needs to have personal needs satisfied

Need for confirmation

Parents want to be treated with respect and have a need to be confirmed when they meet professionals (Marino and Marino 2000; Cox and Bialoskurski 2001; Hallström, Runeson et al. 2002). They describe a fear of losing their child (Cimete 2002) and they say that they have a need to feel that there is hope for improvements for their child (Lindstrand, Brodin et al. 2002). Many parents have a need to please the staff and therefore they do not always lodge complaints and experiences. As a consequence their possibilities to have their needs satisfied decrease (Hallström, Runeson et al. 2002).

Need for time on their own

Parents must have their basic needs satisfied, such as time to sleep and eat (Hallström, Runeson et al. 2002), but also time for reflection and friends (Yiu and Twinn 2001). Those needs are seldom prioritised as the child's needs are found

more important (Hallström, Runeson et al. 2002; Knafl and Gilliss 2002). Parents find it hard to combine work and taking care of an ill child (Walker 2001).

Especially mothers have a need to compromise between gainful employment and taking care of the ill child (Rosenzweig, Brennan et al. 2002). Seventy per cent of elderly close relatives who are acting as primary care givers report that they have too little time for taking care of their own health and their own health is often experiences as bad (Joslin and Harrison 2002).

Discussion

Limitations

By limiting the selection of articles to those written in English and Scandinavian languages, part of the cultural perspective is lost. Table 3 shows that there is a publication bias in favour of the USA and Northern Europe, although some of those articles describe immigrants or individuals from other countries. This jeopardizes the external validity of the results of the literature review. The review might be not only a review of inquiry but also an identification of areas in the world where research describing families' needs when a child is ill in a long-term illness is performed. Another reason for the geographic limitation in writing on the present issue might be priorities of needs. When resources are limited, food, shelter and medicine will be more important to satisfy than other needs and research focused on the needs of relatives will probably receive even lower priority (Sheilds 2001; Shields 2001; Irlam and Bruce 2002; Joslin and Harrison 2002). The literature search was limited to the last 5 years and only to two databases, implying that there might be research and additional knowledge that is not included in this work. The concept of family usually referred to parents, grandparents and siblings, mothers

being the most common group. However, differences in sex are not examined. Most articles are of a descriptive nature, few are interventions, which might be explained by methodological problems in evaluating interventions of this area.

Results and challenges for nursing practice

We used a broad definition for needs (von Wright 1982). The definition is vague, but von Wright asserts that a more precise definition would lead to a false description. Nursing theories were traditionally grounded in patient's needs and the estimation, evaluation, and satisfaction of needs are important goals in nursing care. However, from practice we know this area can improve. Our literature review identifies four areas of importance for relatives living with a sick child. In paediatric nursing practice those areas can serve as practical guidelines when caring for sick children and their families and when evaluating the care the family receive.

The review identifies a great number of needs for families caring for sick children at individual, family, and social perspectives. Certain needs could be regarded as general, for instance physical needs. Other needs, in contrast, vary between different cultures, different families, and also between family members. Certain parents absolutely want to participate in the care of the child, whereas other parents prefer staff members to be the caregivers. Even in one person the needs might vary depending on the time and the situation. Fear and fright may hinder a person from participating, whereas increased knowledge and security can make it easier for the same person to be a part of the caring team. Individual and family perspectives are important aspects when developing and evaluating family nursing in child health care settings. However, social perspectives also need to be taken under

consideration and this literature review point out several areas families find important when caring for a sick child and may serve health care professionals and politicians with useful information.

A literature review from 1983 (Sparling and Lowman 1983) suggested six potential areas of family needs for families of children with and without disabilities: information needs, support needs, explaining to others, community service needs, financial needs, and family functioning. Those areas correspond well to the ones found in our study. We do not believe, however, that it will be possible, or even desirable, to describe individual needs or needs related to a certain illness. In nursing practice it is important to find out the needs of each individual family in the present situation and try to identify and alleviate those needs.

Further research including families from different cultural and ethnic background is suggested in the following areas: the extended family's needs, fathers' and siblings' needs, intervention studies, and replications of intervention studies, prospective and longitudinal studies including health economy aspects.

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Table 1. Results from the PubMed search

	MeSH terms	No. articles found
#1	Child health care	7225
#2	#1 and family caregivers	81
#3	#2 and needs	14

Table 2. Results from the CINHAHL search

	Theseaurus	No. articles found
#1	Child health care	1041
#2	#1 and family caregivers	105
#3	#2 and needs	76

Table 3. Overview of the identified articles

Document type

Article	North America	Europe	Asia	Australia	Africa	South America	Total
Original	20	17	2	5		1	45
Overview	1			1	1		3

Table 4. Classification of the 45 original articles

Study design	No. of articles
Randomized controlled study	-
Controlled clinical study	6
Descriptive study	15
Qualitative study	24

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