



A STUDY ON PARENTING INTERACTIONS FOR DISABILITY

VIJAY KUMAR

RESEARCH SCHOLAR SUNRISE UNIVERSITY ALWAR

DR. AJAY KUMAR SHARMA

ASSISTANT PROFESSOR SUNRISE UNIVERSITY ALWAR

ABSTRACT

The purpose of this research is to get insight into the lives of caregivers who take care of children who have special needs. It makes an effort, using an Interpretive Phenomenological methodology, to shed light on the caring experiences and perspectives of parents. In-depth interviews with parents were used to extract their stories for this research. After that, we do a thematic analysis of the stories. It looks at the larger social environment of caring and how parents make sense of their own identity in relation to that of their disabled kid. The study explains that parents must make deep emotional and behavioural investments in order to provide adequate care for their disabled children. Nonetheless, it is also recognized that parents' interpretations of their caregiving experiences vary widely.

KEYWORDS: Parenting Interactions, Disability, disabled kid

INTRODUCTION

Care is a core concept and identity for many types of assisting careers. But, for a long time, there was a lack of theoretical grounding for both the notion of care and the practice of care in the public and private spheres. Despite the fact that well-established fields like social work and nursing count "caring" among its core defining values, the idea of care has been the subject of intense scholarly study since the 1970s. The two assisting professions, nursing and social work, that have made caring as core to their knowledge and practice are lower in prestige," Kleinman (2007) writes. Families and the sick or disabled people are often the true experts in caregiving (p. 593). Parents of children with a developmental handicap who have limited financial and professional resources are the focus of this study. The level of parental involvement is likely to vary. In terms of its nature, substance, and requirements, it is distinct from professional care.



The overarching goal of this chapter is to present the concept of caring and to describe its contextualization within society. It explains why a systemic perspective is necessary for understanding parents' caring experiences and how these practices are connected with the institutions, structures, and norms of different social systems. In addition, the research challenge is outlined, in which the researcher discusses the tensions between care concepts in disability studies and feminist studies. This chapter critiques caring as a concept in the current literature on disability support. It lays forth the case for studies that delve into what it's like to be a parent taking care of a child.

Care: State, Market, Civil Society, and Family

There will certainly be a wide range of cultural influences, socioeconomic considerations, and historical shifts in the way care is delivered (Montgomery, Gonyea, & Hooyman, 1985; Dalley, & Finch, 1988; Bhavnagri, & Gonzalez-Mena, 1997; Engster, 2005). This is due in part to the fact that the act of care is shared and shaped by a wide variety of institutions, including the state, the market, civil society, and the family. According to Daly and Lewis (2000), "care is an activity and a collection of interactions situated at the crossroads of governmental, market, and family (and volunteer sector) ties" (p.296). It is "an activity shaped by and in turn shaping social, economic, and political processes," they say (p.296). Caring is a socially entrenched behavior, to put it another way.

Caring in society may be studied via the prism of social contract theory. According to the social contract idea, the state has a crucial obligation to look out for its citizens (Cudd & Eftekhari, 2017). Citizens submit to the authority of the state by giving up some rights, making monetary contributions, and abiding by public regulations so that the state may take care of them when they're in need (Myles & Quadagno, 2002). As a result, citizens look to their government to help shoulder some of the load through generous social programs.



Contesting Notion of Caregiving and Care Receiving

Caregiving literature, disability studies literature, and feminist scholarship literature all show conceptual and theoretical differences. Likewise, disability scholars and feminist academics have taken opposing stances in the discussion over caring (Morris, 1997; Galvin, 2004; Hughes, McKie, Hopkins, & Watson, 2005; Beckett, 2007; Kröger, 2009; Rummery & Fine, 2012). While discussing caring, disability academics and feminist scholars appear to hold different perspectives (Dalley, & Finch, 1988; Beckett, 2007; Rummery & Fine, 2012).

Many academics who study disabilities see "caring" as an oppressive term that strips persons with disabilities of their freedom of choice and undermines their agency (Morris, 1997). Care, they say, may perpetuate the stereotype of disabled people as helpless and dependent on others for the rest of their lives. Morris claims that "the only way to empower handicapped people is to throw off the ideology of care," which he sees as "a kind of oppression and a manifestation of discrimination." Care recipients are portrayed as passive recipients, unable to make decisions for themselves. As the theory and practice of caring have contributed to the stereotype that handicapped persons have little agency, the two concepts are mutually exclusive.

Feminist academics have similar concerns about how to approach the issue of caring (Dalley & Finch, 1988; Beckett, 2007; Rummery & Fine, 2012). They challenge the standard view of care, which holds that women are inherently good caregivers (Beckett, 2007). These ideas promote the idea that women are socially 'predestined' to be caregivers throughout their lives. This might put further pressure on women to be the primary caretaker in their families. This, they say, will only serve to strengthen existing patriarchal power systems. For instance, Beckett (2007) contends that the welfare state model's understanding of care engendered false notions about who should provide and who should receive assistance. In other words, it perpetuated negative stereotypes about specific demographics, such as persons with disabilities, and women's traditional roles in society. She goes on to say that the current understanding of care is problematic because it upholds heteronormative views of caregiving in which women are portrayed as the caregiver and because it diminishes the personhood of people with disabilities by denying or questioning their



competence as social actors. As a result, it's possible that both the caregiver and the person receiving care will feel oppressed (Beckett, 2007).

Stress Perspective

Caregiving outcomes are assumed to be the result of a number of interrelated processes in stress perspectives (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980; Gupta, 2007). Background and context of stress, mediators of stress, outcomes and manifestations of stress, and stress itself are the four domains that make up what Pearlin, Mullan, Semple, and Skaffm (1990) call the "stress process" (p.585). In their paper, they note that "the very idea of process demands attention on the interaction among numerous circumstances leading to personal stress and the ways these linkages evolve and alter over time" (p.585). Pearlin, Mullan, Semple, and Skaffm's (1990) conceptual model of caregiving and stress process sheds light on the buildup of stress, the mechanisms that moderate stress, and the manifestation of caregiving outcomes. The stress process model described in the original premise is linear. It should not be assumed from the term "the stress process" that stress always follows a single pathway, as Pearlin (1999) clarified by revising his conceptual schema ten years later. The reverse is really correct. The conditions that control the influence of stressors on people's well-being are complicated and diverse, as are the circumstances that give rise to a specific combination of stressors. Hence, studies investigating social stress cannot blindly adhere to the stress process conceptual paradigm. Instead, it should be seen as a general framework that can help researchers think more strategically about stressful situations, become more attuned to the types of information that need to be sty in these situations, and be led toward more fruitful avenues of analysis and interpretation of the effects of these situations.

The stress model developed from an analysis of research on unpaid caregiving for seniors with dementia and other impairments. It is important to remember that the older persons with dementia were formerly self-sufficient and engaged in mutual caring relationships with their loved ones. The model's one-sidedness and lack of mutual benefit raise the question of whether it provides a suitable basis for caregiving to persons with developmental disabilities.



Parental Caregiving: Research Themes

Parental Stigma

Parents' understandings of caring are likely to be influenced by their own experiences with stigma. It's reasonable to assume that parents' interpretations of their caregiving role will have some bearing on the quality of that role. The holdings of 'attributes that are thoroughly discredited' degrade the person or group that carries it to 'a contaminated one,' according to Goffman's (1963) classical theory of stigmatization. Stigmatization is associated with less life options for the stigmatized person, according to studies of its aftereffects.

To minimize confusion, it is helpful to be aware with the various ways stigma and related ideas have been conceptualized in the past. When an individual adopts cultural prejudices about a marginalized group, this process of internalizing stigma is called self-stigma. Those who are close to the person being stigmatized are rarely considered in discussions about social stigma. The phrase "courtesy stigma" is used to characterize and restrict the stigma one may feel as a result of knowing a stigmatized person. When someone is not directly impacted by a stigma, but is stigmatized because of his or her association with someone who does, this is called "courtesy stigma".

Caregiving Outcome: Caregiving Stress and Caregiving Burden

The experiences of family care giving to people with disability are primarily examined by using the concept of care giving burden. To facilitate the investigation of its many facets, the burden of caring is broken down into two distinct categories: objective burden and subjective burden. Negative caregiving experiences are often linked to the things we call "objective burden". The objective load is quantified by the extent to which caring for someone with a handicap interferes with the caretaker's personal, professional, economic, social, and recreational life. Caregiving can cause a variety of emotions in the carer, and these are collectively known as the "subjective burden" (Green, 2007). How the carers feel and think about the disabled child is a good indicator of this. Feelings of shame, guilt, wrath, concern, and distress are all part of this category.



Caregiving is assumed to place a heavy emotional, financial, and social burden on caregivers due to the findings of studies examining this phenomenon. Example: "individuals with intellectual disabilities need specialized long term care," as stated by Oh & Lee (2009). So, caretakers face not only monetary strain but also emotional distress such as stress, despair, and uncertainty. (p.6). Similarly, Montgomery, Gonyea, and Hooyman (1985) note that families are more prone to feel dread or guilt in the presence and performance of persons with disabilities. Several studies' abstracts begin, "Disability in a child impacts not only the life of the kid but also... the parents, other members of the family, relatives, acquaintances, and even neighbors of a child with impairments". Having a kid with a handicap in the family may be seen as a burden, humiliation, and guilt, and this may be reinforced.

Those opinions, however, are not commonly held within the academic community and have not been contested. Studies of families with children who have intellectual impairments present a contrasting perspective, showing that caregiving is not always fraught with negative emotions. While fewer in number, these reports highlight the benefits of caring for disabled children.

Research on caregiver stress has shown conflicting results. Caregivers' characteristics, such as marital relationship, health condition, and impression of caring time and expense, have been linked to depression, according to a research by Oh and Lee (2009). They contend that factors such as the characteristics of the individual with intellectual impairment and the carers themselves contribute to the variability in caregiving stress and sadness. Poulshock&Deimling (1984) also postulated an explicit link between the care receiver's physical and psychological characteristics and the caregiver's feeling of stress. It has been proposed that the carers' anguish in meeting the physical reliance and expectations of the care recipient should be seen as the load. Caregiver stress is a direct result of the challenges associated with meeting the physical needs of the person receiving care. The term "caregiver burden" was first articulated by George and Gwyther (1986) in terms of challenges attendant to the caring role. "The physical, psychological or emotional, social, and economical challenges that may encounter by family members of caring for the disabled" is one definition of the caregiving burden.



Caregiving Interaction and Engagement

Parents of children with developmental disabilities and multiple disabilities have more trouble interacting with their child, according to previous research (. Parents have a hard time communicating with one another when their kid has sensory impairments in motor skills, perceptual abilities, and cognitive abilities. Parental challenges in identifying, comprehending, and interpreting their children's behaviour, body language, facial expressions, and speech are common among families with children who have a developmental handicap. It has the potential to mold how parents relate to their offspring.

Coordination of behavior toward a common objective and adaptive function makes up the caregiver attachment system. Interaction and communication between parent and kid are crucial to the growth of their emotional relationship (Howe, 2006). The primary function of the attachment system is to serve as a buffer against unsafe emotional states like panic and abandonment.

An essential factor in the type of attachment system that is formed through parent-child contact is the caregiver's closeness to the kid and their emotional reactivity to the child's worry or discomfort. A kid can develop a safe attachment system if the caregiver is sensitive to his or her emotional needs and is there when the child is experiencing worry or discomfort. In a 2006 article, Howe argues that a child's "behavioural, interactional, and communicative features are likely to impact amount of parental stress, quality of caring, and thus security attachment".

At the interface of infant-parent interactions, a safe attachment system is crucial because it forms a sense of care. A child's attachment security might be compromised if his or her parents are emotionally unavailable, unresponsive, and unresponsive. That might cause the kid to feel emotionally abandoned. A youngster may need to exhibit difficult behavior in order to gain the attention of caretakers, which can be stressful for parents.



CONCLUSION

This study attempts to provide light on the social factors that impact parental interpretations of caring by drawing on parental stories of providing care. According to parents' stories, providing care is generally looked down upon and disregarded by society at large. It also gives a detailed overview of how society as a whole disregards their child as a person who can make a positive contribution to a family. These ideas have bearing on how one raises children.

A prevalent misconception regarding the value of a disabled child's existence is that they would be unable to contribute to society in any meaningful way. Disparaging comments diminish not just the value of the disabled person but also the value of the caregiver. Caregiving is frequently seen as a pointless activity. It's deemed unreliable because it undermines popular ideas about how people should treat one another in caring relationships and the idealized picture of a productive personality. Disability may even deprive the entitlement to basic medical treatment, and disparaging comments from friends and relatives encourage parents to compromise on caregiving obligations like responding to the medical requirements of their kid.

This research shows that the effects of decreased personhood extend beyond disabled children to their families as well. A healthy male infant is regarded as the "perfect baby" in patriarchal families. When parents fall short of the ideal of a "perfect baby," their role as parents is called into question. Being a mother means nothing if she can't give birth to a strong, healthy son. Participants' parents reported feeling unappreciated by their wider social networks. They discussed the many times they were excluded from family and friend events because of their sexual orientation. A child's infirmity, as well as the child's and parents' presence at social or family occasions, is seen as a major stain on the event's auspiciousness and the family's prestige.

According to the parents' accounts, their child's lower personhood status restricts their opportunities in terms of schooling, friendships, and health care. Several parents described experiences where instructors or doctors cast doubt on whether or not their disabled kid would benefit from special schooling or medical treatment. As a result of these kinds of tragedies, some parents may begin to hope that their disabled kid would pass away at a young age.



REFERENCES

1. Abidin, R. R., & Abidin, R. R. (1990). Parenting Stress Index (PSI). Charlottesville: Pediatric Psychology Press.
2. Addlakha, R. (Ed.). (2013). Disability studies in India: Global discourses, local realities. New Delhi: Routledge.
3. Albrecht, G. L., Seelman, K. D., & Bury, M. (Ed.). (2001). Handbook of disability studies. Thousand Oaks: Sage Publications.
4. Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in developmental disabilities*, 33(6), 2122-2140.
5. <http://doi.org/10.1016/j.ridd.2012.06.013>
6. Altieri, M. J., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of intellectual and developmental disability*, 34(2), 142-152. doi:10.1080/13668250902845202
7. Anand, S. (2009). *Disability and Impairment: Working with Children and Families*: Peter Burke. London: Jessica Kingsley Publishers, 2008. 168 pp., paperback, \$35.00.
8. Anand, S. (2016). The Models Approach in Disability Scholarship: An Assessment of Its Failings. In *Interrogating Disability in India* (pp. 23-38). Springer India.
9. Aneja, A., & Vaidya, S. (2016). *Embodying motherhood: Perspectives from contemporary India*. New Delhi: SAGE Publications India..
10. Angen, M. J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qualitative health research*, 10(3), 378-395. doi: 10.1177/104973230001000308
11. Atkinson, S., Lay, J., McAnelly, S., & Richardson, M. (2014). *Intellectual disability in health and social care*. New York: Routledge.
12. Awasthi, A., Pandey, C. M., Dubey, M., & Rastogi, S. (2016). Trends, prospects and deprivation index of disability in India: Evidences from census 2001 and 2011. *Disability and Health Journal*. Advance Online Publication : <http://dx.doi.org/10.1016/j.dhjo.2016.10.011>



13. Bailey, J. (2008). First steps in qualitative data analysis: transcribing. *Family practice*, 25(2), 127-131. doi.org/10.1093/fampra/cmn003.
14. Barnes, M. (2011). Abandoning care? A critical perspective on personalisation from an ethic of care. *Ethics and Social Welfare*, 5(2), 153-167. doi : 10.1080/17496535.2010.48426
15. Beauchamp, T. L. (1999). The failure of theories of personhood. *Kennedy Institute of Ethics Journal*.9, (4), 309-32.
16. Beckett, C. (2007). Women, disability, care: Good neighbours or uneasy bedfellows? 27(3), 360-380. doi: 10.1177/0261018307078847
17. Bell, D. C., & Richard, A. J. (2000). Caregiving: The Forgotten Element in Attachment. *Psychological Inquiry* 11(2), 69-83. doi: 10.1207/S15327965PLI1102_01.
18. Benjamin, A. E. (1993). An historical perspective on home care policy. *The Milbank Quarterly*, 129-166. Retrieved from <http://www.jstor.org/stable/pdf/3350277.pdf>
19. Bhavnagri, N. P., & Gonzalez-Mena, J. (1997). The cultural context of infant caregiving. *Childhood Education*, 74(1), 2-8. doi: 10.1080/00094056.1997.10521906
20. Biswas, N. (2006). On funding and the NGO sector. *Economic and Political Weekly*, 41(42), 4406-4411.
21. Blum, L. M. (2007). Mother-blame in the Prozac nation: Raising kids with invisible disabilities. *Gender & Society*, 21(2), 202-226. doi: 10.1177/0891243206298178