

## THE INFLUENCE OF SOCIAL SUPPORT ON STRENGTHENING FAMILIES OF CHILDREN WITH CHRONIC RENAL FAILURE

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*This paper presents a study of the families of children on peritoneal dialysis, emphasizing the identification of social supports and networks to strengthen interventions aimed at health promotion. Our discussion is located in the context of inequalities between developed and developing countries. For this qualitative study, a content analysis was conducted in order to elicit themes from the raw data related to the lived experience of four families that have a child with chronic renal failure. The data were collected mainly by in-depth interviews and the construction of genograms and ecomaps. The identification and characterization of the families' social supports and networks allowed nurses and families to strengthen their coping mechanisms. Because families are dealing with severe economic problems, they need better supportive programs to guide their offspring to their full potential.*

**DESCRIPTORS:** social support; children; human development; family nursing; qualitative; chronic renal failure; health promotion; family

## LA INFLUENCIA DEL APOYO SOCIAL PARA EL FORTALECIMIENTO DE LAS FAMILIAS DE NIÑOS CON INSUFICIENCIA RENAL CRÓNICA

*Este artículo es un estudio sobre las familias de niños con diálisis peritoneal, que destaca la identificación del apoyo y las redes sociales para fortalecer intervenciones dirigidas para la promoción de la salud, en un contexto de desigualdad entre los países desarrollados y en desarrollo. Estudio cualitativo a través del análisis de contenido, con el objetivo de identificar temas en base a datos empíricos de niños de cuatro familias con insuficiencia renal. La recopilación de datos realizada a través de entrevistas a profundidad, construcción de genogramas y ecomapas. La identificación y las características de las redes sociales y de apoyo permitieron a los enfermeros y familias mejorar su utilización y fortalecer las formas de enfrentar la situación. Como las familias tenían graves problemas económicos, necesitaban de programas de apoyo adecuados para ayudar a sus hijos a desenvolverse al máximo.*

**DESCRIPTORES:** apoyo social; niños; desarrollo humano; enfermería de la familia; cualitativo; fallo renal crónico; promoción de la salud; familia

## A INFLUÊNCIA DO APOIO SOCIAL PARA O FORTALECIMENTO DE FAMÍLIAS COM CRIANÇAS COM INSUFICIÊNCIA RENAL CRÔNICA

*Este artigo apresenta um estudo sobre famílias de crianças em diálise peritoneal, enfatizando a identificação de apoios e de redes sociais para fortalecer intervenções que objetivam a promoção da saúde, no contexto das desigualdades entre os países desenvolvidos e em desenvolvimento. Para este estudo qualitativo, foi realizada uma análise de conteúdo, a fim de identificar temas a partir dos dados empíricos relacionados à experiência de quatro famílias que possuem uma criança com insuficiência renal. Os dados foram coletados por meio de entrevistas em profundidade, construção de genogramas e ecomapas. A identificação e a caracterização dos apoios e redes sociais permitiram às enfermeiras e às famílias melhorar sua utilização e fortalecer mecanismos de enfrentamento. Em virtude de famílias viverem em precárias condições econômicas, elas necessitam de programas adequados de apoio, para que possam conduzir seus descendentes a um potencial máximo.*

**DESCRIPTORES:** apoio social; crianças; desenvolvimento humano; enfermagem familiar; qualitativo; insuficiência renal crônica; promoção da saúde; família

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## INTRODUCTION

It is not new that people with high income and education levels tend to be healthier and live longer than people in less favourable socioeconomic conditions, nor that countries where incomes are more evenly distributed have a healthier population in terms of life expectancy, quality of life and mortality rates<sup>(1)</sup>. The state of the economy has a tremendous impact on health on many levels, including psychological and social well-being. Even in countries with a highly unequal income distribution such as Brazil, however, sources of social support and networks can be identified, and these can be health promoting, despite the economic difficulties of families living with chronic diseases. This paper presents findings from a study of families of children on peritoneal dialysis, emphasizing the identification of social supports and networks to strengthen interventions aimed at health promotion, in the context of inequalities between developed and developing countries. The idea of health promotion involves strengthening individual and collective capacity to deal with the multiplicity of factors that condition health<sup>(2)</sup>. Promotion goes beyond applying techniques and norms, recognizing that it is not enough to know how diseases function and to find mechanisms to control them. It has to do with strengthening health by building a capacity for choice, using knowledge to discern differences between events<sup>(2)</sup>. Care delivery for children with chronic diseases and their families is one of the priorities within Brazilian public policy. Such care demands broad and comprehensive knowledge for health professionals to perform technical and scientific skills, with a view to understanding families<sup>(3)</sup>. Chronic renal failure is one of the diseases that affects childhood.

## BACKGROUND

The diagnosis of chronic renal failure has a profound impact on children and their families, with the potential for impairment of the child's physical, mental, and social development<sup>(4)</sup>. Families with a child on peritoneal dialysis have to assume significant burdens of care, which can result in stress and potential complications. This overload is heavier when people face difficulty getting access to and communicating with health services. This difficulty is one of the characteristics of public health service users

in Brazil. The family members cope with the stress generated by the uncertainty by having to live each day as it comes, finding positive meaning, hoping for a transplant, and drawing on God's strength<sup>(5)</sup>. On the other hand, some parents report increased closeness within the family and greater bonding between the child and his/her mother<sup>(6)</sup>. The delay in the child's growth is family members' most constant source of concern. Even when patients with renal disease receive adequate care and nutrition, their height is still reduced because of their poor renal function and stunted growth. In Brazil, this is aggravated by difficulties in obtaining adequate nutritional and medical support for the child's development, due to the high cost of food and drugs<sup>(7)</sup>. Growth delays may also entail psychological disorders<sup>(8)</sup>.

Another factor that should be highlighted when distinguishing between the situation in Brazilian and what is described in international literature is related to the treatment conditions of children with chronic renal failure. Peritoneal dialysis is the preferred treatment for children and families who want to remain independent and children preferring less alimentary restrictions. In some situations, peritoneal dialysis is contraindicated. Family members' inaptitude to learn and perform procedures eliminates it as a treatment option<sup>(9)</sup>. Housing conditions, like cleanliness and space, are extremely important to be included in a peritoneal dialysis program<sup>(10)</sup>. In some countries, a new equipment called Peritoneal teledialysis (telePD) is being used. Literature presents some facilities these families have related to coping with dialysis treatment and with equipments to perform the dialysis at home. The telePD is a modem-based communication link between the patients' cyclers and a computer in the dialysis unit that allows the transmission and storage of a series of automated peritoneal dialysis (APD) treatment data. It offers security and provides a better quality of life to the families<sup>(11)</sup>. The "Respite Care" program has demonstrated a decrease in family stress and greater approximation between the health service, the family and the community, thus increasing the children's and families' quality of life<sup>(5)</sup>. Few studies reveal the importance of assessing social support and social networks to promote the health of families with children with chronic renal failure. In addition, there is little research exploring families' support systems focusing on the families in their community and local health care system contexts. The aim of this study

was to identify social supports of families of children with chronic renal failure receiving peritoneal dialysis by looking at families' health promotion.

## CONCEPTUAL FRAMEWORK

For this qualitative study, a content analysis was conducted to elicit themes from the raw data related to the experiences of families who have a child with chronic renal failure undergoing peritoneal dialysis<sup>(12)</sup>. This technique began with transcribing the data, including nonverbal messages, from audiotapes to hardcopy, and involved reading and rereading the transcriptions. A set of code words for the ideas and themes was outlined. The data was reduced into categories by similarities. Patterns that emerged were analysed and refined to form broad themes. The final process was to articulate the research data and the theoretical framework.

For this study, we used Bomar's family health promotion concept<sup>(13)</sup>. Family health promotion is the "process of achieving family well-being in the biological, emotional, physical, and spiritual realms for individual members and the family unit"<sup>(13)</sup>. This study also takes into account that social support and networks are beneficial to the health of individuals in a variety of ways. They are associated with reduced mortality rates, improved recovery from serious illness and increasing use of preventative health care practices. Social networks are generally understood in structural terms, described as linking to and interacting with surrounding social institutions<sup>(13)</sup>. The social network was analysed through the morphological category, supported by the visualization of the ecomap. The social network was identified by the following categories: anchor, reachability, density and range<sup>(13)</sup>.

## METHODS

### Recruitment and Sample

Participants were recruited from a regional university hospital that served as the referral center for children and adolescents with chronic diseases and was located in the interior of the State of Sao Paulo, Brazil. Each child who took part in the study received initial treatment and all follow up care at the recruiting

hospital. Four families of children with chronic renal failure undergoing peritoneal dialysis agreed to participate in the study, including four mothers, four siblings, one grandmother, one uncle and the four sick children, for a total of 14 participants. The only criterion to include the family in the study was that the sick child had to undergo peritoneal dialysis for more than one year. The children's ages ranged from four to ten years old, and there were two females and two males. The four families who participated in the study lived outside the hospital city; all of them were seen at least six times over a period of six months, which was the time needed to reach data saturation. The content of the interviews was about the care each family member provided to the child, the situations they faced and all kinds of information each of them would like to share with the interviewer. It was necessary to understand the families' story, asking family members about the course of the child's illness, their expectations and social supports they received along their illness experience.

### Setting

The data were collected in two places in the hospital: at the clinical wards, during children hospitalizations and at the outpatient clinic. Another location where data collection occurred was at the children's homes.

### Ethical Considerations

Approval was obtained from the hospital ethics committee. Each family was contacted by the first author to obtain consent to participate in the study. Primarily, families were met personally at the hospital to arrange a first meeting. All contacted children and family members agreed to participate. Informed consent was obtained from all adult participants as well as those children who indicated their ability to assent, and all participants were assured of confidentiality. They were assured of their rights to refuse to answer any question or withdraw from the study at any time.

### Data Collection and Data Analysis

Data were collected from November 2004 till April 2005 by the first author and two research assistants who received extensive training about the

study aim, methodology, ethical requirements, and worked under the supervision of the researchers. The data were collected through in depth interview and demographic data from their hospital records. Furthermore, together with family members, we built a genogram and ecomap for each family, broadening the information about the families and their community contexts<sup>(13)</sup>. The interviews were recorded and fully transcribed. The data collectors interviewed all participants in Portuguese, the national language of Brazil. Analysis was conducted in Portuguese but, for the English publication, selected transcript segments were translated by one of the authors.

## FINDINGS

Four families collaborated with our study, totalling 14 participants. The families are identified by ordinal numbers as Family1, Family2, Family3 and Family4 and their members by their parenthood in relation to the child, together with the family number, for example Mother1, Uncle1, Sister1.

### Family 1

Family1 consists of five members: mother, uncle, two sisters and the sick child. Child1 is male, four years old and his sisters are younger. Mother1 is 22 years old and the age of Uncle1 is 25. The family members have always worked in the rural area. The household is sustained by the child's grandparents and uncles. Child1 displays sequelae of meningitis, has communication difficulties and few motor skills. Uncle1 accompanies the child during hospitalizations and returns, helps his sister to take care of her other daughters and also performs the child's dialysis.

### Family 2

Family2 consists of mother, child with CRI and grandmother. Child2 is female, nine years old, communicative and a dedicated third-year basic education student at a public school. Mother2 is a 32-year old college student and Grandmother2 is a retired lady of 69 years old. Father2 has passed away, as a consequence of a deep depression and suicide attempt, resulting from the impact of the child's health conditions when she was born. After the failed suicide attempt, Father2 remained in a coma for seven years and then died.

### Family 3

Family 3 has four members: father, mother, child with CRI and brother. Child3 is male, four years old and very active during the data collection meetings. He continued playing with his brother during the interviews and interacted little with unknown persons. Mother3 is a 44-year old housewife and responsible for the care of Child3 and the entire family. Father3 is 44 years old and works in a company as an administrative aid. Brother3 is a 13-year old secondary education student at a public school.

### Family 4

Family4 consists of six members: father, mother, sick child, two brothers and one sister. Child4 is three years old and male. Father4 is an alcoholic. Family4 lives in a two-room house, provided by the social service of the community where they live after an assessment of socioeconomic conditions and health needs caused by the child's chronic condition. Child4 is quite communicative, knows all drugs he takes and peritoneal dialysis procedures.

According to the families of children with chronic renal failure undergoing peritoneal dialysis, social supports were very meaningful. The genogram and ecomap helped the researchers to visualize these supports and the social network. The first support identified in the testimonies was emotional. Mother4 mentioned the extended family's concern about the child after the diagnosis of chronic renal failure. Mother3 demonstrated her satisfaction with the closer presence of her brother during some weekends and said that this comforted her.

*Oh my! They [extended family] got very worried, were very supportive and helped us a lot. They have always been very concerned about relatives (Mother4).*

*When my brother comes, I like it! We stay here, Saturday night, all day Sunday until he goes. This is the way to escape a bit from the problem, isn't it? (Mother3)*

The extended family appeared as a source of emotional support. Knowing they can count on relatives' help was a way of calming down and feeling comforted. The grandparents were frequently mentioned, as they demonstrated their availability to help with care for the child. Besides the relatives, other persons were also mentioned, including friends of healthy siblings. Brother3 told that his school friends prayed for the recovery of his brother and helped

him to face the problem. He said: *My friends.... They say they pray for him [Child3]; it helps... they supported me a lot... (Brother3)*. As a result of increased contact, the family felt secure and confident in care delivery to the child and relatives feel rewarded.

Informational support is the set of information professionals give to the families. This support revealed to be deficient, due to information absence and conflicts. The statements below give examples of information conflicts and omission. The first illustrates the contradictory information provided by doctors and mentioned by Mother3. In the second example, Uncle1's testimony evidences that health professionals omit information needed to take care of the child.

*Because the doctor was once making a talk there [at the outpatient clinic] and she said trips were OK. [The doctor said:] "You take the things to have dialysis there". The other doctor didn't advise it, though, so we don't know, do we? (Mother3)*

*I know there is some stuff to get from the government for our child... but I don't know what it is.... He hasn't received it yet. I guess they [health care professionals] should tell us.... We need this help.... (Uncle1)*

Instrumental support refers to the offering of material and operational resources. Uncle1 showed how the extended family has collaborated with care for the child, helping them with food and money. In the same family, Mother1 mentioned that the extended family sustains household expenses by working on a tomato plantation in the rural area:

*They [the extended family] bring food, money. For example, right now, I'll need to phone them [extended family] asking for some of my clothes (Uncle1)*

*My mother, my father and my two brothers all work on farms; so, they all do farming collecting tomatoes. This is where the maintenance comes from....It is not easy, is it? (Mother1)*

Appraisal support refers to all feedback and affirmation received by relatives or actual results from the delivered care. The mothers' testimonies demonstrated that their child was the reason for all of their efforts and keeping him/her alive in the family was the best result. We can perceive in Mother1's discourse that her fight for her son's life was her reward. Mother2 reported that she was proud of her daughter's intellectual development:

*We are struggling for our child's life. That is good! With each experience we feel stronger (Mother1).*

*And that is how it was! And you see, today she is ten years old....she attends the third grade... she is very smart! The teachers say she is one of the smartest students in the class! (Mother2).*

The data also showed that support offered by close ones helps families to feel secure and encouraged to continue taking care of their child, in the search for strategies to adapt to the new living condition. The institutions that gave support to the families were a strong point of connection between the family and society. Uncle1 identified the company that supplies the dialysis machine as an important anchor for the child's care, saying that the dialysis machine's existence was fundamental for the child's life. He showed the importance of the hospital institution in financial help. Mother2 revealed that she found availability in the hospital to help her with her difficulties:

*I think it was the best thing they've ever done; if it wasn't for the machine (dialysis), I don't know what it would be of this boy....I think the biggest drawback is financial. But here, the hospital has helped a lot! (Uncle1).*

*Oh no! Since we've been there [at hospital], every time I needed, they've always supported me (Mother2).*

The hospital and the public social service in the cities were important anchors for the families in care for the child. The families received support from hospital, religious and educational institutions; companies and local governments, which constitute the anchor of the social network.

Reachability is related to the families' ease to have contact with the available resources. Some families use kindergartens, special schools, the companies where they work, local government resources, medication and housing to obtain additional resources that complement care for the child and promote the family's health direct and indirectly. In Mother1's testimony, she indicated her son's special school as an easily accessible resource that is important to take care of the child. Mother3 mentioned that the company where Father3 works donated material to facilitate care for the child:

*My mother used to take him [Child1] to the special school and I would work in the fields. I stayed at her house. At the special school, he received every type of care, physiotherapy, everything (Mother1).*

*They supplied us with the stand [for the dialysis bag]...they also offered us everything we might need in that respect, that they can help. They provided the physiological saline stand, you know, also the bag. They brought us the locker for the boxes, you know? So, in that respect, the firm where we work always helps! (Mother3).*

The density of the social network refers to the depth of the support received as a result of contacts

among family members and the interaction among support-giving persons. Mother3 reported that, after a talk with the doctor, during which he revealed the child's diagnosis, Father3 went into depression. Mother3 suggested participating in a praying group to receive comfort:

*I said to him [Mother3 talking to Father3]: "As you are now, you can't go on!" [depressive state]; then the doctor called us there and explained everything. Then, we joined a prayer group at church, then, oh! Everything was over. His depression disappeared! (Mother3).*

For this family, the praying group established a very significant link that provided comfort and well-being at a critical time, when the gravity of the child's illness was revealed.

The range is perceived by the number of contacts the family establishes with society. Health, education and religious institutions possess a better infrastructure to support the families. These were the most mentioned institutions in the relatives' testimonies. Local governments were also mentioned as offering transport, housing and some material resources, as well as employers and dialysis material manufacturers.

Family members emphasized the need for informational support. Information is an important source of support because it allows family members to make conscientious choices and decisions. Health professionals were always issuing information about how family members should act or charging earlier requests. The testimonies revealed that relatives complained of few opportunities for a dialogue. When there was no dialogue, the health team did not know the family's experiences in the process of taking care of the child. Mother4 complained about how she received information from health professionals about the peritoneal dialysis her son would start. She felt intimidated by the threat of her son's death.

*But, they [health care professionals] didn't tell us. They said they were going to care on a procedure, which was the dialysis, but they didn't explain what it was. But they told us that even with the procedure he [the child] might die, then and even without the procedure he [the child] might die too. You know, they leave us feeling like that (Mother4).*

The data showed health care professionals' lack of sensitivity and commitment in communicating with the family. According to the relatives' testimonies, professionals avoided giving further explanations about treatment, presupposing that parents were not sufficiently able to understand the therapeutic plan.

Another concern in this study was to identify communication within the family. Among family members, some siblings knew that the child was ill, but were unaware of the treatment and the seriousness of the chronic disease. In one family, the sick child and his siblings maintained aggressive dialogues, as the healthy siblings blamed the sick child for the difficult conditions the family was going through.

*Everything is his fault [Sister4 talking about Child4]. My mother says it isn't, but, all that is happening is his fault. We are living here 'cause of him; our situation is like this 'cause of him. It is too difficult! (Sister4).*

*He [Brother 3] won't talk, 'cause he's very quiet. You know, you notice that he also was shaken, you know? And we also don't keep commenting things near him [Brother3], we don't comment a lot near him, you know? (Mother3).*

Another situation mentioned by Uncle1 showed small talk in the family. Caregivers divided the very work-intensive daily tasks, due to hospitalizations and care for healthy siblings, and do not managed to be together with them to share their experiences:

*And the rest of us, we'll have to talk; me and the child's mum haven't talked yet. We get half detached, sometimes she's there [at home] and I am here [at the hospital], it's always dashing in and out. So, we can't talk, you know. It's hard to talk! (Uncle1)*

## DISCUSSION

The extended family has offered financial support and has made available resources for the child's care, decreasing the family's burden. This support is extremely important for the family, as these resources are essential to take care of the child and, without them, the families would not have minimal conditions to survive in daily life. The caregiver should feel encouraged and strengthened each day. This support should be given through positive assertions, encouraging words and humanized care. Literature has shown that families need different kinds of social supports: affective, economic and, mainly, from the team responsible for treatment, which reinforces this study<sup>(14)</sup>. Nurses need to assess families to recognize their needs and close partnerships with available social supports and networks to implement the family's health promotion. They also need to encourage families to use and enhance support networks. Furthermore, nurses should reconsider investigating social support as a nursing intervention<sup>(15)</sup>.

Public policies, mainly related to the availability of benefits for children with chronic disease, should be informed to the family in a clear way and in due time. Orientations can neither be ambiguous nor provoke confusion. It is important for the health team to transmit information coherently, as it gives rise to the need to adopt certain behaviours. The family needs to feel secure in communication with health professionals. The sender and receiver of the message should keep the communication channel open. Health professionals should not make precipitated or prejudiced judgments about family members' ability to understand.

Literature confirms conflicts, omissions and misunderstandings between the family and health professionals, similar to data found in this empirical study<sup>(16)</sup>. Relatives expect health professionals to share information for the child's care. Nurses were indicated as the professionals who demonstrate more positive attitudes to share care<sup>(17)</sup>.

Chronic illness in a child creates new demands for family members. Encouraging family members to mutually share their feelings allows for efficient communication, leading to healthy problem coping. Nurses should open up channels to listen to family members and take their testimonies to the other team members who deliver care to the child, such as psychologists, social workers, nutritionists and physicians. Communication should be fluent both between the family and the team and among team members. Often parents can be left feeling distressed, angry, confused, and de-valued as a result of a communication incident that health professionals have barely registered because it was so 'routine'. Nothing about communication is routine for parents: everything we say and do, or don't say or do, is significant. The communication skill is not acquired through books or reading. Instead, it should be practiced daily by health professionals<sup>(18)</sup>.

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## CONCLUSION

This research has pointed out that families of children with chronic renal failure need care plans that consider the family as a facilitator of the child's therapeutic process. Peritoneal dialysis requires a process in which the family will adapt itself to the new routine. Nurses can help by making good assessments, paying special attention to social support and communication. The family's knowledge about the disease and treatment facilitates its adaptation. This study highlights the need for intersectorial and multiprofessional action by health care workers, within the larger network of the social sector.

The identification and characterization of the types of support allowed both nurses and families to improve their use and to strengthen coping mechanisms. Families provide many of the basic resources people need to be healthy. Because they are dealing with severe economic problems, they need adequate supportive programs to guide their offspring to their full potential. Governments and the health sector should play a leading role, creating supportive policies for families.

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