

Fathers in the Care of Children with Disabilities

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quality of life

children with disabilities

1. Introduction

To speak of care implies understanding all those tasks necessary to ensure the daily well-being of all people, tasks that are present throughout the life cycle in one form or another. For this reason, it is necessary to understand the concept as a fundamental attribute for the maintenance and sustainability of life, and as a basis for the development of social life ^[1]. Although the term includes countless activities (childbirth, child rearing, feeding, supervision, listening, cooking.), it is a recent term and generally understood as “those tasks that are done to maintain the well-being of people in a situation of dependency, that is, who cannot look after themselves because of some disability” ^[2]. However, as Joan Tronto and Berenice Fisher point out, caring is “an activity characteristic of the human species that includes everything we do to maintain, continue or repair our “world” so that we can live in it as well as possible. This world includes our bodies, our individualities, and our environment, which we try to maintain in a complex web that sustains life” ^[3].

In any case, care in general, and child-rearing more specifically, have traditionally been tasks associated with the role of women in any culture and context ^[4]. As a result, there is still an unequal distribution of care tasks between women and men, as they are not usually understood as a male responsibility. Thus, unpaid care work is mostly carried out by women in their homes, and paid care work continues to be feminized, less valued and poorly paid (nursing assistants, household cleaners, caregivers, etc.) ^[5]. This unequal distribution of care tasks has a significant impact on women's lives, as it takes away time and opportunities, and in many cases health and quality of life ^[6]. Traditionally, studies on caregiving have focused more on the tasks carried out by women ^{[7][8]}. However, in recent years, greater attention has been paid to caregiving undertaken by men. Recent studies shows an increase in their involvement in caregiving, as well as a rethinking of the priorities and functions they carry out ^{[9][10]}.

A study ^[11] conducted in the United States comparing 6572 fathers and 7376 mothers suggests that fathers' attachment to caregiving is largely dependent on employment and income, so they are more likely to be involved in routine caregiving when their wives contribute a significant portion of the household income. Other studies ^{[4][5][12]}

[11] suggest that women's increasing entry into the labor market has not always been accompanied by a proportional increase in men's participation in caregiving occupations, again overburdening the mother or other women in the family. In any case, the results of the study [11] show that fathers spend much less time with children than mothers, approximately 31 h per week (50 h/s for the mother).

For parents the birth of a child is a source of stress but, according to the data found in a systematic review [13], it seems that when the child has a health problem this stress intensifies notably more in mothers than in fathers, they tend to experience depressive periods and emotional anguish that persists over time as a consequence of the need for constant care (and this differentiates them from mothers of children without disabilities). Men, on the other hand, experience greater stress due to the impact of child care on marital life and marital intimacy, referring to not spending time as a couple without the child and even abandoning the family more frequently [12]. Their concerns also include the social acceptance of the child and their own attachment to them. For others, however, income is the most worrying issue.

When coming to terms with the arrival of a child with health problems, while mothers experience more sadness, fathers feel more rage and anger [13] and show feelings of inadequacy related to guilt [14], they may blame the mother for the "biological failure" or feel guilty for not having provided their children with the necessary components to lead a healthy and happy life [12]. They seek social and emotional support from other family members and are more likely to express their emotions publicly than mothers are. Fathers are more likely to avoid or deny the problem, hiding their vulnerability, not accepting that their child is different and delegating the responsibility of care, etc. Disappointment is not something present in the parents. However, they often admit to comparing their children with other children of their age, their expectations are usually related to them managing to develop basic skills to be self-sufficient [12].

2. The Perceptions and Experiences of Fathers of Children with Disabilities

For the fathers who participated in the study, the birth of their children with disabilities and being involved in their care has had a significant impact on different areas of their lives: many of them have had to readjust their working hours, reduce their working day or give up their job altogether to care for their children; they have given up their social life, they lack leisure time, time to spend with their partner, to do sport or rest, to take care of themselves. These consequences have also increased the already existing stress and caused a decrease in the emotional well-being of these fathers. So, the distribution of care tasks also has a significant impact on men's lives, it also takes away time and opportunities, and sometimes health and quality of life. As other studies [14] have shown, caring for a child with a disability has significant consequences for fathers' physical, mental, and social well-being, freedom and independence, family well-being and financial stability.

Mothers in the research are not the only caregivers or those who suffer the consequences of providing constant care [4][5][6], some of the fathers are the main caregivers, so they spend most of their time caring for their children, which allows them to be involved in routine care tasks: they shower their children, dress them, feed them, prepare

food, among other activities that relieve the overload of their wives. This does not follow the findings in other studies ^{[5][15][13]} where the figure of the father was mainly involved in leisure and play time, outings outside the home, or occasional supervision while the mother performs other care tasks.

For the fathers, caring for their children with disabilities is a task they share with their mothers, to a greater or lesser extent. Their participation depends above all on the time that their jobs allow them to spend at home and on whether their wives contribute financially to the household's upkeep ^[11]; thus, those who work full-time devote less time to routine care and are more involved in occasional care ^{[6][12]}.

For both parents taking on the birth of a child with a disability is a complicated event. Fathers described it as difficult to cope with, a time filled with fears and uncertainty. Although the literature suggested that guilt could be a problem for these fathers ^{[12][13]}, most of the men interviewed did not describe this emotion. Some studies ^[13] state that stress is often more noticeable in mothers than fathers and sometimes this may be the case. However, the fathers in this study were quite emotionally affected after the birth of their children, some because of the stress of caregiving and others because they were not yet coming to terms with the reality of their children ^[12].

3. Conclusions

Caring for a child with a disability has important consequences for the physical, mental, and social well-being of fathers, as it has a significant impact on different areas of their lives. However, their involvement in caregiving is always job dependent. Fathers of children with disabilities who are heavily involved in their care perceive disturbances in the work environment, neglect their social participation, lack time for leisure, for their partner, for sports or rest, in short, for taking care of themselves. Furthermore, the parents state that the news of the arrival of a child with a disability is something difficult to cope with and has an important impact on the couple.

In future research it would be relevant to contemplate the experiences of parents who live alone or who have children with other types of disabilities.

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