

FAMILY SELF-CARE: THEORETICAL ESSAY FOR FAMILIES WITH CHILDREN WITH INTELLECTUAL DEVELOPMENT DISTURBANCE

Autocuidado Familiar: ensaio teórico para famílias com filho(s) com perturbação do desenvolvimento intelectual

Autocuidado familiar: ensayo teórico para familias con niños con discapacidad intelectual

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ABSTRACT

Background: self-care arises in the family context, despite being seen as a determinant of individual health. The family, understood as a system and social unit, converges towards a pattern of self-care and not a sum of it. **Objective:** to convert individual self-care into family self-care, considering the needs and characteristics of families with children with intellectual development disorders, by adopting family self-care as the central concept of a standard of care. **Methodology:** theoretical essay reflecting on the concept of family self-care in the families identified, grounded in the Nursing Self-Care Theory, the Care Partnership Model, the Mid-Range Theory of Self-Care in Chronic Illness, and the General Systems Theory. **Results:** factors that influence the development of family self-care were identified, which precede four domains in constant interaction with the environment, society, and community. Through these, the family seeks to maintain, protect and/or promote health, mediated by monitoring and disease management behaviours. **Conclusion:** the families under analysis seek to achieve family health, maintaining it through health promotion and disease management practices, always mediated by family self-care behaviours.

Keywords: self-care; family nursing; intellectual disability; chronic disease

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RESUMO

Enquadramento: o autocuidado surge no contexto familiar, apesar de ser encarado como um determinante de saúde individual. A família, entendida como um sistema e unidade social converge para um padrão de autocuidado e não para um somatório do mesmo. **Objetivo:** Efetuar a transposição do autocuidado individual para o familiar, atendendo às necessidades e características da família com filho(s) com perturbação do desenvolvimento intelectual, através da adoção do autocuidado familiar, enquanto conceito central de um padrão de cuidados. **Metodologia:** ensaio teórico que reflete o percurso reflexivo de conceção do autocuidado familiar nas famílias identificadas, ancorado na Teoria do Autocuidado de Enfermagem, no Modelo de Parceria de Cuidados, na Teoria de Médio Alcance do Autocuidado da Doença Crónica e na Teoria Geral dos Sistemas. **Resultados:** identificaram-se fatores condicionantes ao desenvolvimento de autocuidado familiar, que antecedem quatro domínios em constante interação com o ambiente, sociedade e comunidade. Através destes, a família procura manter, proteger e/ou promover a saúde, mediada por comportamentos de monitorização e gestão da doença. **Conclusão:** as famílias em análise procuram alcançar a saúde familiar, mantendo-a por meio de práticas de promoção da saúde e gestão da doença, sempre mediadas por comportamentos de autocuidado familiar.

Palavras-chave: autocuidado; enfermagem familiar; deficiência intelectual; doença crónica

RESUMEN

Marco contextual: el autocuidado surge en el contexto familiar, a pesar de ser visto como un determinante de la salud individual. La familia, entendida como sistema y unidad social, converge hacia un patrón de autocuidado y no una suma de ellos. **Objetivo:** transponer el autocuidado individual al autocuidado familiar, teniendo en cuenta las necesidades y características de las familias con niños con trastornos del desarrollo intelectual, adoptando el autocuidado familiar como concepto central de una pauta de cuidados. **Metodología:** ensayo teórico de reflexión sobre el concepto de autocuidado familiar en las familias identificadas, anclado en la Teoría del Autocuidado de Enfermería, el Modelo de Asociación de Cuidados, la Teoría del Autocuidado Medio en la Enfermedad Crónica y la Teoría General de Sistemas. **Resultados:** fueron identificados factores que condicionan el desarrollo del autocuidado familiar, que anteceden a cuatro dominios en constante interacción con el ambiente, la sociedad y la comunidad. A través de ellos, la familia busca mantener, proteger y/o promover la salud, mediada por conductas de monitoreo y manejo de la enfermedad. **Conclusión:** las familias analizadas buscan alcanzar la salud familiar, manteniéndola a través de prácticas de promoción de la salud y gestión de la enfermedad, siempre mediadas por comportamientos de autocuidado familiar.

Palabras clave: autocuidado; enfermería familiar; discapacidad intelectual; enfermedad crónica



INTRODUCTION

The origin of self-care [SC] arises in the family context (Gray, 1996), although it is seen as a relevant determinant of individual health (Riegel et al., 2021). Currently, SC has several meanings and dimensions, and can be analyzed from various perspectives, transposing the reflection of the integration of various terms, and the exponential prevalence of chronic diseases in the population (Tulu et al., 2021). In this perspective, it is intended to carry out the transposition of individual SC to the family, considering the needs of the family with children with intellectual disability [ID], as a system and social unit, adopting Family Self-care [FSC] as a standard of care, determinant of family health.

Having a child with ID or another chronic health condition is a life event that can present, and most often presents, negative effects on psychological health and family well-being (Mas et al., 2019). The evidence indicates that families of children with ID have higher levels of stress, anxiety, depression and attenuated psychological well-being (Mas et al., 2019; Kruithof et al., 2020). The level of support and health care these children need differs in part from the nature and severity of ID (Mas et al., 2019). ID are a group of etiologically diverse conditions originated during the development period, characterized by an intellectual and adaptive functioning significantly below average, with an estimated IQ below 20 (Kruithof et al., 2020). Deficits in intellectual and adaptive functioning are the main characteristics of IDs, with a worldwide prevalence validated between 1% and 3% of the population per country (Mas et al., 2019). During childhood, the delay in gross motor skills is the most common symptom. In the pre-school and first cycle,

language, learning and difficulty in study are the most common in children with ID (Kruithof et al., 2020).

The ID can also impair the adaptive functioning in one or more activities of daily living, such as communication, social activities and self-care in the various contexts where the child develops: such as home, school or community (Patel et al., 2020). Therefore, children with ID are dependent on others. This dependency means that the families/parents of these children play a vital role throughout their children's life path (Hockenberry & Wilson, 2018). And for this to happen, families/parents need a wide network of family and social support, and close involvement with health professionals, particularly nurses. Therefore, nursing care based on the philosophy of Family Centered Care and the Care Partnership Model are considered ideal to assist families in fulfilling the role they need to play at home (Hockenberry & Wilson, 2018). In this sense, nurses and other health professionals need to hold knowledge that allows them, in an integrated way, to approach, care, assist and tutor the family as a fundamental unit of society, in the acquisition and conservation of SC (Figueiredo, 2012; Tulu et al., 2021). In this context, the family being the agent of SC, also the identification of the person who is responsible for the provision of care is an essential data in the context of family care (Figueiredo, 2012). Thus, the concept of the role of caregiver assumes a prominent position in the current perspective. At the same time, the implementation of SC will improve well-being, reduce morbidity and mortality, and reduce costs associated with health care (Riegel et al, 2021).

Thus, this essay aims for the family to be seen as a system and social unity, in which the whole it represents is greater than the sum of its parts (Wright & Leahey, 2012), and the SC a basic dimension of it (Orem, 2001; WHO, 2022). The SC exhibits individual competence to take care of itself, is inherent in the human being and develops throughout the life cycle (Orem, 2001). Thus, it can be understood as a health resource, of extreme relevance to the well-being and quality of life in the family context.

As the concept of FSC was not identified in computer research (national and international context), a long process of manual documentary search was made in the consultation of bibliographic sources. We identified only two authors that approach, sparingly, this concept. And, both direct their conceptual approach to family and family health, with no specificity for the pediatric approach. Gray (1996), addresses the FSC based on the General Nursing Theory of Orem, encompassing principles and practices, as well as tools and techniques, which allow families to take responsibility for the health of their members and the family as a unit. Lopes et al. (s.d.), on the other hand, proposes the concept of FSC as an integrator of new care models, adding SC of an individual nature to the socio-family.

In this sense, the interest in studying and developing nursing knowledge focused on the family with children with ID, particularly in the idiosyncrasy of SC, was related to the current and growing appreciation of SC in the health field (WHO, 2022).

In this pursuit, there was a research and review of the scientific literature on the various concepts identified: FSC; family and ID in pediatric age. The conceptual framework of this essay refers to the concept of FSC in

its individual aspect and transposition to the family, alluding to four theories: the Nursing Self-care Theory of Orem (2001), the Care Partnership Model of Anne Casey (1988), the Middle Range Theory of Chronic Disease Self-care by Riegel et al. (2012) and the General Theory of Von Bertalanffy's Systems (2015), considered unavoidable in the present perspective. It is approached in this way, the conception of FSC, and its correlation to the specific context of families with children with ID in adaptive phase, directed to the promotion and protection of health in the home context, as well as to the variables that can influence this FSC.

Thus, the main objective of this essay was to identify and develop the concept that unites the family to FSC, that is, to understand if there is a pattern or culture of FSC and demonstrate how it can develop. That is, in a reasoned and coherent way, it is intended to demonstrate that FSC is indispensable in the individual context (Orem, 2001; Riegel et al., 2012), and the family the primordial unit where it develops (Casey, 1988; Gray, 1996) does not direct us to a sum of FSC within this same family, but eventually to a pattern of FSC, which assumes relevance at certain key moments of the life cycle. In the families under analysis, it is emphasized that the child cannot be dissociated from the family, so that parenting, in this context, assumes the functions and activities developed by the caregiver (s), with a view to the healthy and full development of the child in charge. In this thread, a pattern of FSC is inherent to the family that conditions and is conditioned by each of its members (Lopes et al., s.d.). Accordingly, it is intended that this concept transposes to family health, which the whole is greater than the sum of its parts (Wright & Leahey, 2012).

DEVELOPMENT

Thinking about the FSC, refers us to a powerful concept in the context of Health and in particular Nursing as a discipline, care. This term is a central and transversal question in the life of all people, present in human life, and in their vital process, from conception to death. Apparently, given the current presence in everyday language, it would be an easy task to define FSC, joining the prefix self to care. However, if we try to find the origin of this concept, we lose ourselves in time, and there seems to be consensus that it is associated with the idea of taking care of oneself, and that it arose in the health field (Martinez et al., 2021). Since the beginning of humanity, the dominant paradigm of health was centered on individual care, family and community. In this period, people were responsible for their health and the health of their families because self-reliance was mandatory (Martins & Brito, 2021). During the nineteenth and early twentieth centuries, due to the significant technological and scientific advancement, especially of medicine, FSC ceased to be valued, being often seen as an unnecessary practice (Martinez et al., 2021). The resurgence of FSC is associated with the positive health movement, after World War II, diverting the focus of attention from the disease to health, being accompanied by the appearance of a set of new concepts (e.g., salutogenesis, resilience, among others) (Martins & Brito, 2021). And it aroused interest in the year 1948, in the Congress of Constitution of the World Health Organization, in conceiving health as a «state of complete physical, mental and social well-being», not only consisting of the absence of disease, but recognizing the psychological and social components, as well as the interaction between these factors,

attributing an important role to risk behaviors in the health context (WHO, 2022). Thus, the adoption of a biopsychosocial perspective was initiated, which points to an integral care of the person, directed to the promotion of self-responsibility in FSC, as a resource to promote quality of life and well-being. However, its conceptualization was initiated by Dorothea Orem in 1956 and formally validated in 1967 through the work done by the Nursing Development Conference Group. Orem (2001) developed the Nursing Theory of Self-care Deficit that encompasses three interrelated theories, taking as central construct the term FSC: the Self-care Theory, the Theory of Self-care Deficit and the Theory of Nursing Systems. In the present context, the Self-care Theory has special relevance to the extent that every person has the potential to self-care, by possessing skills, knowledge and experience acquired throughout life and in situations where FSC supplants its ability to perform it, needs support from both people with social responsibilities (e.g., family, friends) and health professionals (e.g., nurses). For Orem (2001), FSC can then be defined as, "acquired capacity, complex, to meet the requirements of continuing to take care of itself (...) of the structure and human functioning, as well as its development and promotion of well-being" (p.254), and effectively implemented, contributes specifically to the integrity of the human structure, the functioning of the person and his development. The basic premise of Orem's concept of FSC is the individual responsibility to develop self-care measures, that is, the action of self-care. And an important indicator of outcome is that the person can perform FSC with poor contacts to health services. The conceptual relationship that is desired in this theoretical essay, allows the family to exercise control over the environment and «work» to achieve pre-

established health behaviors. These behaviors can be deliberate and transcend the action oriented FSC process. The FSC phenomenon will thus encompass the domains: cognitive, psychosocial, physical and behavioral (Matarese et al., 2018; Riegel et al., 2021). Each of these areas is interrelated and involved within the family. The FSC can thus be assumed as a complex union of domains that guide the family to be, behaving and becoming autonomous in the FSC (Gray, 1996). According to Martinez et al. (2021), the capacity of FSC varies from person to person and develops in the daily course through a process of spontaneous learning. It assumes a different nuance according to culture, emphasizing that FSC behaviors are transmitted from generation to generation, according to different contexts, resulting from the interaction of the so-called basic conditioning factors of Orem. Matarese et al. (2018) highlighted the historical, social, economic and political factors, stressing that the concept of self-management is related to FSC and is often interpreted as a subset of it. In the same line of thought, the concepts of self-management, self-monitoring, self-efficacy and management of symptoms associated with FSC were identified. There is consensus that this concept refers to an activity started, consciously, appropriate to the situation and focused on a goal. It is also found that it is widely used in contexts of chronic diseases, given the context of acute diseases (Riegel et al., 2021). Martinez et al. (2021), corroborate that FSC is a concept that has evolved over time, associated with the terms autonomy, independence and responsibility, and that can be conceptualized as a process of health and well-being, innate, but also learned. It can, similarly, be understood as the focus and result of health promotion and interventions to manage the disease aimed at improving the physical,

psychosocial and overall health condition of individuals. It is also verified that today, the complex phenomenon of FSC reflects the integration of various terms, and the exponential prevalence of chronic diseases in the population (Tulu et al., 2021) challenges of families with the need to be able to manage the disease throughout life. These terms comprise, overall, the association of FSC with self-control, self-confidence, management of symptoms, self-efficacy, self-management, conservation and self-monitoring (Matarese et al., 2018; Riegel et al., 2021). It has also been associated with broader notions of autonomy and responsibility (Martínez et al., 2021), reflecting the effective participation of the person/family in their health condition. In this thread, the ISF (2023), presents the FSC as a set of activities centered on the person, which all citizens must perform for the conservation of health and well-being. It highlights the great potential of making FSC «clearer», and increasing its role in personal, family and community health. Through FSC behaviors, which involve individual capacity, opportunity and motivation, people/families can and should be healthier, and remain so, managing their diseases more effectively. Based on these assumptions, it has developed a structure for FSC around seven «pillars» or domains, which support a wide range of interconnected activities, covering the cognitive, psychological, behavioral and physical aspects. These focus on knowledge and literacy in health, mental well-being, physical activity, healthy eating, risk prevention, "good" hygiene and the rational and responsible use of products and services. They also reflect the current perspective of FSC, in which the focus began to be placed on understanding the processes that people/families experience, allowing them to achieve or maintain health and well-

being (ISF, 2023). Also in this perspective, WHO recently updated the definition of FSC, transmitting it as the ability of individuals, families and communities to promote health, prevent disease and maintain health, even with diseases and/ or deficits, adding that it can be developed with or without the support of a health professional (WHO, 2022). In this assumption, it is found that the attitude of people has been changing, as in other areas of social life, with a growing tendency to be an integral part of the decision-making processes under preventive and treatment measures. This participation necessarily requires appropriation of relevant information and ability to decide with confidence and autonomy in health, which corroborates the learning aspect of FSC through an efficient teaching, tailored to the needs and objectives of each person/family (Martins & Brito, 2021). It is then, in this perspective, that the systemic conception of the family gains expression (Bertalanffy, 2015), facing its totality and complexity, instead of dividing it into elements, to find a cause-effect relationship. It will also be seen as an open socio-cultural system, continually confronted with requirements to change, both internally and externally (Gray, 1996). Indeed, within the family context, people must learn to adapt to the demands and stress, and it is in this perspective that the family system distinguishes and carries out its affective and socialization functions through subsystems, which can be individual, relational or interpersonal. In this thread, the family translates a complex network of relationships and emotions, seen as a social unit (International Council of Nurses, 2012) or a collective whole, composed of members connected through consanguinity, emotional affinity or legal kinship, including people who are important to the client, target of care. The concept of family, for

Figueiredo (2012) is also specified in a systemic perspective, which recognizes its complexity and "(...) integrates its evolutionary and contextual dimensions that give it an identity path, which emerges from the reciprocity of the processes of mutual interaction with the environment and the characteristics of globality, equity and self-organization" (p. 67). Thus, it is essential to analyze individual behavior, but in the context in which it occurs, passing the focus of analysis to be necessarily systemic. The [individual] person is no longer seen as the cause and the explanation of his problem, leaving the family with the explanatory responsibility for this observed [dis]functioning (Seltzer, 2019). The currents that are dedicated to the analysis and study of the family, based on epistemological models and theories, particularly of systemic influence (Wright & Leahey, 2012), converge in the sense of considering, clearly, a «being» one and. The family is thus understood as a system, a whole, a globality that only in this holistic perspective can be correctly understood. Assuming systemic thinking as an epistemological reference that supports the understanding and interpretation of complexity and intersubjectivity inherent in the family, it was considered pertinent to invoke the General Theory of Von Bertalanffy's Systems (2015), which assumes continuous interaction between the various members of the family system and with the environment, if change in any «part» of the system affects all other «parts» (circular causality). In this perspective, it is dared to affirm that the family understood as a system is not a sum of people inserted in a certain space or time, but a group co-responsible for the well-being of all its members, so that everyone feels like an integral part of this whole. Whatever kind of family we face, they are all organized through a relational structure

where roles and functions are defined analogous to social expectations (Wright & Leahey, 2012). In this conjecture, families have the primary responsibility [as a function], to meet the health needs of their members, and for this it is essential that they have resources, opportunities and well-being (Gray, 1996). In this way, family health translates, "(...) the ability of the family system to promote strategies that allow its functionality as a unit, maintaining its organization and producing structural changes, and simultaneously responding to the individual needs of its members" (Figueiredo, 2012, p.68). Thus, a pattern of family self-care can be especially relevant in specific contexts of the family life cycle, especially when there are children, who due to their specific characteristics are unable to self-care. And in this context, the family assumes a set of tasks and functions aimed at ensuring the survival, development and well-being of children (Farrell, 1992; Hockenberry & Wilson, 2018). In the exercise of their parenting, they presuppose the support, protection, affection, love, among other tasks and functions, performed throughout the life of children (in disparate conjunctures) but in the family context, especially by parents, according to their personal characteristics, and to environmental factors that surround them, providing conditions for the protection, conservation and promotion of health (Sanders & Mazzucchelli, 2018). Thus, parenthood, conceived as an elementary and essential dimension of our human condition, is preliminarily, the process by which a generation transmits to the next the values, skills and attitudes necessary for survival as a species. Parents/family are responsible for a set of tasks that society expects to be fulfilled, ensuring not only their survival and safety, but also a development as harmonious as possible (Hockenberry & Wilson, 2018; Sanders & Mazzucchelli,

2018). The confrontation with a deficit associated with the child affects the process of parenting and consequent FSC, assuming considerable relevance, not only for the impact generated, but also for the changes that affect the whole family. The impact that a deficit or disturbance has on the family can be disparate, considering its uniqueness and uniqueness, but this too will adapt to the «different» situation of family life (Hockenberry & Wilson, 2018). The name «disturbance of intellectual development», as a translation of Intellectual Disability, was proposed by the classification DSM-V-TR [Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition] (American Psychiatric Association, 2023), replaced the previous designation of mental disability used in DSM-IV. The DSM-V-TR considers this terminology as equivalent, which will be used in the future ICD-11 classification [International Classification of Diseases, 11th revision] of the World Health Organization, and that seems to mirror in European Portuguese the reality of children with this deficit.

According to the DSM-V-TR, ID is characterized by deficits in reasoning, problem solving, planning, abstract thinking, judgment, academic learning and experience learning. Inherent to these deficits, the critical components are verbal comprehension, working memory, perceptual reasoning, quantitative reasoning, abstract thinking and cognitive effectiveness. The deficits mentioned above, result in the inability to comply with development and socio-cultural standards for personal independence and social responsibility (American Psychiatric Association, 2023). We can thus assume this disorder as a chronic disease within the family, which gives the family increased tasks, responsibilities and concerns (Hockenberry & Wilson, 2018).

The physical and emotional health of these children, as well as their cognitive and social functioning, is strongly influenced by proper family functioning and the inherent stage of development associated with them (Farrell, 1992). The importance of FSC is particularly evident here in the care of children with special health needs. As the family begins to know the health needs of their child, it often becomes an expert in promoting this care, aiming to maintain, monitor and manage FSC effectively (Hockenberry & Wilson, 2018). Health professionals, particularly nurses, are adjuncts and facilitators in this process, forming partnerships with the family, at times when professional intervention so requires. It is invoked in this follow-up, the Care Partnership Model of Anne Casey, which guides the care partnership between parents/ family and nurses, through a process of understanding and flexibility, which sees the family in the process of care (Casey, 1988). Concurrently, communication and effective negotiation between family and health professionals are essential to meet the management of chronic disease (Casey, 1988; Hockenberry & Wilson, 2018; Riegel et al., 2012). The family-centered care aims to assist the adaptation of the family throughout the trajectory of chronic disease, in its various changes, promoting the skills inherent in achieving self-care (Bastos et al., 2022).

In the family, the international standard established and aimed at supporting one of its members who is dependent on the FSC, corresponds to the role of the caregiver (Figueiredo, 2012). In the families under analysis, care can and should be exercised by one or more family members, thus maintaining the focus on the family system in interaction with the surrounding social and environmental values. Perpetuating this approach, within the family with a child with chronic

disease, Riegel et al. (2012), with the Middle Range Theory of Self-care of Chronic Disease, came to attribute to FSC the essence of the management of this disease, defining it as a process of maintaining health through health promotion practices and disease management. This theory divides the process into three interrelated elements, which make perfect sense in a familiar approach: self-care conservation, self-care monitoring and self-care management. Demonstrably, and after several transitional periods, the family of children with adaptive chronic disease assumes the responsibility of performing complex technical care and controlling symptoms, protecting and defending the child, in addition to seeking and coordinating health and social resources for your sick or incapable child, without forgetting your own well-being (Kruithof et al., 2020). The family manifests in this framework the ability to self-care: being a whole; behaving through a process of learning and prior adaptation; becoming autonomous in the various domains of FSC. In this sense, FSC as a framework for the discipline of Nursing can be defined as a specific approach to clinical practice that recognizes the singularity and the family as a system, emphasizing its ability to promote, maintain and protect health. Being accepted this definition, the decision to engage in FSC behaviors and the effectiveness of the inherent actions will always be the responsibility of the family. This assumes the family providing care understood as responsible for the prevention and treatment of the disease or the disability of a family member (International Council of Nurses, 2012).

In this sense, and to schematize the development of FSC in families with child(s) with ID, a conceptual synthesis of it was made, as a standard of care, in the form of a diagram that is presented below. This

diagram addresses the factors conditioning the development of FSC, and that involve not only the intrinsic characteristics of each family, but the resources they have and the environmental factors that surround them. Following these factors, the FSC based on the triangulation of autonomy, responsibility and independence that the family pursues, will respond to the four domains identified in the

literature. If the family with child(s) with ID is conceived as a social system and one, the AF will develop in a continuous interaction with the community, society and environment where the family is inserted. For this to be so, the conditioning factors are determinant for the acquisition of family health because of FSC, as well as nursing interventions after the needs diagnosed with the family (Figure 1).

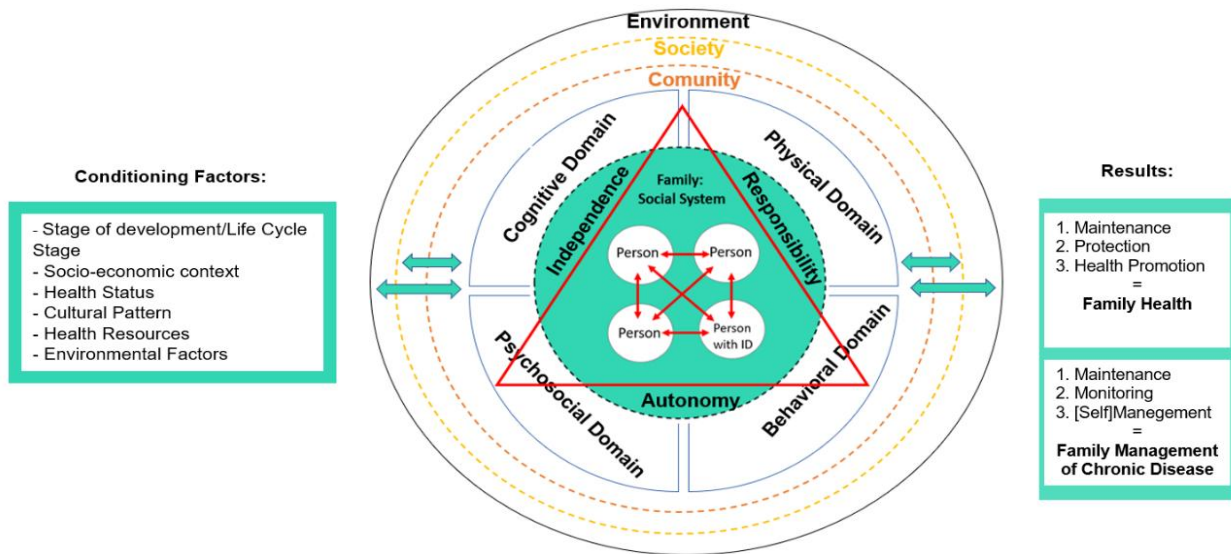


Figure 1

Conceptual synthesis of Family Self-Care: pattern of care in families with children with ID

CONCLUSION

In a context of families with children with ID, in which the descendant does not have, or will have, individual ability to self-care, the pattern of FSC can assume a significant relevance, in the sense of maintaining life, health and well-being, demonstrating that the requirements of the SC exceed the individual capacity, requiring the cooperation of others, performed in their family and home context. In this line of thought, evidence has shown that the family transforms itself through time by adapting and restructuring itself to continue to function. Undoubtedly, «we live» in

different groups (e.g., family, neighbors, friends, work context, among others), in which we interact and develop. However, although the most diverse social groups influence the life of each one of us, the family emerges as the most significant social group, assuming a socializing function [in all cultures], facilitating the integration of the individual in society, becoming, in a way, the bridge between the individual and the collective.

In this sense, through this theoretical essay, it was conceived the importance that FSC can add to Family Health, specifically in the families in focus. The

importance of the partnership of care in a pediatric context, and the uniqueness of the family as a social system (in permanent and constant evolution), refers us to the focus on the determinants that condition the FSC, and on participation, negotiation and shared decision making that is intended with these families.

The FSC is now prioritized by individuals, families and communities and is the first line of approach in each meeting inherent in health care. People's attitudes have been changing, as in other areas of social life, with a growing tendency to be an integral part of decision-making processes in the context of preventive and treatment measures. This participation necessarily requires appropriation of relevant information and ability to decide with confidence and autonomy in health, which corroborates the learning aspect of FSC through an efficient adapted to the needs and objectives of each family.

It is intended that this essay contribute to increase the knowledge, in nursing, particularly, on how FSC develops and perpetuates, in the context of family health and self-management of a chronic disease, in allowing an early and systematic reflection on its importance for this discipline. Intervening in this assumption means perceiving the structure, functioning and development in relation to the family health-disease process. Therefore, this analysis will allow us to perceive whether families have a resource-rich environment that allows them to develop FSC behaviors, or whether they constitute a health problem in themselves.

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