

FAMILY-CENTERED CARE IN THE CONTEXT OF CHILDREN WITH DISABILITIES AND THEIR FAMILIES: A REFLECTIVE REVIEW

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ABSTRACT: This theoretical-philosophical study addresses Family-Centered Care and the practice of healthcare teams in caring for children with disabilities and their families. The birth of a child with a disability brings about a crisis that affects the entire family, shaking its identity, structure, and functioning. Family members find themselves unprepared to cope with or manage this new way of being a family; the child with a disability does not meet expectations, there is change of roles, and families may even break apart. The Family-Centered Care Model can support strengthening of the family, encouraging their potential, and promoting empowerment. Although this model recognizes the family as a unit of care, a gap remains between theoretical knowledge and its application into clinical practice by health professionals, revealing the need for further research to indicate a means to transfer knowledge of this kind.

DESCRIPTORS: Family nursing. Disabled children. Nursing care.

O CUIDADO CENTRADO NA FAMÍLIA NO CONTEXTO DA CRIANÇA COM DEFICIÊNCIA E SUA FAMÍLIA: UMA ANÁLISE REFLEXIVA

RESUMO: Trata-se de uma reflexão teórico-filosófica sobre a perspectiva do Cuidado Centrado na Família e a prática da equipe de saúde no cuidado à criança deficiente e sua família. O nascimento de uma criança com deficiência provoca uma crise que atinge toda a família, abalando sua identidade, estrutura e funcionamento. A família se vê despreparada para enfrentar ou lidar com esse novo modo de ser família, pois o filho deficiente representa a quebra de expectativas, a alteração de papéis e a não-continuidade da família. O Modelo de Cuidado Centrado na Família pode oferecer subsídios para fortalecer a família, estimulando seu potencial e promovendo seu empoderamento. Embora esse modelo reconheça a família como unidade de cuidado, há uma lacuna entre o conhecimento teórico e a aplicação na prática clínica pelo profissional de saúde, revelando a necessidade de ampliar estudos que apontem direções sobre como realizar a transferência de conhecimento.

DESCRIPTORIOS: Enfermagem familiar. Crianças com deficiência. Cuidados de enfermagem.

CUIDADO CENTRADO EN LA FAMILIA EN EL CONTEXTO DE LOS NIÑOS CON DISCAPACIDADES Y SUS FAMILIAS: UNA REVISIÓN REFLEXIVA

RESUMEN: Es una reflexión teórico-filosófica sobre la perspectiva del Cuidado Centrado en la Familia con la práctica del equipo de salud en el cuidado al niño con discapacidad y su familia. El nacimiento de un niño con discapacidad provoca una crisis que perjudica toda la familia, con problemas para su identidad, estructura y funcionamiento. La familia se muestra sin preparación para enfrentar ese nuevo modo de verse familia, pues el hijo representa una experiencia traumática que puede alterar el estado emocional entero de los miembros. Las presuposiciones del Cuidado Centrado en la Familia pueden fortalecer a la familia, estimular su potencial y promover el fortalecimiento familiar en su trayectoria con el hijo. Aunque con las presuposiciones del Cuidado Centrado en la Familia se reconozca a la familia como la unidad de cuidado, una laguna se observa entre el conocimiento teórico y de aplicación en la práctica clínica por los profesionales de salud, revelando la necesidad de ampliar los estudios que indiquen caminos hacia la transferencia de conocimientos.

DESCRIPTORIOS: Enfermería de la familia. Niños con discapacidad. Atención de enfermería.

PUTTING THE PROBLEM IN CONTEXT

The birth of a disabled child brings about a crisis that affects the entire family, shaking its identity, structure and functioning. The family sees itself as unprepared to cope with and manage this new way of being a family because a disabled child does not meet the family's expectations, leads family members to exchange roles, and sometimes even causes the family to break apart. Family life changes in the face of emotional demands and new requirements resulting from the child's condition, generating conflicts and emotional instability, changing the couple's relationship, and causing estrangement among its members.¹

A situation of disability in a child can fragment the parents' feelings of being able and self-confident, causing a profound wound that takes time to heal. The family seeks to adapt to a new reality and reorganize itself to cope with the experience of living with a child with a disability, trying to reconstruct its identity as a family group. This situation involves a feeling of vulnerability and emotional readjustment, which requires time.

There are families who are able to cope with the challenge but others have greater difficulty and are not able to reorganize. These families show signs of hopelessness, dismay, and fatigue in their journey with their child and often their structure is threatened and their ability to cope with potentially destabilizing situations is weakened.

Another aspect to take into account is that the family needs to reconsider its organizational structure as a group during the process of becoming adapted to the new situation generated by the needs of a disabled child; the child may require the constant presence of one of the family members, which can overload the family.

Recognizing the importance of the participation of the family in the care provided to the child means to value the family in the context of care.² However, the ability of families to care for their members and deal with suffering generated by the impact of striking situations, such as disability, congenital malformation, or prolonged hospitalization, may be compromised, reduced or absent.

Providing care to families who experience life with a disabled child is essential to the task of enabling them to cope with adversities arising from their children's disability and to maintain healthy family interactions and functioning.

This study presents a reflection concerning the practice of the health staff in providing care to

families of disabled children in light of the principles of Family-Centered Care (FCC). This study was based on Brazilian and international literature published in the last 20 years. A systematic search was conducted in two important databases (PUBMED and BIREME).

DISCUSING THE PREMISES OF FAMILY-CENTERED CARE AND PROFESSIONAL PRACTICE

FCC is an approach that acknowledges the importance of the family as a recipient of care, ensuring the participation of all its members in the planning of actions and revealing a new model of care, offering the opportunity for the family itself to define its own problems. Respecting the child's individuality and that of his/her family is decisive³⁻⁴ and represents a permanent challenge for health services and health workers, as well. It requires the staff to be open and attentive to the interactions and impact of experiences and also to provide knowledge concerning the dynamics, beliefs, and ways families can adapt to different situations. Eight structural elements of FCC are described in the literature⁵, which are considered essential when one seeks to apply this care approach in clinical practice.

Recognizing the family as being a constant element in the child's life

Professionals should work in such a way that the importance of the family is acknowledged because it is the unit within which the child grows and develops. The time when the diagnosis of disability is disclosed often leaves the parents confused and without proper guidance, it may interfere in the bonds established with the disabled child. In recognizing the family as a constant element in the child's life, professionals should provide answers to the family's doubts concerning the child's development and acknowledge the family has the right to obtain complete instructions concerning the child's diagnosis and care delivery appropriate to their understanding. Studies⁶⁻⁷ indicate that the family constitutes the universe of social relationships of the disabled child. For the family to become a reference for the deficient child, it needs, at the time when the diagnosis is disclosed, to feel safe, supported, and has to have confidence and dignity, aspects that can help the family to cope with reality.⁸⁻¹⁰ Despite a theoretical acknowledgment concerning the importance of

family for the child, studies show there is a lack of guidance concerning how to care for a child with cerebral palsy and what his/her specific needs are⁷, in addition to a feeling of estrangement from health workers, which makes the family feel excluded from the care process⁹.

Facilitating collaboration between parents and professionals in care provided to the child

In recognizing the importance of families as participants in care, health workers should effectively stay at their side, listening to their fears, doubts and needs, and supporting them – provided their limits, difficulties, beliefs and values are respected – in order to enable families to care for their children the best they can. However, the literature reveals that the family is not being properly guided and trained to provide care to a disabled child; neither are they encouraged to participate in care delivered and decision-making. The family faces difficulties caring for their children at home, which leads to doubts and anxiety, and hinders care provided to the child.^{7,10-11}

Continually sharing impartial and complete information with parents concerning the child's care delivery

Communication and the relationship established between health workers and families are essential in the care process of children with disabilities.¹² Health workers should share health and care information with families in an open and candid manner so they have the opportunity to participate in care delivery and decision-making. The literature⁸⁻⁹, however, reports that the experience of families with disabled children is permeated by a lack of information and estrangement from health workers. Such a situation is not conducive to the establishment of goals and paths for the family's care for itself or for its disabled child.

One study⁸ reports that families have difficulty guiding their attitudes when faced with the health professionals' own lack of knowledge and misinformation. This is also due to the perception of a lack of involvement and support on the part of health workers, which would be necessary for families to adapt to the situation and make decisions. It is disturbing for the family to come across

a discrepancy between their emotional turmoil and the insensitivity of professionals.

Predicting the implementation of appropriate policies and programs promoting emotional and financial support for the family's needs

The FCC model recommends the implementation of policies promoting emotional and financial support for the family's needs. A study¹³ addressing the influence of social support on strengthening families of children with chronic renal failure reported that families require different types of support, not only affective and economic, but also support from the professional staff. The Statute of the Child and Adolescent (ECA*)¹⁴ reiterates that children have the right to protection, life, and health through the implementation of social policies that permit them to be born, grow and develop within dignified living conditions. It also ensures specialized treatment and resources related to the treatment, habilitation or rehabilitation of disabled children. There are, however, few references in the literature to programs supporting families of children with disabilities.¹⁵⁻¹⁷ These families need appropriate support programs to enable them to make the most of their abilities, with preventive and therapeutic actions promoting improved quality of family life.¹⁵ One study¹⁶, aimed to understand how mothers of disabled children identify and access social support resources to meet the needs of their children and families, stresses that the rights of both families and children are configured in equal continuous access to life in society and all sorts of opportunities. Another relevant finding refers to the absence of social and economic support, which results in families having difficulty accessing health and rehabilitation facilities and a lack of physical structures and health workers to guide and care for the families in these spaces.¹⁷

Acknowledging the family's strength and respecting its individuality and manner of providing care

According to the FCC, the family should have its potential and individuality respected, taking into consideration that for that to happen, intrinsic conditions should be revealed – hence the role of professionals in helping families to acknowledge their own strengths and capabilities. Studies^{3,7-8,11,15-18} report that the family experiences

* Acronym in Portuguese.

radical changes in its routine when the child's disability is diagnosed. The family needs to (re) structure itself to care for the child, since being the mother and father of a deficient child requires a new role that needs to be learned. Nevertheless, these studies indicate that families have difficulty finding in health workers the support they need to cope with the experience and to provide care for their child with more confidence. Families share inauthentic experiences with the nursing staff because they cannot express their feelings and attitudes in relation to their experiences and suffering.⁸ They feel the staff charges them with playing the role of caring for and providing the child with the conditions necessary for his/her healthy growth and development.^{8,13}

Understanding the developmental needs of the child and adolescent, and the needs of the family in the different systems of health care delivery

Professionals should be able to identify the needs of both the child and family in the different contexts of care. In the case of disabled children, the different spaces refer to the inter-relationships among the environments in which the child and family participate, which can either favor or hinder the family's internal functioning.¹⁹ The authors of a study²⁰ investigating the experience of mothers in raising children with Down syndrome verified that professionals seem to have difficulties understanding the needs of families and in providing conscientious care and welcoming the families. Instead, they act in an evasive manner or restrict themselves to merely transferring information, not dealing with or becoming concerned with the family's emotional dimension.

Family members feel a lack of guidance or encouragement to the family's psychotherapeutic follow-up. Another study²¹ addressing the reaction of parents in the face of their children's diagnosis of cerebral palsy reports a lack of institutions providing integral care to disabled children and their families and also note that the attitude of professionals denotes a lack of commitment and involvement with the needs of children and their families.

Encouraging and facilitating support among families

The families of disabled children experience additional overload at all levels: social, psychologi-

cal, financial, and in relation to the care and rehabilitation required by children, and for this reason they need access to social support networks available in the community. The role of professionals is to encourage and facilitate the referral of families to competent agencies and entities and to groups of families who experience similar situations. It is observed in the literature²² that institutions are support sources and constitute strong ties linking families and society. In terms of meeting the needs of families, the families consider that the support provided by institutions rehabilitating disabled children is extremely important. The institution still is a place where families experiencing common situations meet, which enables them to share feelings and experiences.^{8,16} The proximity of nurses showing their availability and helping families to reorganize can help the family to better cope with the situation of having a disabled child.²³⁻²⁴

Ensuring a flexible and accessible health care system according to the needs of each family

Professionals should fight for a health system that favors the inclusion of disabled children and their families. The literature^{8,16,22} shows that families seek out a rehabilitation institution for disabled children with the expectation to be welcomed and have its needs met. Nevertheless, families often remain deprived of follow-up and interventions directed to the demands that emerge from the disabled child's condition. Depending on the type of disability and the child's health condition, families often have to bear most of the financial expenses related to their child's treatments, including the acquisition of orthoses and prostheses, rehabilitation therapy, special educational follow-up, specialized medical follow-up, surgical interventions, technological resources, adapted services, and other services, because the system does not provide for all these demands. The authors of a study²⁵ addressing the meaning of caring for a child with Down syndrome from the perspective of mothers reinforces the idea that public policies play an essential role, especially in relation to low-income families, since specialized treatment is expensive.

Such policies should ensure these children access to uninterrupted follow-up, mainly health and educational support directed to the development of their potential and abilities, taking into account the unique needs of each family and child. However, not all resources required rehabilitating and including children and supporting families

are provided by government agencies or devised by public policies.¹⁶

The Family Health Strategy (ESF)**, which sought to reorient the care model in Brazil, recommends, among other objectives, that the family and its social space be the focus of health care provision. It also provides for actions that ensure problem solving capacity and quality of care to meet the needs of families.²⁶ The families of disabled children have difficulty receiving integral care and accessing health actions and services – which should be available through the Single Health System (SUS) – and believe the ESF is actually a service directed to vaccination. What is recommended by the ESF diverges from the reality and needs of these families' experience; they do not have their rights served given the incongruence of the system and face inaccessibility in all spheres of health care, including referral and counter-referral.²⁷

REFLECTIVE SYNTHESIS

It is possible to see that there is still an estrangement between the health staff and the family because the families of disabled children are not cared for as a unit by the professionals who base the care they provide on the biomedical paradigm. Even though the FCC was proposed four decades ago, the theory remains an ideal and has largely not been applied by professionals in their routine practice. The focus remains on care provided for the pathology itself, while the family is relegated to the background, perceived only as a source of information and the provider of care to the disabled child. It is necessary to advance and use knowledge that is produced in clinical practice with families.

The term “knowledge translation”²⁸ has been used in the literature and applies to this context. Theoretical knowledge has to be used to transform current reality so as to include families as participant agents of care in a collaborative manner, acknowledging their expertise and potential.

Nurses, as members of the health staff, need to be able to recognize situations that threaten the autonomy of families and act to ensure relationships among subjects include the ethical criteria of autonomy, beneficence and justice.²⁹ It requires that the model of family care advance in a such a way to include the family as participant agents of care, making it stronger and capable to deal with its own problems and decision-making.

Therefore, it is crucial that pediatric nurses develop skills to care for the family as the recipient of care, understanding the repercussions and implications of the disability for the family as a whole. Nurses' interventions need to extend over the family's trajectory together with the child and nurses should be qualified to care for the family, strengthening it in order to retain family cohesion so that it can perform its functions concerning care provided to the disabled child. In this context, recognizing the strengths and potential of families, as well as their needs and fragilities, enables the proposition of interventions intended to alleviate suffering and promote change.

Nurses can help families to cope with the situation of having a disabled child through the application of the FCC approach in their practice. Its principles favor bringing together professionals and families, respecting the families' individuality and enabling them to become stronger.

Considering that the relationship of nurses with families should include respect, commitment and openness to dialog, including listening, reflection and action, the FCC appears to be a relevant approach to be used because it promotes the empowerment of families of disabled children.

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