

THE NURSING SCIENTIFIC PRODUCTION IN THE CONTEXT OF THE FAMILY FROM DISABLED CHILDREN

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The family nursing area is still in the process of formation of a theoretical knowledge to support its practice. In this sense, nurses are challenged to carry out researches to produce the best evidence for the care of family in situations of sickness of one of its members. The transfer of the theoretical knowledge provided by those researches become fundamental to promote changes in the professionals practice with the family.

When it comes to families living in the context of child disability, the challenges are even more striking, influencing the well-being of the whole family. In a literature review about the family experience with a disabled child, the authors grouped the findings into five thematic axes: The deficiency diagnosis and its repercussion in the family, whose studies show the emotional impact in the family life in an occasion of the birth of a child with disability, the changes in the family dynamics and their relationships; The family coexistence with children and teenagers, highlighting studies that deal with the burden of family unit living with deficiency, family arrangements to manage the situation, the redefinition roles and family priorities; The challenges of a family with disabled children and teenagers, studies that emphasize the need of information and social support networks, as well as the need to increase public policies that guarantee the family access to technological resources for health maintenance, growth and development of the child; Family forces in the disability context, bringing studies that discuss the positive adaptation and family strength to face the disability situation, with the prospect that this situation will bring positive contributions to the life and well-being of the whole family; The family relation to healthcare provided by the Health Team, put in evidence how the family perceives the approach of health professionals and the unpreparedness of the team in approachin the families(1).

Despite the advances in the knowledge about the experience and the everyday functioning of families in the deficiency context, and the movement of researchers interested in this subject, it is observed that there is still a gap related to intervention studies. There studies are essential to promote the family care, to help them to face this experience, to contribute to the management of family interactions and to subsidize the creation of public policies to meet the needs and demands of this population.

A study reflexion emphasizes that family research is one that is understood and operationalized to enable sensing the family unit. The authors refer to two main challenges presented to the researcher and in

particular in the area of family nursing, namely: to improve the quality of family research, and to make the results of these researches relevant to the public that consumes it.

We, as nurses, also need to devote ourselves to produce measurement instruments of subjective phenomena that involves the family as a unit care, like as family stress, anxiety, vulnerability, among others. The studies focused on the family come mainly from qualitative research, with theoretical-philosophical foundations that consider the human beings and their interactions. However, it is necessary to make progress in the generation of randomized clinical studies that produce highly recommended evidence.

Proposals for interventions with families still need to be evaluated regard their efficiency. In this sense, it is necessary to identify new constructs to be measured, to develop skills for assessing the quality of the measurements instruments, to identify common elements that can be shared in practice or research programs, to explores new approaches to understand families and to incorporate family variables into the documentation system.

Thinking about the direction we want to take in our research and advancing the aspects covered, and the expansion of existing programs of evaluation and intervention with families in their social and political context, will ensure new data on effective interventions, providing the advancement of professional practice and policies focused on family care and family nursing science.

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