

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

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ABSTRACT

The current study aimed to investigate the effect of caregiving burden on the mental health of fathers with intellectually disabled children. The study also aimed to uncover domains of life impacted by caregiving, challenges in care, coping strategies employed, and the experience of fatherhood alongside thoughts and perceptions about the future. A qualitative research design with the narrative inquiry paradigm was used. In-depth interviews were conducted with 11 participants. The men explained experiencing feelings of sorrow and sadness, feeling defeated, mental exhaustion, and despair due to the unchanging nature of their child's disability. Similarly, they identified areas such as marital relationships, work, social life, and family environment as the domains of life impacted by caregiving responsibilities. Some challenges in caregiving include improper disability management, unpleasant experiences at the hands of medical professionals, and a lack of proper resources. When speaking of coping, the fathers talked of acceptance of and courage to face challenges, social support, and determination and perceived competence in the effective resolution of conflict. The experience of fatherhood touched upon sub-themes such as unmet expectations of fathers, their perspective on caregiving, and perceptions of a father's duty. The study found that fathers had a sense of uncertainty about and lack of hope for their child's future, and a lack of interest in their future. The emerging themes include the nature of government support, concerns regarding medical management, regrets for their own life, and the different ways of thinking employed by the father. The study has demonstrated that fathers also experience caregiving burden. This caregiving burden has affected their mental health and overall well-being.

Keywords: Caregiver burden, Mental Health, Fatherhood

Who is a caregiver? A caregiver is a person who helps another with their activities of daily living. They can be someone in the family, a close friend, or someone who is employed for that very purpose and thus receives remuneration in exchange for the services they provide. In the context of India's cultural setting, it seems only natural for the immediate family to provide care. However, society is more open to hiring help when the

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Received: October 31, 2023; Revision Received: December 27, 2023; Accepted: December 31, 2023

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A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

care recipient is of advanced age. The duty of providing care for a younger care recipient automatically falls on the shoulders of the parents or guardians. Oftentimes, given the patriarchal nature of our society and the notions attached to the experience of being a mother, this burden falls on the mother. Parabiaghi et al. (2007) found that higher patient psychopathology, a larger number of patient-related needs, lower global functioning of the patient, and poor quality of life of the patient, were all related to the experience of family burden. The study also found that the caregivers experienced high-level burdens as they lived near/with their mentally ill family members, and spent most hours of the day together.

In the backdrop of deinstitutionalization that has occurred, those suffering from mental health issues are often taken care of by their families, leaving the caregivers in the family to fill the gap between such deinstitutionalization and the shortage of community services (Kardoffa et al. 2015). This means that individuals with relatively less knowledge about the various nuances of mental illness are left to provide care for the mentally ill, often resulting in distress and anguish in the caregiver. Caregiving an intellectually disabled child is a heavily taxing and challenging task as the nature of the disorder is such that it involves limitations in executive functioning occurring alongside global impairments in important areas such as social skills or intelligence.

Furthermore, the Indian populace is only now beginning to discuss mental illness freely. In many parts of the country, it is still taboo. This makes it extremely difficult for patients to access care. It also creates an environment where families with mentally ill patients are socially isolated or ousted. The lack of discourse on mental illness in various rural areas of the country also renders the caregivers helpless as open discussions on their doubts and challenges of caregiving are rarely heard. Moreover, strong cultural and religious explanatory styles for causes of mental illness exist in the country with many believing that bad *karma* on the part of the parents can lead to their child being born with a mental illness (Zechella & Raval, 2015). Zarit and colleagues define the concept of caregiver burden as “The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning” (Zarit et al., 1986). Studies have demonstrated that caregiver burden can negatively predict poor mental health of both parents of physically and intellectually disabled children (Arif et al. 2018). The study outlined areas that the caregiver burden extends to such as lack of financial support, poor usage of appliances, lack of accessibility to good quality healthcare services, compromised skill in disability management, and eventually the decreasing physical and mental health of caregiving parents.

What does it mean to raise a child with a disability? Some of the factors of raising such a child include physical care, health, employment, career, the support offered by the community, financial burden, possible social embarrassment, and the relationship between the child and parents (Peshawaria). Once it becomes evident that the child suffers from a disability, parents find themselves focusing all their attention on the disabled child. Such undivided attention, when directed at the disabled child, is no secret that it affects the siblings that the child might have. This can create feelings of sibling rivalry and an atmosphere for possible child neglect for the normal child. This indicates that tension is caused in the subsystems covering parents and siblings (Canam, 1993). Literature regarding caring for intellectually disabled children has shown difficulty in dealing with behavioral issues like aggression, pinching, inappropriate urinating, and defecating etc (Masulani-Mwali et al. 2016). Research has repeatedly shown that parents of intellectually disabled children score

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

high on domains relating to depression, stress, and anxiety when compared to parents of non-disabled children. Upon developing the aforementioned psychopathologies it was studied that the parents displayed characteristics of being oversensitive, and emotional, and thus used emotion-based coping patterns as a result of the pathologies (Arzeen et al. 2020). Previous research has also indicated that parents whose children have fewer symptoms experienced more degrees of intimacy and caregiving satisfaction (Pickett, et al. 1997). When the relationship between parents and their adult children is warm, enjoyable, and supportive, it results in more positive appraisals of the relationship (Eggbeen, 1992).

When speaking of caregiving, it goes without saying that at least one parent is forced to stay at home with the disabled child. This would mean the loss of income for one parent. Thus the burden of taking care of the family's financial considerations falls on the other parent, which often is the father in the Indian context. Insurance companies don't cover most of the small costs that can come with childcare in this context such as a ramp for a wheelchair, computer devices such as monitoring cameras for the disabled child, etc. thus, the financial burden only ever increases. Fathers play a crucial role in ensuring that the family is provided for and that their child is given the necessary medical as well as psychological attention.

According to Antonak and Levin (1991), a family's response to such a diagnosis of their child will be characterized by

1. Early reactions of Shock, anxiety, and denial
2. Intermediate reactions of depression, internalized anger, and externalized hostility
3. Later reactions with knowledge and adjustments

Therefore, it becomes important for the physician to understand the parents and the child as one and the personality of both. It is only then that a diagnosis and its impact can be anticipated. While this model describes how most families come to terms with the diagnosis, oftentimes, it is difficult to find parents who are truly fully adjusted to this situation. Multiple variables at play affect how the family copes with such diagnoses. It becomes meaningful to study how exactly these variables interact with each other to help the parents come to terms with such news.

Among various factors to be considered when caring for children with disabilities, parental age becomes an important component in caregiving. Parents of different ages will have different capacities and experiences. Parents belonging to the later part of young adulthood and were older were more resilient when compared with parents in the earlier parts of young adulthood (Santosh, 2016). There exists limited literature on the details of such experiences. Therefore, there is a need to understand such experiences in detail and also to comprehend the various nuances associated with them.

Edwaraj et al. (2010) in a study conducted to explore perceptions about intellectual disability in Vellore, South India, found that fathers were generally described as distant. They were also described as unconcerned and offering little input in training the children. Other ways in which family members understood such mental illness were as the mother's incompetence. Therefore, it becomes important to understand why fathers experience apparent immunity from the consequences a mother has to face. The nature of a mother's caregiver burden has been studied extensively and it has been found that mothers with children who are intellectually disabled are vulnerable to having lower physical health, impaired social relationships, (Singh et al. 2016) poor quality of life, (Kumar, Santhosh & Joseph, 2013)

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

experienced higher family burden than their male spouses, (Rathee, Kumar & Singh, 2019) and poor marital and couple quality of life (Norlin & Broberg, 2013). This makes it imperative to investigate the nature of a father's caregiver burden in the same manner.

Everyone is focused on the care recipient, be it the medical professionals, parents, other immediate family members, and even the community. This immense light of the attention that shines on the care recipient casts an even greater shadow on the caregiver whose services go unnoticed and whose health is easily unseen, both by themselves and by others. They thus become the 'invisible patient' (Adelman et al., 2014). Studies that assessed the effect of the caregiving burden and the mental health of both parents have now revealed that oftentimes there is no significant difference between the caregiver burden experienced by both parents. Rathee, Kumar, and Singh (2019) found that there is no significant difference in the quality of life and family burden experienced by both parents. This implies that the father is also as affected as the mother. This makes it important to study the father's experience as a parent, an integral part of the child's environment. It becomes essential to learn how this affects the life of the father.

There is a strong theoretical basis that attempts to explain the processes and sub-processes involved in caregiving and the caregiver burden experienced. A few include the Risk Resilience model proposed by Wallander et al., the Caregiving stress process model, and the Multidimensional model proposed by Raina et al. (2004). Wallander and colleagues noticed a broad variation in the psychological adjustment of children suffering from chronic physical illness. In trying to understand the differences in children with chronic illness in terms of risk and resistance factors, they divided resistance factors into three categories namely person factors, stress processing factors, and social-ecological factors. Most importantly, parent well-being was also discussed in this model wherein King et al., stated that a parent's perception of the quality of outside care received by their child was a predictor of parent well-being. According to the modified version of the model, better parent well-being was related to the perception of having received family-centered care, the presence of socio-ecological factors of protective nature, lesser child-behavioral problems, and lastly, increased satisfaction with care.

Most caregivers don't have a choice in becoming a caregiver. They happen to belong to the immediate family and therefore shoulder the responsibility of taking care of the disabled individual. The caregiving stress process model assesses this informal caregiving process and its effects on the caregiver's health. Pearlin and colleagues have described stressors as those "problematic conditions and difficult circumstances experienced by caregivers" that cause strain or supersede the individual's ability to adapt. Stressors can be primary or secondary of which primary stressors refer to those related to the individual and the disability directly while secondary stressors are caused by the demands of the caregiving role. Such stressors exist in a complex system that leaves space for moderators to impact the situation. Some examples of moderators include social support, mastery, and self-efficacy which may all help sustain the caregiver and thereby reduce the burden of stressors.

Raina et al., (2004) opined that a multidimensional model is required so that future research may be guided while studying caregiver health. This is a hybrid model that makes use of literature from the geriatric and pediatric populations. It focuses on

- Formal and informal caregiving processes
- The function of formal caregiving processes in determining caregiver health

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

- Separating the constructs of child disability and child behavior problems
- Expanding King et al.'s concept of socio-ecological factors alongside family function and social support
- Inspecting both physical and psychological health as consequences in the model

This model considers the caregiver's health as an outcome of the caregiving processes because these outcomes are mostly based on the conditions of the child. To explain the areas of child health services that are less addressed by the healthcare sector, this model focuses on five constructs which are background and context; child characteristics; caregiver strain; and intrapsychic factors. They also include coping/supportive factors as well as health outcomes. The background and context help us understand the setting of caregiving, alongside the social and economic aspects of the family. Similarly, child characteristics directly affect the conditions of caregiving and therefore decide the variety of adult care demands. Various studies have shown that less severe forms of disability are linked to better psychological and physical health (Breslau et al. 1982; Sloper et al. 1993; Cadman et al. 1991; Pless et al. 1975; Silver et al; 1998), lower caregiver demands (Palfrey et. al. 1989), and more perceived family-centered care services being availed (King et. al. 1996; King et. al. 1999).

RESEARCH METHODOLOGY

Study Design

The present study aimed to understand the effect that the caregiving burden has on the mental health of fathers of children with any type of intellectual disability. It attempts to look into the primary concerns of a father with an intellectually challenged child.

The main objectives of this study included:

1. To assess the effect of the caregiving burden on the mental health of the father
2. To evaluate the eventual well-being of the caregiver
3. To identify domains of life impacted by caregiving responsibilities
4. To understand the areas of concern such as challenges in care, service inaccessibility, stigma, discrimination, etc
5. To explore coping strategies employed to deal with stressful situations in caregiving
6. To understand, assess, and reduce the negative impact of caregiver burden on fathers of children with intellectual disabilities.
7. To understand the experience of fatherhood as understood by the participants

The study's method and procedure are tailored to focus on the subjective experiences and narratives of the participants. Creswell (2012) states that qualitative research is most appropriate to address that research problem in which the variables are unknown and therefore require exploration. Therefore, a qualitative research design alongside a narrative inquiry paradigm was adopted to understand how people create identities by way of discourse (Bamberg, 2012). Data analysis was done using Thematic Analysis as proposed by Braun and Clarke (2006). The thematic analysis allows the formation of a major idea in the database that can aid in decoding the major chunk of data collected (Creswell, 2012).

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A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

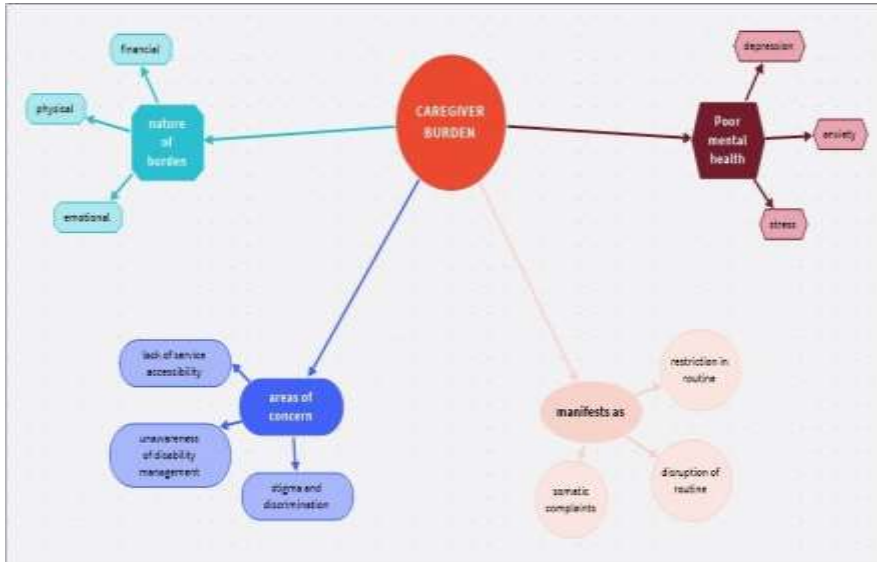


Fig. 1 Illustrating the concept of research

Research Paradigm

According to Habermas (1996), qualitative research provides pluralization of life worlds. It helps understand the “individualization of ways of living and biographical patterns” (Beck 1992). Through this, subcultures, milieus, and other ways of living can be studied in detail (Flick 2009).

The study aims to understand the effect of the caregiving burden on the mental health of fathers with intellectually disabled children. It attempts to explore the various primary concerns a father might have in caregiving for his disabled child. It also attempts to understand their experience of fatherhood in the cultural backdrop of India, a historically, largely patriarchal country.

Michael Bamberg (2012) when describing narrative inquiry and research spoke about how people tend to construct identities by way of discourse. People also tend to construct identities through practices that position the self -

- As the same as, similar to, or different from others
- As having the power to act on the world or as acted on by the world
- And as remaining the same or changing over time.

Understanding the narratives of the participants in this context will aid in perceiving their experience through the identities they create both to associate with as well as demarcate themselves from others. It will also help look into their standing in society which will then help grasp their caregiving experience better. Through such narrative inquiry it is possible to bring to the fore, the voice of fathers who have not been studied extensively when compared to the mothers. Such a narrative inquiry can then contribute to social change (Denzin & Lincoln, 2018). Doctors, therapists, lawyers, social workers, and more have the social power

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

to make a difference in the lives of patients, students, or clients (Goodson, Loveless, & Stephens, 2012; Gunaratnam & Oliviere, 2009; Kitchen, Parker, & Pushor, 2011; Trahar, 2011). Hence such a narrative inquiry becomes important to not just study the discourse provided by the participant but also to place the discourse in the larger context of life, and then work towards the betterment of the individual experience.

Such a research design and paradigm provides the ability to be flexible with the research process and a narrative study of the information collected makes it easier to assign meaning to the experience of these individuals while also humanizing the said experience. Most studies, as mentioned earlier, tend to focus on the experience of the mother rather than the father. Thus, it becomes even more valuable to study the narratives of fathers with children who suffer from any intellectual disability. This study, therefore, assigns much weight to the subjective experience of a father with an intellectually disabled child.

Sampling and Data Collection

The sampling method of purposive snowball sampling was used in the study which enabled the researcher to choose participants who fulfilled the inclusion criteria of the study. Purposeful sampling involves selecting information-rich cases to study their experiences in depth. Such a sampling method allows for selecting those participants who can contribute to answering the various questions posed by the current research. The study required the individuals to be of middle age; aged approximately between 40 to 65 years. They must be the parents of a child/adult with any type of intellectual disability. Fathers who are separated from their families were not included in the study as they were assumed to play a minimal role in the caregiving of their children. An interview guide was prepared with the help of relevant literature reviews and was further refined. This guide was employed in collecting in-depth data during the interviews. Such a data collection method allows room for analyzing and assessing data through the words uttered by participants, and their interpretations of their experiences.

The domains covered by the interview guide were

- About self and life in general
- Initial feelings, and experiences associated with the child
- Sources of stress and support
- Perceptions about Child's Disability
- Impact on themselves and family
- Impact on marital relationship
- Perceptions About Child's Future
- Coping resources
- Service accessibility/inaccessibility
- Perceptions about one's future
- General mental well-being

Data Analysis

The current study has employed Virginia Braun and Victoria Clarke's thematic analysis (2006) to make sense of the data collected. One of the advantages of using this model is that it is not dependent on a particular epistemological or theoretical perspective (Maguire & Delahunty, 2017). Thus, it is extremely flexible and does justice to the diverse data collected using qualitative methods.

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

Ethical Consideration

Ethical considerations were taken into consideration during the sampling as well as data collection procedures. Informed consent, confidentiality, right to withdraw from the study, researcher's bias, and necessary research information were provided to all the participants. Upon reading the study information sheet the researcher had provided the participants, it was explained to them that their responses would be audio recorded. The researcher also explained how their responses would be used in the study. The researcher ensured that the interview did not begin until participants consented to the process. The researcher ensured the participants that their answers would not be made use of in such a way that allows for the identification of their responses. Participants were informed that participation in the study was entirely voluntary and that said participation could be terminated if and when they desired. Apart from the study information sheet, the doubts of the participants were cleared after the interview was completed. The researcher acknowledged the possibility of being biased and kept a check on herself throughout the entire study, be it during the interview, data analysis, or interpretation.

Need for the study

Concepts such as caregiver burden and its effect on mental health are often studied from the mother's perspective. Due to the patriarchal nature of our society and due to the notions attached to being a mother and father, somehow the mother bears the bigger part of the burden when raising children with special needs. India, with its diverse socio-cultural background, faces a multitude of challenges when it comes to providing mental health care services and associated support for the mentally ill in general and intellectually disabled children in particular.

Studies about the mother's experience have been extensively conducted showing that mothers of children with intellectual disabilities often don't feel accepted by their family members, and also feel ridiculed by society (Raval, 2005). Other studies have also found that mothers are 40% more likely to have sleep disorders and depression (Wayte, S. et al. 2012). While such studies are extremely important and the emerging statistics are significant, it becomes evident that fathers are not studied as extensively as mothers. It also becomes evident that there is a certain level of difficulty in distinguishing their parenting experiences. Such in-depth data collection on the experience of the fatherhood of those individuals with an intellectually disabled child is this study's purpose.

Not only is there very little information on the caregiver burden and coping mechanisms employed by fathers, but the attention is also largely biased towards the mother (Piazza, V. E., et al 2004). While one can agree that in India mothers are more involved in caregiving in most of the cases, it will only be possible to understand the exact nature of caregiver burden as experienced by fathers if it is studied widely. Moreover, studies do show that the long-term effects of caregiver burden can set the stage for deteriorating physical as well as mental age with increasing age (Seltzer, et al, 2011). This only cements the need for a study exploring fatherhood and caregiving in the context of having an intellectually disabled child.

RESULTS AND DISCUSSION

The findings of the study portray the difficulties experienced by fathers with intellectually disabled children and explore such areas as domains of life impacted, challenges in caregiving, and perceptions about a possible envisioned future for the child. The findings indicate their wishes for the child, the things that cause them despair, and how they cope with

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

stressful situations pertaining to caring for their child. The study findings would highlight the experience of being a father and some of the primary concerns experienced by them in the context of caregiving. The individuals interviewed shared important and in-depth details of their lives based on the questions that were asked. They reflected on what it means to be a father, and what the duties of a father are. There have been similarities in ideas and opinions in certain domains due to the larger socio-cultural background that they belong to. There have also been stark differences of opinion in certain areas as their individual life experiences are unique to each of them.

Table 1: The table below presents the classification of themes and sub-themes considered in the study

THEMES	SUB-THEMES
Effect on mental health and Well-being	Sadness and sorrow feeling defeated Mental exhaustion Despair due to unchanging situation
Domains of life impacted	Marital relationship Work Financial difficulties Social life Family environment
Challenges in caregiving	Disability management Unfortunate experiences Lack of resources
Coping	Coping techniques Acceptance and courage to face challenges Support from family Determination and perceived competence
Experience of fatherhood	Unmet expectations Father's perspective Duty of a father
Thoughts about future	Uncertainty about and lack of hope child's future Lack of interest in own future Plans for future

One of the main objectives of the study was to understand the effect of caregiving burden on the mental health of fathers of children with an intellectual disability. The study also aimed to look into the overall well-being of the individual as well. Under the main theme of 'Effect on mental health and well-being,' the researcher identified the existence of the sub-themes namely sadness and sorrow, feeling defeated, mental exhaustion, and despair due to unchanging situations. The participants spoke of feeling depressed or more so an evident lack

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

of happiness. They talked about feeling defeated while raising their child as the challenges never seemed to end.

Sadness and Sorrow

The birth of a child is always an occasion of joy as our culture brings people together on joyous occasions. However, it is not in the nature of our culture to openly discuss issues such as having a child with an intellectual disability. One participant said, *"These days I feel depressed. There is no such thing as feeling happy. I bury my sorrow inside me and I smile. So, people always commend me on that. So I tell them, I wish to be the same throughout. There are concerns like needing resources to go to Bangalore (to treat the child) and when I speak to others, I believe in not relying too much on others, so I forget about my concerns and talk to people with a smile. I actually don't know how to talk about such things. It is only now that I am able to speak about it all."* It is very common for women to express their feelings in a wide variety of ways and in a wide variety of contexts given the space to do the same. However, the participant's words confirm how it can be difficult for men to express their emotions when the culture they grew up in did not provide them with enough examples or opportunities for the same.

Mental Exhaustion

Studies have evidenced parental burnout to be associated with having to parent a child with a chronic illness (Norberg & Green, 2007; Basaran et al., 2013). Mental exhaustion can arise due to various factors some of which as gathered from the information provided by the participants include the incapability to cope with behavioral issues of their growing child, strain in the marital relationship, lack of a change in the child's situation despite years of adhering to treatment and so on. In the words of one participant, *"Now, my wife is scared of him (their son). Because he will sometimes hit her. If he gets angry sometimes he will strike at her. This is not the age for us to cope with that pain. If we were young, it would have been easier. It is difficult for us."* He explains how the parent-child relationship between his wife and son has shifted from being about nurturance to one of fear. He says that he is hardly at the age where he needs to be thinking of ways to cope with the pain his son causes him, both physically as well as mentally. Understanding a child with an intellectual disability can be challenging for parents as they don't communicate the same way as other children. Therefore, this leads to mental exhaustion in both him and his wife.

This study also aimed to uncover the areas or domains of life that were affected by caregiving in whatever capacities. Some of the sub-themes under this theme include marital relationships, work, financial difficulties, social life, and family environment. Bringing up an intellectually disabled child can also impact every area of a person's life. The domains impacted and the degrees to which they are impacted are also connected to the mental health and well-being of the individuals.

Marital Relationship

It is often easy to maintain a good relationship with one's partner when things are smooth sailing. However, having a child with an intellectual disability can be challenging at every turn. Oftentimes, couples experience some of the worst times because of the nature of the challenges. such strain can lead to parental stress. Research shows that parenting children with developmental disorders can lead to experiencing increased parenting stress (Hartley et al., 2011). In the words of one participant, *"I think in terms of marital relationship, there's nothing like a marital relationship at the moment. We are just together that's it. And life goes*

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A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

on.” He speaks about the distance between his wife and him saying there is no such thing as a marital relationship. He says that they just happen to live under the same roof. Even though it seems as though there is a world of difference between them, he stresses that “life goes on” implying that despite all the problems life moves forward, and inevitably so does he. However, it may appear as though having a child suffering from intellectual disabilities will inevitably lead to the downfall of the marital relationship. This is not true. Contrary to what was said by the previous participant, another says, “I have my wife and she has me. So, we talk it out with each other. Talking to other people won't be the same because they will always look at us and at our child with sympathy. That's not how it should be actually.” He explains that someone outside their family would always look at their child with sympathy-filled eyes which does nothing to help with their problems. Hence, he finds comfort in leaning on his wife and she does the same.

Caregiving and Work

India is a patriarchal society which means that the man becomes the breadwinner of the family by default. Patriarchy places the male at the center of societal progress both materially and physically (Khurana, 2018). The participants of this study are middle-aged and hence in the prime of their youth the women headed home while the men worked to provide for the family. In exploring the domains of life impacted by caregiving, fathers spoke about the need to work even if they may not find well-paying jobs so as to move forward in life and also to find the means to provide for the treatment requirements of their child. “After we finished the treatment there (in the Shoranur district of Kerala) - I am a tailor - so it was not like Kannur (another district of Kerala) there... And to do any other work... It was not something I could get used to. Even though there are (tailoring) companies there the salary provided is very low. Then I did some work as a catering supervisor. But the problem was that we would only have a job for three or four days a week. Working like that was a little impractical because we had needs that were not being met.” Despite finding work, the participant speaks of how he didn't have enough to work every day in the catering company. This was inconvenient as he needed all the money he could get. His words shine light on the lack of resources for parents of children with disabilities. Without work, and without enough money, he would not be able to provide for his family. His words indicate his determination to work as much as it indicates his lamentation for the lack of opportunities to do so.

The study also aimed to investigate what some of the challenges in care could be, as experienced by the father. The sub-themes that emerged were disability management, bad experiences, and lack of resources. Lack of knowledge about the nature of their child's disability, the lack of patience to help their children, discrepancies between the child's capacities and parents' wishes, and difficulty adjusting to the nature of disability were important points of discussion under disability management.

Disability Management

As mental health and discussions about the same are still largely considered taboo in the country, it becomes difficult for the caregiver to garner information regarding the true nature of their child's disability and the various ways in which symptoms can manifest in their child. Similarly, they are sometimes uninformed about the ways in which they can constructively help the child through this disability to establish their life. One participant mentioned, “The thing is, sometimes, when he sees someone else's bicycle, he goes to grab it. How can I put it? It causes your mind to feel as though it has had enough. Sometimes, I think of some unnecessary things. He is becoming stronger. He won't comply with our words. So when he

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A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

goes to another house and brings home some other child's bicycle and we tell him off, he tries to lunge at me. So if I hit him, he will tell everyone in the town." He speaks of instances where his child tried to take away something that belonged to another person. He lacks the ability to communicate with his son effectively causing distress and distance in their relationship. He laments the lack of knowledge of what exactly to do in such situations. There is a clear gap in his knowledge when it comes to proper disability management for his child.

Lack of Resources/Infrastructure

Resources in this context can mean enough finances, mental health care facilities, infrastructure, good quality care, and such. Caregiving for an intellectually disabled child is complex in nature. This only cements the need for good quality resources to combat the same. Voicing this issue, a participant said, *"Everybody will give speeches about this, but nobody does much about it practically. It is a very difficult thing to look after children. I believe the community support is more in Karnataka, that is what I have understood. I came to this conclusion because I was there for a short while as part of my training. Moreover, I used to take him (his son) to hospitals there so I know. So if you take him to hospitals here and ask the warden where the doctor is, he is likely to reply with statements such as 'Don't you have eyes? Can't you see what is written there?'* At the same time, *if we go to Karnataka, even the professor will help us find the way. That I think differs from state to state."* He speaks about the lack of community support in the state of Kerala as perceived by him. He recounts his experience with healthcare workers in the states of Kerala and Karnataka and how it differs from one state to the other. Moreover, he explains that in Kerala, people tend to give speeches about how to manage children with such disabilities but in actual practicality do nothing to better the situation. So there is a gap between the awareness of the issue and action taken to make the situation better.

The current work aimed also to explore the coping strategies employed to deal with stressful situations in caregiving. The sub-themes that emerged involved coping techniques, acceptance and courage to face challenges, support from family, and the determination and perceived competence to take the family forward. One participant mentioned that practicing yoga, and meditation helps them deal with stress while another participant explained how traveling to certain places such as the beach or a temple helps them cope with stress. Most fathers expressed acceptance of the situation and the courage to face challenges.

Acceptance and courage to face challenges

"But now, after listening to many classes (psychoeducative classes) and all, I believe that where there is a will, there is a way. So now I am ready to more or less face it. But my wife is very tense about it. I have taken care of the financial part of it. Another major plus point is that his elder brother cares for him more than I do... The thing is, I believe that we must face whatever we have to in our lives. So I don't dwell on things too much. Moreover, I try to be as free as possible, because of overthinking and all... it is like saying you can only test it if there is a wall. He is testing me only because I am there for him. I wasn't there for him, he wouldn't be able to test me like this. So I just stay tension-free." He believes that there is a way out of any problem given that you have the courage to face it. He speaks about how his eldest son cares deeply for his second son, who is disabled, and how this is a source of strength for him as he moves forward in life. Further, he says that in all reality, he is ready to face all the challenges that come their way as it means he is currently alive and breathing to be able to solve said problems for his family. This is a unique way of looking at such a difficult situation but it is also liberating in many ways. Similarly, another participant said,

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

"If we must go forward, we must face difficulties. That's all. We don't have many financial resources. But I am content with what I have." Hence most participants showcased determination and resilience in moving forward in life despite the challenges.

Support from family

Social support is one of the major protectors of mental health across all situations. An individual's immediate social environment is his family and receiving support from the family can help gain the courage to face the challenges in care head-on and effectively. A participant when sharing his views on the importance of social support said, *"My family is very supportive of me. My sisters are very supportive. It is not the kind of support you get from a man. It is a different kind of support; that of women. Even their husbands are supportive. There is no such thing as 'yours' or 'mine.' So even when they come to our house, they buy the dresses and everything that my children may need. They will bring things for the house. Moreover, I have my mother. My father passed away. My mother takes care of my children. My mother is the only person my children are scared of. Moreover, my mother does everything the children ask for."* He distinguishes the support he receives from his sisters from that one receives from a man. He says that the support provided by his sisters is a 'different kind of support' and that they usually take care of even the seemingly unimportant needs of his daughters. He further speaks about the support he receives from his mother explaining how close his children are with her. Support from the family is crucial in helping caregivers face difficult days without giving up.

The present study also attempted to understand the experience of fatherhood as perceived by the participants. The sub-themes that emerged included unmet expectations, a father's perspective, and the duty of a father. Fathers spoke of unmet expectations of theirs. They mentioned how they wanted their child to reach great heights but this was curbed by the diagnosis of an intellectual disorder. Similarly, they spoke of a father's experience in trying to make the world a better place for their children. They mentioned the need to rid their child of the disability, to find a cure, and eventually find a companion in the child.

A father's perspective

Speaking of what caregiving is like from the father's perspective, a participant commented, *"The thing about being a father is that I have this immense desire to rid him of his issues. We have struggled for so many years. I want to see him cured. We have struggled so much and spent so many lakhs on this. I just want him to be cured of this illness. I don't want anything else, I just want to see him sitting on the front porch. I would like for him to then help me with whatever activities I am doing in the house such as watering the plants or collecting the areca nuts."* His words reflect the hope of a cure that most parents battle coming to terms with. In trying to understand what exactly a father's perspective is on the disability experienced by his child, it was evident that most fathers distinguished their experience of parenting from that of the mother. They wanted to find a cure or create a better world while they assumed the mothers to be preoccupied with the equally important act of making the child more self-sufficient. The aforementioned participant spoke about how he has this strong wish to rid his son of the problems associated with the disability. He truly wishes for there to be a change in his son. He does not wish for his son to be like other seemingly normal children. He just wishes to develop a bond with his son over sharing chores such as watering the plants and collecting the areca nuts. He wishes for a companion for his son.

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

Finally, the study explored the thoughts about an envisioned future with the child. Under the main theme of thoughts about the future, the sub-themes included uncertainty about and lack of hope for a child's future, lack of interest in their own future, and plans for the future. The fathers spoke of how the unchanging nature of the disability made them lose a lack of hope for a better future. They also mentioned being worried about what will come of their child in the wake of their passing. They lamented the lack of infrastructure when it comes to places that will take care of their children after their time.

Uncertainty about and lack of hope for the child's future

When the care recipient is younger than the caregiver, as in the parent-child relationship, there may come a time when the parent might not be there for the child to lean upon. In speaking of such inevitability, one participant said, *"In the initial days, I was extremely worried. Because I was thinking 'What will become of him after my time?' Even now that's what I think about. One can never say much about the life expectancy of a human being, we can also not say who will pass first. But I keep thinking about what he will have to face in society after our time."* As the treatments sought provide no cure for the conditions, the days to come become increasingly similar to the days that have already passed. The participant has accepted that human life is only mortal, however, such acceptance does not mean freedom from worry as well as apprehension about what is to become of their children once they pass. Caregiving, therefore, has many layers to it and can include such things as uncertainty and lack of hope for the future.

Lack of interest in their own future

The fathers have shown an equal disinterest in thinking about their own future and what could be in store for them. Based on the information provided by the participants it appears as though they have difficulty distinguishing their future from that of their children. In the words of the participants, *"There is no point in thinking about my future. All I have to do is think about my daughters. What future is there?"* Similar words by another participant were, *"I don't think about it (own future) at all. There is no thinking about it. Not even a little bit. I will take things as they come. The house has been built. Now things can go their way. There is nothing else."* Most of the participants spoke about their future as though it did not exist. With their advancing age they appeared to have settled into their identity and role as a parenting figure and only thought of themselves as an extension of their children.

Plans for the future

Driven by the evident lack of hope for the future, most participants envisioned a world where they create living spaces for their children to stay in once they pass. Some also mentioned how they work to create, run, and sustain institutions like orphanages in the hope that someday, such a house may take their child in. They spoke of creating safe spaces for their children and making them self-sufficient. Others secured finances for their children while some thought about starting to invest with the future of their child in mind. One such participant said, *"Like I said, I run an orphanage. So I had plans for him as well. To buy some land and make space for such children. We need like 2 to 3 acres of land. I had in mind an accommodation in which the mother/father or caregiver can reside with them. So there are many families like this. Thus, if we pass away or if they (caregivers of other children) then we will be able to take care of these children. Because we know the nature of their struggles and what it is like to take care of them. I have this thought of creating such a space."* Therefore, it appears as though the identities of the fathers change from being individualistic to seeing themselves as an extension of their children so much so that they no

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

longer envision a future for themselves but elaborately plan for a secure future for their children.

The obtained literature also provides information regarding a few themes that were not exactly touched upon by many of the participants but still are relevant to the subject matter of study. They have been classified into emerging themes for the purpose of further studies investigating their relevance to the subject.

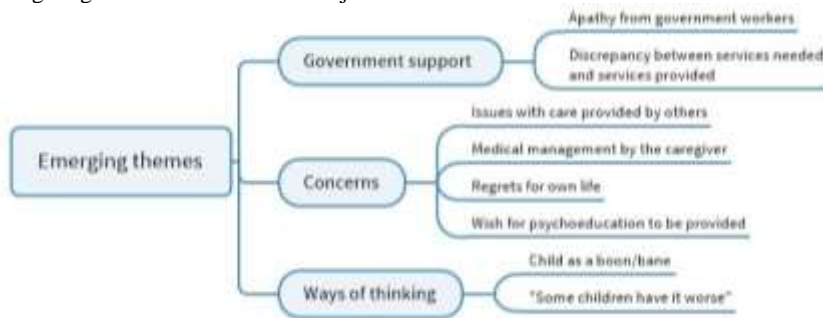


Fig. II depicts the emerging themes from the research literature

CONCLUSION

The study aimed to comprehend the impact of the caregiving burden on the mental health of fathers with intellectually disabled children, exploring various aspects such as life domains affected, caregiving challenges (including care difficulties, stigma, and discrimination), coping strategies, fatherhood experiences, and thoughts about the future. Conducted through a qualitative and narrative inquiry design, interviews were conducted with 11 men aged 40-65, each having a child with intellectual disabilities in Kannur, Kerala, and Bangalore. Thematic analysis, following Braun and Clarke's (2006) approach, helped organize the data into main themes:

Effect on Mental Health and Well-being: Participants revealed mental exhaustion and despair due to the unchanging nature of their child's disability and challenges in daily life. The study found expressions of sadness and sorrow encompassing various aspects of their lives, impacting marital relationships significantly. Work-related financial struggles, social life, and family environment were also adversely affected.

Domains of Life Impacted: Participants detailed the challenges associated with work, financial strain, and societal reactions to their child's disability. Traditional gender roles were discussed, emphasizing the man as the breadwinner.

Challenges in Caregiving: Challenges in caregiving were linked to inadequate disability management knowledge, negative healthcare experiences, and a lack of resources, including finances and health services.

Coping: Fathers coped with comparing their child's behavioral issues to those of other special children, finding solace in the idea that "some children have it worse." Some expressed both the positive and negative aspects of their child's birth as an inevitable fate.

A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children

Experience of Fatherhood: Fathers spoke about parenting expectations, unmet aspirations, acceptance of the diagnosis, and the duty to support their children through difficulties.

Thoughts about the Future: Concerns about the child's ability to fend for themselves after the father's passing were expressed. Some envisioned building centers to cater to similar children's needs, emphasizing collaborative efforts among parents.

Emerging Themes: Issues of government support and the gap between provided services and actual needs were highlighted. Some fathers expressed the desire to manage their child's medication independently, reflecting on regrets and the need for psychoeducation.

These findings provide a nuanced understanding of the challenges fathers face in caregiving and fatherhood, shedding light on societal perceptions and the fathers' self-perceptions. Themes like government support, medication management, psychoeducation, and coping strategies warrant further exploration. The study contributes to a deeper comprehension of the intricate dynamics of caregiving for intellectually disabled children and the role of fathers in this context.

The implications of such research are substantial, contributing to heightened awareness of fathers' experiences and the recognition of their challenges in navigating the complexities of raising intellectually disabled children while providing for their families. Notably, the majority of participants hailed from rural areas where mental health services are scarce, prompting consideration of community-based interventions as cost-effective solutions tailored to the unique needs of fathers in these regions.

A critical aspect underscored in the study pertains to societal norms and sanctions. Unlike mothers, fathers rarely receive support such as maternity leave or societal approval for being homemakers. Participants recounted the need to seek transfers to stay close to their families, shedding light on the necessity for policy changes that acknowledge and accommodate fathers' caregiving roles. Longitudinal studies in the future would assist in unraveling the long-term effects of fathers' caregiving experiences in a more objective fashion. Furthermore, the integration of quantitative research methodologies on a larger scale is recommended for obtaining objective, reliable, and generalizable data.

A few limitations of the study include a small sample size and time constraints. The lack of in-depth exploration into various caregiving domains and the subjective nature of the study pose challenges in distinguishing between actual phenomena and participants' subjective experiences. The qualitative approach relied on the participants' subjective words, necessitating caution in interpreting the results. Additionally, the focus on middle-aged fathers recalling parenting experiences from their youth raises questions about the accuracy of their recollections and the potential influence of memory on provided information. To address these limitations, future studies should conduct more extensive investigations with larger sample sizes, providing clearer insights into the complex constructs at play in the caregiving experiences of fathers with intellectually disabled children.

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Acknowledgment

The author(s) appreciates all those who participated in the study and helped to facilitate the research process.

Conflict of Interest

The author(s) declared no conflict of interest.

How to cite this article: Kavya A.C. & Karmakar, R. (2023). A Father's Experience: Unveiling The Depths of Fatherhood Caregiver Burden and Mental Health in Fathers with Intellectually Disabled Children. *International Journal of Indian Psychology*, 11(4), 2962-2979. DIP:18.01.280.20231104, DOI:10.25215/1104.280