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Research Paper

To the Brink of Trauma: Trauma Response in Informal Caregivers Caring for Chronic Illnesses

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ABSTRACT

While caring for a loved one, the role of the family caregiver can be highly stressful and result in many adverse outcomes, ranging from mild psychological stress to an increased risk of death. Due to the discrepancy and the inherent ambiguity within the term chronic illness, there is very little evidence that looks further into episodic care for chronic illnesses; after a stroke, cancer, trauma or episodic mental illnesses such as schizophrenia. The present study aimed to understand the trauma-related stressors faced by Informal Caregivers in India who care for people with mental or physical chronic illnesses using a qualitative research design through purposive sampling. Eight participants were interviewed about their lived experiences as informal caregivers. Popular themes which arise out of thematic coding suggest the presence of healthy family communication as a protective factor for those who have had overwhelming emotional experiences throughout their caregiving period. Research findings also highlight that participants who have faced significant losses throughout their caregiving period are vulnerable to developing symptoms of trauma and stressor-related disorders in the future.

Keywords: *Caregiving Burden, Trauma Response, Family Caregivers, Chronic Illnesses*

The South Asian cultural understanding of an informal caregiver has strong ties with people belonging to either immediate family or linked through some familial relationship; this is evident through practices such as Filial piety, a traditional virtue espoused by religion and culture in India, which places the responsibility of support and care for the elderly on the family; "care given for care received".

Bhalla *et al.* (2014) highlight that caregiving in India by family members (informal caregiving) is unique compared to our understanding of the developed world, where caregiving is often equivalent to formal or paid care. According to Larsson et al. (2002), spouses, adult children, and extended family members are some of the first to consider caregiving duties for their older relatives when care needs arise. These are known as informal caregivers; they deliver on the fundamental all-consuming role of a mediator between the care recipient and the health care services. The roles and responsibilities of being an informal caregiver are rarely discussed and most often implied in the hour of need.

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It is interesting to note that in the South Asian demographic, there is rarely research done to understand the burden family caregivers face in their long-standing roles. A *caregiving burden* is a physical, psychological, social, or economic strain that caregivers may experience while caring for a loved one. Caregivers are often overwhelmed in the early period of critical illness, so they struggle to understand basic information about their loved one's diagnosis, treatment, or prognosis (Carmassi, C et al., 2020). It is noted that these family caregivers who were in "high contact" with patients with chronic illness in their daily life often face the highest burden. The aspect of significant emotional involvement and the physical responsibility of caretaking adds to the burden of care.

Azoulay, E. et al. (2000) note that the role of the family caregiver can be highly stressful and result in many adverse outcomes, ranging from mild psychological stress to an increased risk of death. While struggling to adjust to new responsibilities and roles, family caregivers may experience adverse psychological outcomes, including new or worsening mood disturbances, the emergence of anxiety, and symptoms that resemble or mimic Post-Traumatic Stress Disorder (Chiou, C. J. et al., 2009). WHO statistics regarding the prevalence of trauma indicate that nearly 70% and above in a community sample experienced lifetime trauma, with exposure averaging 3.2 traumas per capita. While recent research indicates a substantial difference between Experienced Trauma and PTSD, the population remains at greater risk and vulnerability for the same.

Due to the discrepancy and the inherent ambiguity within the term chronic illness, there is very little evidence that looks further into episodic care for chronic illnesses; after a stroke, cancer, trauma or episodic mental illnesses such as schizophrenia.

The following research aims at understanding the discrepancy and the implications of bridging the gap between current research and available evidence. It aims to understand the trauma-related stressors faced by Informal Caregivers (in India who care for people with mental or physical chronic illnesses) and their predominant emotional responses to those stressors using a qualitative research design. The study results aim to provide insight into the trauma responses that can help clinicians tailor interventions for caregivers.

Aim
The proposed study aims at understanding how people taking up the role of a 'temporary caregiver' for a person with chronic illness perceive their role and responsibility during a short period.

The following research objectives have been formulated based on the aforementioned aim of conducting this study.

Research Objectives
The study proposes the following research objectives.
1. To understand the experience of a temporary caregiver during a short period.
2. To determine the predominantly perceived emotions felt by the temporary caregiver.
3. To identify the meaning-making process used by temporary caregivers during their time with the person they are caring for.

The study results aim to provide insight into the trauma responses that can help clinicians tailor interventions for caregivers.

REVIEW OF LITERATURE

There are discrepancies in the present literature regarding caregivers' care. Chronic illness has an ambiguous definition, with very little evidence that looks further into episodic care after a stroke, cancer, trauma or episodic mental illnesses such as schizophrenia. The present review highlights the vulnerability of caregivers (temporary, informal) to developing mental health disorders during or after their care. These mental health disorders fall primarily under the blanket symptomatology that presents as Mood and Trauma/Stressor related disorders.

Carmassi C. et al. (2020) conducted a systemic review of caregivers' risk and protective factors for people suffering from severe medical illnesses. They found the role of sociodemographic characteristics, interpersonal relationships, health distress and maladaptive coping as a host of risk factors that increased the vulnerability of caregivers to develop PTSD. Furthermore, they found that female caregivers were more affected by PTSD symptoms.

In contrast to the presented risk factors, Stukas et al. (1999) found that having a higher level of family cohesiveness was a protective factor against the symptomatology of PTSD, highlighting perceptions of friendliness and supportiveness between family members as reasons why family caregivers were less vulnerable to develop trauma-related symptoms. They also noted that different types of chronic illness might yield different rates of PTSD and its symptoms.

Azoulay, E. et al. (2000) note that the role of the family caregiver can be highly stressful and result in many adverse outcomes, ranging from mild psychological stress to an increased risk of death. Family caregivers may also experience adverse psychological outcomes, including new or worsening mood disturbances, the emergence of anxiety, and symptoms resembling Post-Traumatic Stress Disorder (Chiou, C. J. et al., 2009).

Zarit, S. H. (2004) highlighted that *end-of-life care* had been severely neglected in the literature. They hypothesise that this is the case because its duration is fairly short compared with the assistance given to people with chronic illnesses such as Dementia that can span a decade or more. In such long-term care conditions, caregiving severely impacts the health and well-being of family caregivers. Between 40% and 70% of caregivers were found to have clinically significant levels of depressive symptoms. At some point in their caregiving careers, as many as 50% would meet the criteria for a diagnosable depressive disorder.

Through his study, Bachmann P. (2020) found that caregivers communicated more about activities closer to the content occupying the persons with Alzheimer's or the problems they must cope through. The study also found that detailed insight into the individual categories exposed the highest need for communication in feeling exhausted and giving up. The study also confirmed the lack of time for the carers and enabled an insight into the stress level experienced compared to other caregiving activities/issues.

Schulz et al. (2006) found that nearly twenty per cent of caregivers caring for people with Dementia faced complicated grief along with high levels of depressive symptomatology post-death of the loved one receiving care.

Boerner & Schulz (2009) found that caregivers of people with Dementia were found to have clinical levels of complicated grief not only when faced with difficult caregiving situations but also some who conveyed very positive features of the caregiving experience (Schulz et

al., 2006). This finding suggests an essential factor otherwise neglected that positive and negative aspects of caregiving can co-exist and that even with some positive caregiving experiences, a caregiver can be at risk of bereavement difficulties.

Black B. S. et al. (2013) focused on socioeconomic factors of caregivers' caring for people with Dementia. The study found that caregivers' unmet needs were most common in resource referrals, caregiver education, and mental health care domains. The study also looked at unmet needs and mental health disorders; having more symptoms of depression were significantly associated with more unmet needs for caregiver and people with Dementia.

Ferriter, M., & Huband, N. (2003) studied parents of twenty-two patients diagnosed with schizophrenia. They interviewed the participants on various topics to understand their role as a caregiver. These topics included the disorder, the emotional burden and the helpfulness of others when seeking support during their caregiving period. The study identified stress, loss and fear as the most commonly documented reactions. Many participants felt guilt, usually in the absence of being blamed. They also found that parents often blame themselves for the disorder, even when not blamed by others.

There is a definitive lack of research in the field of grief, loss and trauma recovery for caregivers without formal training in care for chronic illnesses. This extends to the south Asian and Indian demographic, where the research currently limits itself to prevalence-based studies focusing on interventions. The currently identified lacunae are the vulnerability of caregivers caring for chronic illnesses in the Indian sub-continent and their lived experiences of the stressors they face. The present study aims at exploring the same.

METHODOLOGY

Research Design

The research will follow an Exploratory Qualitative Research design emphasizing Thematic Analysis. Qualitative methods achieve a more in-depth knowledge of people's perceptions concerning a particular phenomenon (Merriam, 2009). Creswell (2013) states that qualitative research is performed when a concern needs to be "explored" and that exploration is needed in circumstances in which variables cannot be easily measured or in which "silenced voices" need to be heard (p. 47–48). The proposed study aims to understand how caregivers perceive their roles and responsibilities during caregiving; phenomenology will be employed to explore their lived experiences.

Qualitative Research design looks beyond discovering meaning and employs a double hermeneutic approach, which includes discovery and interpretation of the meaning of an experience while remaining intrinsically focused on the individual and the experience itself (Smith et al., 2009).

Participants

The research will be conducted with six to eight caregivers who have cared for people with chronic mental and physical illnesses without formal training.

Data Collection

A primary research question was framed for this study, followed by three research questions: What are the lived experiences of caregivers? These questions and the literature review (Chapter 2) helped shape and inform the semi-structured interview questions that will be the

primary basis for the data-collection phase of the study. A semi-structured interview protocol was created for the data collection process, heavily based on the literature presented earlier. The protocol will include ten open-ended questions designed to allow participants to explore their experiences and create a space for a co-constructed interview in which both the participant and the researcher are actively engaged in the conversation and the recollection of the lived experiences.

Data Analysis

The following data collected will be analysed using Thematic Analysis as a framework. Michelle E. Kiger & Lara Varpio (2020) understand Thematic analysis as a method for analyzing qualitative data that entails searching across a data set to identify, analyze, and report repeated patterns called themes from the data. It is a method for describing data but also involves interpretation in selecting codes and constructing themes. In many interpretive orientations, thematic analysis can highlight the social, cultural, and structural contexts that impact individual experiences, allowing the expansion of knowledge that is constructed through interactions between the researcher and the research participants and demonstrating the meanings that are socially constructed.

Ethical Considerations

According to the American Psychological Association's "Ethical Principles of Psychologists and Code of Conduct" 2017, under section 8, "Research and Publication", several ethical considerations must be considered. (American Psychological Association, 2017)

1. Prior institutional approval will be required for researching a sensitive population.
2. Informed consent would be taken, wherein the participants will be informed about the purpose of the research, its duration and procedures. They would have a right to decline participation and withdraw from the research once participation has begun. They would be informed about potential risks, discomfort or adverse effects.
3. Offering financial inducements would be avoided as it would persuade the potential participants to participate without any will.
4. Debriefing is imperative to inform the participants about the nature, results and conclusions of the research and the possible misconceptions of the participants. Under no circumstances would there be a delay in sharing this information with the participants.
5. Data would not be fabricated; if any errors are found or reported, reasonable efforts would be taken to rectify those.
6. Data that has been previously published will not be considered for the research results.
7. Only the relevant data is obtained; it would be shared with other professionals who seek to verify the researchers' claims, keeping in mind that the participants' confidentiality is maintained. Data will be shared, if requested, with a suitable proposal for the purpose of the data obtainment.
8. Confidentiality would be strictly maintained; however, the participants would be made aware of selective access to their data (e.g., the Research Guide).

Findings

Carmassi C. et al. (2020) found that identifying modifiable risk factors, such as communication, may allow health providers to recognise caregivers vulnerable to developing psychological disorders, such as PTSD, and then target them with focused interventions. For this study, eight in-depth telephonic interviews were conducted with

participants who very recently experienced being temporary, informal caregivers to their loved ones with chronic mental and physical illnesses.

Azoulay, E. et al. (2000) note that the role of the family caregiver can be highly stressful and result in many adverse outcomes, ranging from mild psychological stress to an increased risk of death. While struggling to adjust to new responsibilities and roles, family caregivers may experience adverse psychological outcomes, including new or worsening mood disturbances, the emergence of anxiety, and symptoms that resemble or mimic Post-Traumatic Stress Disorder (Chiou, C. J. et al., 2009).

According to Larsson et al. (2002), spouses, adult children, and extended family members are some of the first to consider caregiving duties for their older relatives when care needs arise. These are known as informal caregivers; they deliver on the fundamental all-consuming role of a mediator between the care recipient and the health care services.

Due to the discrepancy and the inherent ambiguity within the term chronic illness, there is very little evidence that looks further into episodic care for chronic illnesses; after a stroke, cancer, trauma or episodic mental illnesses such as schizophrenia. The following research aims at understanding the discrepancy and the implications of bridging the gap between current research and available evidence.

Caregiving Period. Out of the eight participants, the distribution of their caregiving periods was followed. The most common prevalence was seen to be 1-2 months and 6-9 months, followed by an on/off lifetime role as an informal caregiver.
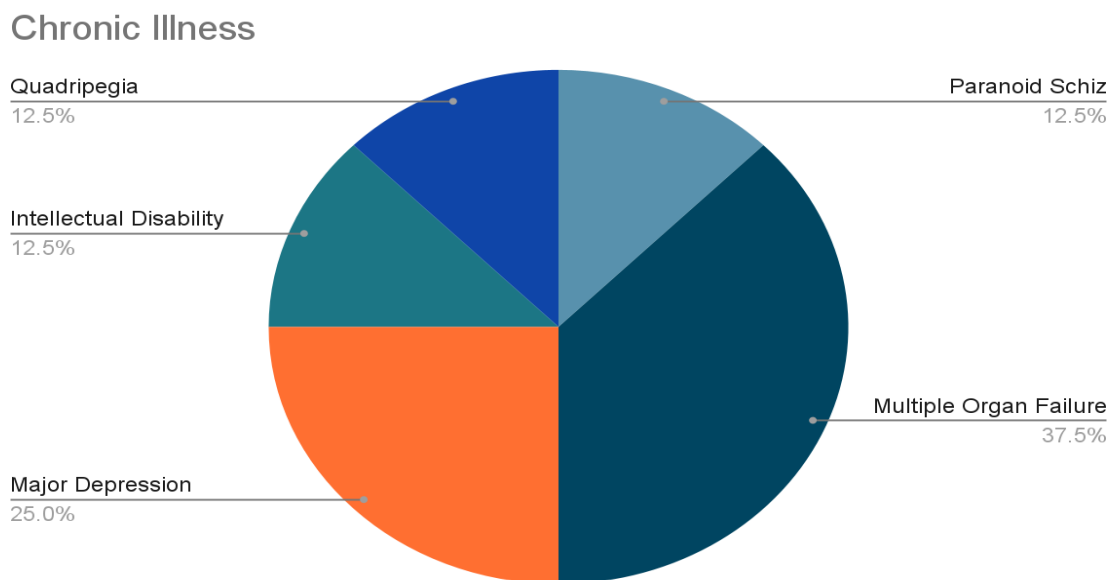
Chart 1: Caregiving Period

Caregiving Period

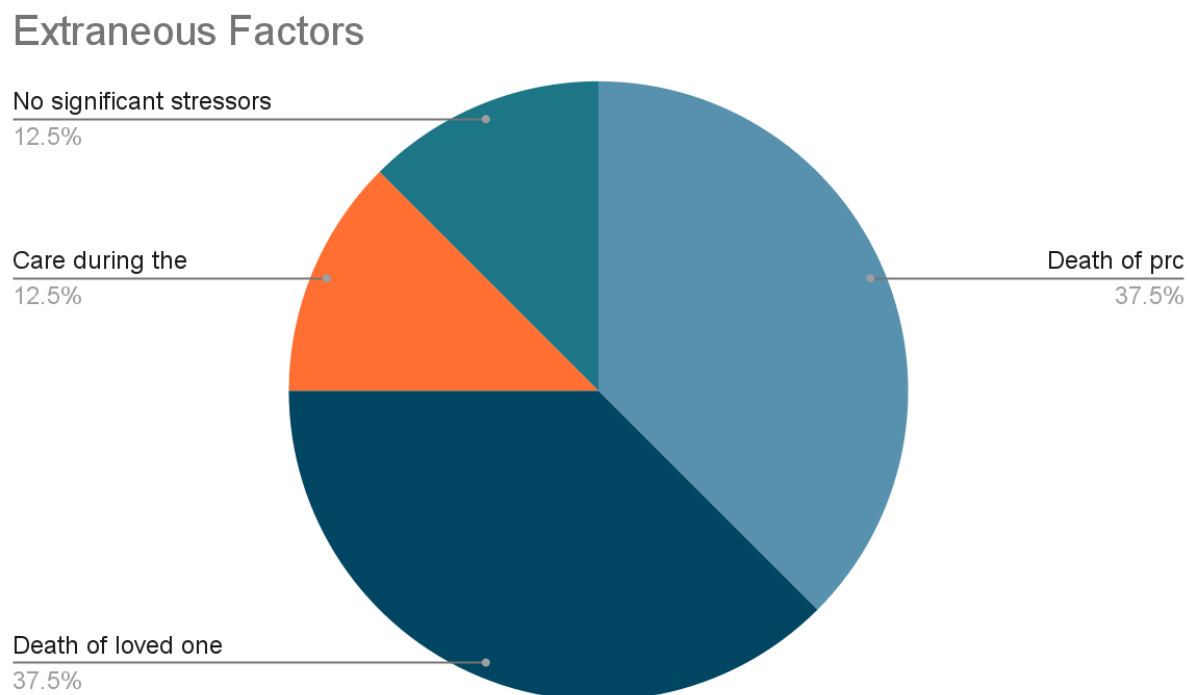lifetime care
25.0%

1-2 months
37.5%

6-9 months
37.5%
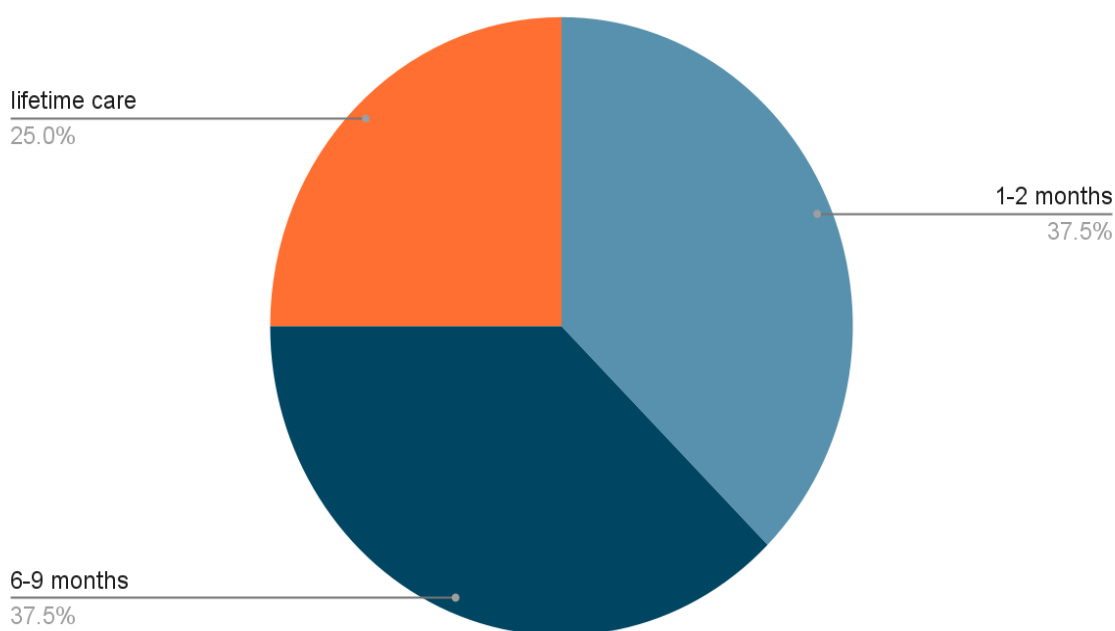
Chronic Illness. The chronic illness equally ranges from physical to psychiatric each with four participants acting as primary informal caregivers.

Chart 2: Chronic Illness

Chronic Illness

Quadripegia
12.5%

Intellectual Disability
12.5%

Major Depression
25.0%

Paranoid Schiz
12.5%

Multiple Organ Failure
37.5%

Extraneous Factors. It is also important that we note the extraneous factors that may or may not have impacted the role of a caregiver. Many participants noted that they went through periods of grief and bereavement during their role as informal caregivers. This reflects in the thematic coding of their telephonic interviews as well.

Chart 3: Extraneous Factors

Extraneous Factors

No significant stressors
12.5%

Care during the
12.5%

Death of loved one
37.5%

Death of prc
37.5%

Data Analysis Strategy

The phases of thematic analysis, as described by Braun and Clarke (2006), allow for a systematic way of seeing as well as processing qualitative information using "coding". The several phases of the thematic analysis as used in the current research are described in the following (Braun & Clarke, 2006):

1. Data familiarization: this step involves transcribing the data, reading and re-reading the data, and noting down the initial ideas.
2. Generating initial code: While translating and transcribing, features were coded as a small phrase or keyword representing a specific idea. Memos were written down to keep track of the condensed information. (Re: Appendix Page 34)
3. Searching for themes across the data: "Collating codes into potential themes, gathering all data relevant to each potential theme" (Braun & Clarke, 2006, p. 87). The data were read and re-read, and the cycle was repeated several times to narrow down the number of codes and categorized them into identifiable themes.
4. Reviewing themes: "Checking if the themes work in relation to the coded extracts at the first level and then the entire data set at the second level, generating a thematic map of the analysis" (Braun & Clarke, 2006, p. 87). The complete interview data were re-read to validate the codes.
5. Producing the report: Several vital statements/features representing the data were extracted to showcase the resulting outcomes as statements in the form of ideas and feelings. Visual representations are drawn using interconnections between codes.

Discussion of Basic Themes

On the basis of thematic analysis and coding, the following **basic themes** were identified:

- Response to Illness
- Family Communication
- Overwhelming Response

Family Communication

The caregiver described the importance of an open communication channel during the critical period to regulate mood swings, fluctuations in caregiving motivation and overall emotional support.

"I share a very strong bond with my father, and the best part was even when he was having the episodes, he knew who I am and what I meant to him- so that way you know it was (pause) strong. It's good."

"Somebody was looking after my father if I was at home. I was not the only caregiver. Which is probably why I wasn't as stressed out or battered by it. We could talk about it amongst ourselves. When you have someone right beside you going through… it helps."

These accounts highlight how the informal caregiver felt that they needed to actively communicate with their spouse, children and family members to influence positive decision-making for the older relative. In a state of panic, caregivers often enter a heightened state of alertness that clouds their decision-making and affects the caregiving process. Hypervigilance, as noticed as a trauma response in such a situation, is often curbed due to healthy conversations and boundaries being set.

A recurring theme of the temporary caregivers' descriptions is their extensive use of open communication and perceived roles and responsibilities. As mentioned, the work division allows for a healthier coping environment where individuals can efficiently process their time during the critical period and in isolation from the immediate environment.

Overwhelming Response

Throughout the interview, the informal caregiver established a fundamental support system that followed an open communication model previously used to cope with the stress of the critical period. However, recurring themes of maladaptive communication and coping were noticed.

"I felt sad, isolated, ummm, to a point I thought I might be depressed. Hmmm"

Isolation of self during a crisis period is a common emotional response strategy; however, here, it was aided by the immediacy of assuming the role. This could be due to the quality of the pre-existing relationship between the participant and their loved one.

'Uncertainty was in my mind, but I did not discuss it with anybody. That was own fight that I had. I kept it to myself, and each one of us was preparing ourselves for the worst. That's how life moves on, and then whatever life offers becomes."

This raised anxiety about the future, a fact that the participant denied on many accounts and led to signs of hypervigilance which were seen soon after their departure from the role of the temporary caregiver (Wingham et al., 2017).

"The first time I realized that was very scary in terms of I didn't know what I was going to do now, what I was going to do tomorrow, what I was going to do in the future. So that was pretty scary."

The caregivers perceived the interview as a therapeutic intervention and relished the opportunity to talk to someone about how they felt as an informal caregiver in a year where they have previously lost family and friends due to the pandemic. The theme of Overwhelming emotions was seen throughout the eight participants.

Response to Illness

The standard codes that came up during the analysis were the topics of illness-related anxiety and uncertainty. Across all eight participants, response to the illness affected their perception of their roles as a caregiver in that period.

"I didn't expect him to be this unwell for such a long period of time."

"... anything like that for them, you know, controlling them, asking them to go to the washroom, asking them whether they have done their bit in the toilet and all and pause) uhh, so it is difficult, you don't visualise yourself in that position- no child does…?"

The participant here was caring for their father, who was suffering from an active episode of Schizophrenia with additional Kidney problems. The participant recalls that they did not expect their father to be unwell for an extended period and that controlling their washroom habits took an emotional toll on them, which they had not previously experienced.

"So you apply that gel, personally, with your fingers. Okay? Someone else's does that. And then the layers tend to come to start coming to open up, period. Okay. So that was a little unusual experience. Okay. Starting with a, it was kind of a new thing."

Another participant recalls having to apply the gel inside the mouth of their bedridden grandmother at the age of twenty and how that response to his grandmother's illness was to treat it as a task that had to be done.

"When my father's accident was announced to me in terms of not announced but informed to me, I got a call from a stranger. And when I went there, I saw him at the hospital. And eventually, when you realize the nature of the injury, you realize that you have to take care of your parents."

*"Everything for them right from his brushing his teeth to cleaning him to giving him a bath and everything like everything we were doing for him, he was immobile, and he was uh fallen twice, he was hospitalized, and that was uh I mean I, I really can't say how it was- It was frustrating to see a person just wither aw*ay you know."

Similarly, the responses to the illness can be seen as a common theme among all participants, which aided in their emotional responses during the caregiving period.

On the basis of the similarity of content within these basic themes and their relatedness, these were organized into two **organizational themes**:
1. Caregivers' communication with family and friends
2. Caregivers' emotional response to the caregiving period

Based on a previous review of literature, these two organizational themes share a common theme amongst them; these are grouped as a global theme of the **Maladaptive Emotional Response post-caregiving.**

Limitations and Future Scope
Due to the use of questionnaire methods in the analysis, the social approval variable may have impacted the study's results. The most important limitation, however, is the small size of the studied group. Therefore, the results should be treated as preliminary. The presented research, despite its imperfections, maybe the starting point for further exploration of this topic.

However, the most critical asset is the attention paid to the rarely discussed and critical topic, i.e., the burden of care in persons looking after mentally ill family members and the protective factors in place to reduce the vulnerability of trauma and stressor-related disorders.

CONCLUSION
The present research indicates that caregivers caring for people with chronic mental and physical illnesses are vulnerable to developing mood and stressor-related disorders. The common theme among the participants identified is the Maladaptive Response Strategy of caregiving, where the caregivers were noted to have severe grief responses to the ones they lost and suggested that caregivers often lost touch with reality showing signs of Hypervigilance post their caregiving periods. The research also highlights healthy family

communication as a protective factor to reduce caregivers' vulnerability to stressor-related disorders.

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