

The Impact of Parental Chronic Illness on Children: Experiences of Young Adults

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ABSTRACT

An exploratory study with the aim to understand the lived experiences of 12 young adults (4 males and 8 females) between the age group of 16 to 25, growing up with parents having physiological chronic illness. Data collection and analysis was done through semi structured interviews and thematic analysis respectively. The main challenges that are faced by participants with respect to their parent's illness are identified as educational, social and financial. The study also focuses on understanding of their ways of coping with aforementioned challenges. Self-care social and familial support and avoidance are the major coping strategies. Finally, the participant's emotional and psychological states are discussed, with focus on themes such as feelings of helplessness and victimization, fear of future manifestation of illness and also development of maturity.

Keywords: *Chronic illness, Challenges, Family, Coping, Emotional and Psychological States*

The National Centre for Chronic Disease Prevention and Health Promotion (2022) defines chronic diseases as “conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both.” Curtin & Lubkin (1995) define chronic illness as “the existence, accumulation, or delay of illnesses or impairments that affect the entire human environment and necessitate supportive care and self-care in order to maintain function and prevent additional disability.” Ailments like heart disease, cancer, diabetes, and arthritis, are examples of common chronic illnesses. As a disease that cannot be cured by medical treatment, chronic illness requires ongoing observation and supportive care to minimize its severity, maximize the patient's functioning, and promote self-care (Cluff, 1981).

According to research by Kaasbøll and others (2021) the number of people suffering from chronic illnesses is increasing. Between 4% and 12% of children grow up in a home with a

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Received: February 15, 2023; Revision Received: June 27, 2023; Accepted: June 30, 2023

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parent who suffers from a chronic illness. A majority of the existing research related to chronic illness focuses on its impact on patients. However, it is also important to look at how the disease impacts the family.

A few studies have found favourable results in terms of parental chronic illness, improved interpersonal interactions, and higher child maturity (De Souza et al., 2010). More research has revealed that parental chronic illness increases the risk of poor family functioning as well as behavioural and social-emotional problems in children and adolescents (Pakenham & Cox, 2014). The duration and intensity of the parent's disease may enhance the chance of negative effects in kids. Children with chronically ill parents may have different outcomes depending on the child's and parent's gender. Chronic maternal diseases have been linked to poor developmental outcomes, especially in daughters.

According to a report published by May (2017) titled *How Emerging Adults are Affected by Parental Chronic Illness: A Study of Psychosocial Functioning and Academic Achievement*, multiple aspects of psychosocial functioning were significantly impaired in the study's participants, including sadness, anxiety, stress, and a lack of optimism.

Impact of Chronic Illness on Family Relationships

Family is defined as a kinship unit consisting of a group of individuals united by blood or by marital, adoptive, or other intimate ties. Although the family is the fundamental social unit of most human societies, its form and structure vary widely (APA, 2022).

Most chronic diseases have effects on family members in terms of psychological and emotional functioning, disruption of leisure activities, influence on interpersonal relationships, and financial resources. However, some elements of an illness may take precedence over those of other disorders (Golics et al., 2013).

As a result of the patient's disease, family members of patients feel a negative impact on their family ties, between both the family and the patient, and between various family members (Golics et al., 2013). Poor family ties, regardless of the ailment, do not bode well for chronic disease management, and many family members find interactions challenging because they do not know how to emotionally support one another.

Chronic physical illnesses are difficult to treat because they are complex, long-term, and difficult to diagnose. People who suffer with this illness frequently have poor physical and social functioning, and a decreased sense of well-being. Because of these concerns, the effects of a physical sickness can extend beyond an individual's immediate family.

Emotional Impact on Child

An overwhelming sense of helplessness and powerlessness commonly contributes to the psychological distress of family members. Family members express a variety of feelings, including guilt, anger, concern, upset, frustration, embarrassment, despair, loss, and relief. Each emotion impacts family members differently and to varying degrees, depending on the severity of the patient's sickness and the length of time since the diagnosis (Golics et al, 2013).

Financial Impact on Child

The financial cost to the family is one of the most significant burdens on patients' families. Education fees, worry for the siblings' education, pressure on single earning members of the

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family, future possibilities of financial constraints are all examples. Financial strains experienced by patients' families frequently cause stress and worry. The child perceives that there is a budget constraint but parents don't show (Golics et al, 2013).

The present study aims to explore the experiences of young Indian adults growing up with parents having physiological chronic illness.

METHODOLOGY

Participants

For this study, the sample included 12 (4 males and 8 females) participants falling in the age bracket of 16-25 years. They belong to middle or upper middle socio-economic backgrounds in India and come from both nuclear and joint families. 10 participants are pursuing their education and 2 are in the occupational sector. They were chosen through purposive sampling, where either of their parents suffered from a physiological chronic illness.

Design

This is an exploratory and qualitative study to explore the experiences of young adults growing up with a parent having a physiological chronic illness.

Tools

Semi-structured interviews were used to for data collection. Some interviews were taken online, and the others in real time.

Procedure

Purposive and convenience sampling were employed in the data collection process. Participants were contacted and face-to-face semi structured interviews were used for collecting data. The participant's verbal consent was obtained during the interviews. Then, to ensure that the participant felt comfortable, a cordial rapport was built with them.

Data Analysis

The data obtained was analysed by developing codes for thematic analysis of Braun and Clarke. Thematic studies focus on detecting and defining both implicit and explicit ideas within the data, or themes, rather than counting explicit words or phrases. The selected themes are then usually represented by codes, which are applied or connected to raw data as summary markers for later analysis (Guest et al, 2014). Thematic analysis is a method for detecting, analysing, and reporting patterns (themes) within data. It organizes and describes the data set in (rich) detail to the bare minimum. However, it frequently interprets a variety of aspects of the research problem (Boyatzis, 1998; Braun & Clarke, 2006).

RESULTS

The data was analysed using thematic analysis with respect to the three undermentioned objectives, and these following themes were identified.

Objective 1: To understand the challenges faced by young adults growing up with a chronically ill parent.

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Table 1 Themes under Objective 1

Verbatim	Sub theme	Theme
“If the same case would've been about five to six years ago then we would have felt that bridge.”	Constraints resolved with time	Financial constraints
“My mother is having the whole burden of finance on her shoulders. So, my mother is the only one who is earning right now. If you are chained to a single earning person, that pressure is there in the family.”	Currently facing constraints	
“If we opt for a transplant for my dad and all, it will be a little out of our budget.”	Preoccupied with the possibility of future financial problems	
“I had to drop one year of my graduation.”	Delay in education	Difficulties faced in education
“Yes, it does affect me in a big way actually.”	Hindrance in education	
“In 10th and 12th, it impacted me in a much greater amount”		
“Since I am staying in a far-away place, if there is any emergency in the future I wouldn't be there for help. So that burdens me when it comes to education.”	Possibility of potential difficulty in case of crisis	
“I do feel that I have to censor some of my thoughts.”	Hesitancy in conversations	Issues faced in social life
“At times we feel scared, and fear social settings.”	Fear of illness getting triggered	
“We have to get used to the climate before entering or exiting a place so that the sneezing does not get triggered.”		
<i>Translated</i> “People keep asking about the disease, and it gets awkward”	Feeling low after social interaction	
<i>Translated</i> “At the wedding, we had to cut down the number of events because of the illness.”	Compromised social events	

Objective 2: To understand the ways of overcoming these challenges.

Table 2 Themes under Objective 2

Verbatim	Sub theme	Theme
<p><i>About sister:</i> “She'll be the first one to like, stand with me, support me there.” “I can share the darkest things, I think, with my sister.”</p>	Supportive family members and open communication about illness	Familial support
“And even if I want to rant about anything in the middle of the night, she'll be up to hear that for hours.”		
“I can share the darkest things, I think, with my sister.”		
“So, we have had a community in my society so I can talk to my friends about it.”	Community support	Social Support
“They have been very supportive and my friends were comforting for me, like sharing all the burden and all the responsibility with them.”	Support through friends	
“So, you need to sit with some people to have positivity all around and all the negative things would go away by itself.”	Positive social interactions	
“I take deep breaths.”	Grounding techniques	Self-care
“Saying that he is fine and then moving on. And he's gonna be fine.”	Self-reassurance	
“I take a break when it gets too heavy.”	Taking a break	
“I write about it.”	Writing	Channelising emotions through hobbies
“I write often, a lot of my poetry has a lot of mentions of menstruation.”		
“I mean dancing is something that I see as a coping mechanism.”	Dance	
“I would just listen to music to feel okay.”	Listening music	
“I don't really think about it and I keep avoiding it.”	Emotional avoidance	Avoidance
“I try to be a bit emotionally detached from the problems.”		
“We don't talk much about his illness. That's out of the conversation all of the time.”	Problem avoidance	
“I tend to disconnect a lot from my family, and that helps me deal.”		

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Objective 3: To understand the emotional and psychological state of young adults growing up with a chronically ill parent.

Table 3 Themes under Objective 3

Verbatim	Sub theme	Theme
“I worry about thinking about their deaths or thinking about how they will cope with health problems in the future.”	Anxiety, worry and fear	Emotional issues
‘Traumatized’ is a very harsh word, but less than that, I think. It’s not the trauma of the disease that’s happening. it’s the thought or the image the mind creates that what would happen if this goes bad?”		
“My father and I cry sometimes.”	Emotional outbursts and crying	
“I have had a lot of emotional outbursts recently.”		
<i>Translated</i> “When I got to know about my mother’s cancer, no one sat and explained the situation to me, and it took me a lot of time to process everything.”	Inability to process emotions	
“I tend to disconnect a lot or dissociate completely.”	Disconnecting and dissociating with issues	Dissociation
“I routinely have thoughts like why does everything only happen to me and my family?”	Lingering questions of “Why us?”	Victimization
“Especially with regard to my sister, it does bother me”	Concern for health of sibling	Concern for one’s own and family's illness
“My sister has a sweet tooth, and because of diabetes in the family, I am always worried for her. She was pre-diabetic a while ago.”		
“Eventually 10 years, 15 years down the line, if I were to have my own kids, is this going to affect my ability to, you know, be a mother in any which way?”	Concern for one’s present and future health	
“Felt that I grew up in this process, like in this whole process of dealing with the disease.”	Personal growth	Maturity
“I think I feel more responsible.”	Becoming responsible	
“So, after the news of the illness came, we had no help.”	Helplessness	Helplessness

DISCUSSION

The aim of the study was to explore the lived experiences of young adults growing up with parents having physiological chronic illness. Three objectives have been considered for this study. First, to understand the challenges faced by young adults growing up with a chronically ill parent. Second, to understand the ways of overcoming these challenges. And third, to understand the emotional and psychological state of young adults growing up with a chronically ill parent. In order to explore this, 12 participants belonging to the age group of 16-25 years of age were selected using purposive sampling for conducting interviews. Additionally, thematic analysis was used to analyse the data (Braun and Clarke, 2006). The types of illness taken into consideration in this study include physiological chronic illness of the participant's parents, namely cancer, diabetes type 2, endometriosis, chronic kidney disease, and chronic respiratory disease.

Challenges Faced

For the first objective, it was observed that as the challenges faced were from financial, educational and social backgrounds, the main three themes were determined i.e., financial constraints, issues faced in education and issues faced in social life.

Financial Constraints

It was reported by some participants that financial constraints were resolved with time. A few were still amidst the financial issues while some were preoccupied with the possibility of future financial problems. For example, the higher education of siblings; *“So when it comes to the current situation, there's no such financial burden from my side, but my sister, she's going to appear for boards so it is likely to”*. A few participants thought their parents were being more liberal and didn't let their kids know about the economic shortages while in reality there were.

Difficulties Faced in Education

Some hindrances were observed in the education of the participants as one suffered in the final board exams of twelfth grade, another had to drop out of college to look after their ill parent; *“I dropped one year of my graduation”*. It was observed that the challenges in education were also due to the mental impact of the illness. In a study by Golics et al. (2013), it was found that living with or caring for a sick relative can have a significant impact on family members' schooling and employment. This could involve disruption of schoolwork for the patients' relatives or children, as well as adult employment and the weight of care placed on them. Some families with disabled children were concerned that some of their family members may be unable to work or attend school in the near future. Three reasons were given: the necessity to care for the patient, the requirement to attend hospital visits, and the emotional effects on work. Caregivers for family members were late for work, absent from work, spending time at work chatting on the phone with their relatives, and some even quit their jobs owing to their caregiving commitments (Golics et al., 2013).

Issues Faced in Social Life

The social life of the young adults also suffered as there was a feeling of being low after the social gatherings for a few participants while others preferred not discussing and a sense of hesitation while conversing about the parent or illness. They had a fear of getting triggered and hence a few also avoided some of the gatherings or festivities with their relatives; (Translated) *“When everyone in a family gathering asks about mom, then it hurts a little bit and even we don't feel like staying there anymore.”*

Ways of Coping with Challenges

The second objective of this study is to understand the ways of overcoming these challenges. According to a study by Werf et al (2019) more than half of the participants aged 16 to 25, who grew up with a chronic illness in the family face unfavourable implications in their daily lives. According to Lazarus, children and adolescents from low-income homes may lack the resources needed to cope with a chronically ill family member and may feel more stress, which can lead to more negative outcomes in daily life (Werf et al., 2019). In our study, the multiple themes identified under ways of coping include family support, social support, dissociation, self-care, channelising emotions through hobbies or/and avoidance.

Family Support

Firstly, support from family members plays a major role along with open communication about the illness. One of the participants said that *“even if I want to rant about anything in the middle of the night, she'll be up to hear that for hours.”* Therefore, this kind of relationship and open dialogue with family helps dealing and overcoming challenges.

Social Support

Social support includes community support, support through friends and seeking a positive social environment. This helps in terms of distracting themselves from the problem, venting, seeking positivity from them, validating their own experience or gaining financial support. It was noted that *“so when I talk to them, they sometimes share worries that they may face in their lives. And it both validates my experience and lets me know that this is something that a lot of people face. And also sometimes, though this hasn't happened yet, I think if I need any health resources, they will help me out also”*.

Avoidance

Avoidance was another way to face the challenge. It was in the form of disconnecting from the issue or/and detaching oneself emotionally from the someone or people around in general. A response from a participant where it surfaced was *“I take a break, I tend to disconnect a lot or dissociate completely with, you know, whatever's going on will be in like a free space of mine”*.

Self-Care

Self-care refers to *providing adequate attention to one's own physical and psychological wellness* (Beauchamp & Childress, 2001). Self-care by using grounding technique, self-reassurance and taking a break was noticed. A response where this was observed was: (Translated) *“Act normally. Whatever is going on with you inside, let it happen. You've to deal with yourself sometimes.”*

Distraction through Hobbies

Next way of overcoming it was by channelising one's emotions through hobbies like writing, dancing, poetry, and listening to music. Fortunately, it has been demonstrated in research that when family members take the initiative to plan leisure activities, they usually work out positively, despite the limitations imposed by the relative's illness, and families express high levels of pleasure with their accomplishment (Golics et al., 2013). And finally, avoidance was another technique in the form of emotional avoidance or problem avoidance. This surfaced in responses like *“I know that it is a fact but I don't sit and contemplate about it”*.

The Emotional and Psychological State of Young Adults Growing up with a Chronically Ill Parent

The third objective of this study is to understand the emotional and psychological state of young adults growing up with a chronically ill parent. Living with and caring for a sick person has a significant emotional impact on family members, with the consequences of some diseases being felt by everyone in the family (Golics et al., 2013). Certain beneficial features, such as the strengthening of family bonds (Golics et al., 2013) might also emerge as a consequence of illness in the family. Individuals' quality of life (QoL) is directly linked to the QoL of others around them, such as spouses or parents. As a result, every chronic sickness has the potential to affect the family's life.

Themes were identified in the present study with respect to the emotional and psychological states of young adults living with a chronically ill parent and how they are impacted by having chronic illness in the family (as depicted in Table 3).

Emotional Issues

Many participants reported facing emotional issues such as experiencing anxiety, worry and fear about developing the illness themselves or their siblings due to predisposition. One participant whose mother has endometriosis reported that she is worried about the future prospect of having children as it might be a difficult process for her. Some participants even reported facing “*trauma-like symptoms*” on having to deal with the constant illness of their parents. One participant whose mother suffers from chronic respiratory illness reported that “*It’s not the trauma of the disease that’s happening, it’s the thought that or the image the mind creates that what would happen if this goes bad?*”. Moreover, emotional outbursts and crying were also common as noted from statements like “*My father and I cry sometimes*”. Inability to process emotions also came up as a sub theme as participants reported not being able to deal with overwhelming emotions, often due to paucity of time available after caring for their parents.

Dissociation

Several participants reported disconnecting and disassociating from issues in the family caused by the chronic illness. This helps them distance from issues so that they don't have to deal with them at the moment. Participants mentioned “*zoning out*” when things get difficult for them to manage.

Victimisation

Many participants talked about feelings of victimization, in the form of lingering questions of “*Why us?*” or “*Why does this happen in my family?*”. These comments don't have any logical backing, but they do indicate pessimism in young adults. The tendency to compare oneself with peers, family friends is also common which usually spirals into a negative review of one's own conditions due to lack of hope.

Concern for One's Own Family Illness

This is extended into a sense of concern for their own present and future health as well as their siblings' health. Participants often feel helpless in cases where they feel they have no control over what is happening to them or their parents. Family members' psychological suffering is frequently caused by experiences of helplessness and lack of control (Golics et al., 2013). Some participants even reported worrying about social situations as there are certain elements present in the outside environment which might trigger their parent's

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illness. Moreover, censoring of thoughts and practicing non-self-disclosure also emerged as factors associated with social interactions.

Maturity

Finally, there is also a positive outcome associated with living with chronic illness in the family. One participant whose father has diabetes reported that “*I feel like I have grown up through this process*”. Feelings of becoming more responsible also surfaced.

This study is ridden with certain drawbacks. Due to the limitation of time, the sample for this study included a small number of 12 participants and all the participants belonged to middle and upper middle socio-economic classes. Along with the kinds of challenges faced by people growing up with parents having a chronic illness, this study also highlights the ways of coping with and overcoming these challenges. Lastly, this study inspires further research to understand how the lives of family members of a chronically ill person are impacted.

CONCLUSION

Through our study, we found that young adults growing up with chronically ill parents appear to be facing challenges which are negatively impacting their personal, social life, mental health and adding limitations to their future prospects. In addition, they have also adapted healthy as well as unhealthy ways of coping. Not just the patient facing the illness, but family members also require support from their relatives, peers, social circle or from a mental health professional. Nonetheless, further research is needed to gain a more in-depth insight into the impact on the family members of a patient having any physiological chronic illness.

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Acknowledgement

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: Chaudhary, S., Chandra, A., Bharadwaj, I. & Kapoor, D. (2023). The Impact of Parental Chronic Illness on Children: Experiences of Young Adults. *International Journal of Indian Psychology*, 11(2), 2974-2984. DIP:18.01.292.20231102, DOI:10.25215/1102.292