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Exploring the Lived Experiences of Individuals with Prolonged Grief Disorder: A Qualitative Study

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Abstract

This qualitative investigation delves into the lived experiences of seven individuals diagnosed with Prolonged Grief Disorder (PGD), who were recruited through a clinical sampling methodology. Comprehensive interviews and thematic analysis elucidate the complexities inherent in PGD, encompassing its repercussions on daily functioning, interpersonal relationships, and overall psychological well-being. The findings underscore the critical importance of factors such as the nature of the death, individuals' perceptions of their present life circumstances, available support systems, and alterations in personality traits as pivotal elements in shaping the grief experience. The study emphasizes the necessity for diagnostic approaches and interventions that are culturally sensitive and specifically tailored to the unique needs of individuals experiencing PGD. The outcomes possess significant implications for clinical practice, highlighting the necessity for evidence-based therapeutic interventions and supportive dynamics aimed at alleviating the difficulties encountered by individuals suffering from PGD.

Keywords: Prolonged Grief Disorder, Bereavement, Thematic Analysis, Coping, Support Systems, Psychological Well-Being

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INTRODUCTION

Grief is the emotional response to a loss of loved ones; it can be individualized and personalized reactions and feelings that an individual experiences in response to actual, perceived, or expected loss. These emotions might involve anger, disappointment, isolation, sorrow, remorse, and acceptance. Grief impacts survivors on physical, emotional, social, and spiritual levels. Grief is a natural and universal human response that arises after the loss of a loved one. The grieving journey can be understood as a challenging process of finding new significance in life without the presence of loved ones (Nursing et al., 2021). There is no right or wrong feeling. (Kalantari et al., 2023). Grief is not a static condition but rather an ongoing process. (Mughal et al., 2023)

Feeling sad after losing a loved one is normal, but only a subset of grieving individuals will experience a prolonged grief disorder. Now, both the DSM-5 and ICD-11 have official criteria for diagnosing prolonged grief disorder, and PGD happens about 6 to 12 months after a loss. This disorder involves symptoms like constantly thinking about the person who passed away. Numerous assessment measures, which include self-report or clinician-rated questionnaires, can be used to assess for specific grief symptoms and the progress of treatment. (Szuhany et al., 2021).

A study compared COVID-19 deaths to other causes of death in terms of the likelihood of developing Prolonged Grief Disorder (PGD). They found that COVID-19 deaths were more likely to be linked with Prolonged Grief Disorder compared to deaths from dementia and similar to deaths from other natural causes. Surprisingly, deaths from homicide were less likely to be associated with Prolonged Grief Disorder compared to COVID-19 deaths. Factors like a shorter time since the death, having a sibling or another close relationship with the deceased, and accidental deaths increased the likelihood of developing Prolonged Grief Disorder. On the other hand, having a more distant family relationship with the deceased or death due to dementia decreased the likelihood of developing Prolonged Grief Disorder. (Gang et al., 2022). Across different cultures, like refugees, migrants, and survivors of conflict, may be more likely to develop Prolonged Grief Disorder due to the unique challenges they face when dealing with loss. (Hilberdink et al., 2023)

Maccallum and Bryant (2019) showed that symptoms of prolong grief disorder such as role confusion and meaninglessness were associated with less psychological quality of life, difficulty trusting others was associated with declined social quality of life and bitterness was linked with decreased environment quality of life. Sarper and Rodrigues (2024) concluded that social support highlighted the adverse influence of anxiety and defensive role of self-compassion when individual was managing their loss. Individuals who experienced anxiety reported strong symptoms only when they had less social support. In contrast individual with great self-compassion showed less symptoms only when they have more social support.

The Dual Process Model of Copying with Bereavement: This model was developed by Kubler Rose named as Kubler Rose Cycle. It is widely used to understand the process of grief. According to this model, Grief is considered as a fluid not a continuous process so that's why most people do not go through stages of grief in organized ways. Grief cycle comprised of five stages, denial (conscious and unconscious dissent to acquire facts and logics), anger (people suffering with emotional pain may exhibit anger toward others or their lost one), bargaining (trying to bargain from divine), depression (person may exhibit

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feelings like sadness, fear and uncertainty) and acceptance (person become emotionally detached from their loved ones and tried to move on in life) (Tyrrell et al., 2023)

The Dual Process Model of Coping with Bereavement: Prolonged grief disorder is a persistent and progressive grief symptom that extends beyond the expected time frame following a loss. Person experience prolong grief when he/she suffers from imbalance or difficulty shifting between two processes. This model highlighted two types of stressors, one is loss-oriented stressor (involving confronting and processing emotional pain linked with the loss) and the other one is restoration-oriented stressor (performing same tasks that their loved one used to do). This model proposed that adaptive coping is composed of confrontation-avoidance of loss and restoration stressors. Its need for dosage of grieving that is, the need to take break from dealing with either of these stressors as an integral part of adaptive coping (Stroebe & Schut, 1999).

Rationale

This study found a difference between normal and pathological Grief. This research contributes how the loved one's death or detachment affected the person and what areas or factors contributed to prolonged grief disorder. Previous studies lack important information regarding the differences between PGD and PTSD, which are more apparent. In PTSD, people typically fail to assimilate their experiences and have prevailing perceptions of their fundamental beliefs, like avoiding driving after experiencing a road-traffic accident, or holding unrealistic beliefs about the likelihood of physical altercations, and severely restricting one's social life after a serious physical assault. The consequence of PTSD is a persisting inconsistency warning signal, accompanied by strong negative emotions, which result in the psychological system being constantly preoccupied with detecting dangerous inconsistencies. In contrast, in PGD, the predominant feeling is not threat but loss-related distress. The purpose of the study was to explore new psychological disorders and how they affect a person's well-being. While these aspects of research are important, we argue that a core understanding and appreciation of the disorder must also be promoted.

Objectives

The objectives of the present study are:

- To investigate factors that contributed to the person's grief and had difficulty in managing grief.
- To explore the impact of a person's persistent grief on their personality and on daily functioning.
- To investigate different thought patterns that contributed to increasing a person's grief.
- To explore the supportive factors that contributed to reducing a person's grief.

RESEARCH METHODOLOGY

Research Design

The study was carried out phenological myresearch design. The present study is aimed at understanding and appreciating the disorder and to distinguish prolonged Grief from Bereavement-Related Depression and PTSD (post-traumatic stress disorder).

Phase I: Prepration Questionnaire of Prolonged Grief: This phase was intended to explore the nature and symptoms of prolonged grief and its difference from bereavement-related depression and PTSD. For this purpose, interviews some questions prepared with the help of prolonged grief literature review, previous scales and also obtained opinions of clinical psychologists and psychiatrist.through committee Approach selected suited

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questions for semistructured interview on the base of judgemental validity and content validity.

Sample: A Sample of 7 participants was approached using a clinical sampling technique. From both males and females who were suffering from prolonged grief disorder and they were diagnosed patients of prolonged grief from different psychic clinics.

Phase II: Transcription and analysis of interview guides: After investigating the participants with prolonged grief disorder, in the second phase, interviews were transcribed by listening to the tapes repeatedly. After obtaining the verbatim data, thematic analysis by Clarke and Braun (2013) was employed, followed by data familiarization and reduction for the sake of analysis. This objective was achieved in seven steps, which include transcription, reading and familiarization, coding, searching for themes, reviewing themes, defining themes, and finally finalizing themes.

Table 1: Demographic Characteristics of Interviewees (N=7)

Interviewer	Age	Gender	Profession	Grief period
1 st	35 years	Female	Housewife	3years
2 nd	39 years	Female	Housewife	3 years
$3^{\rm rd}$	24 years	Male	Student	2 years
4 th	30 years	Female	Private job	4 years
5 th	35 years	Female	Housewife	2 years
6 th	30 years	Female	Restaurant staff	4 years
_7 th	28 years	Male	Property dealer	2 years

Procedure and analysis: For interviews, participants from both genders were contacted. They were informed about the purpose of the study and significance of the study. After taking their consent, they were interviewed. Most of the participants showed immense interest in the topic. After each interview, they were thanked for their time and cooperation. Audiotapes obtained during interviews were then subjected to thematic analysis. This approach was opted for because of its flexibility. Initially, codes were assigned to data. After that, similar codes were clustered, and themes were formulated.

Table 2: Major Themes, subthemes and codes of prolong grief disorder (N=7)

Table 2. Mujor Themes, subthemes and codes of protong grief disorder (N-7)					
Sub theme	Codes				
	Sudden, unexpected, and foreseen.				
	Denial, Devoid of feeling, shocked, and				
	emotional numbness				
	Life seemed difficult, challenging, and				
	disappointing toward life				
Negative support	Negative: sympathy pain, negative attitude				
system	of others, disappointment from loved ones				
Positive support	Positive: Family cooperation, strong bond				
system	with blood relations, positive attitude of				
	others, and religious practices				
Self-competency	Competency: shifting attitudes toward				
Self-incompetency	activities, emotional relief through				
	interaction and minimizing pain in front of				
	others				
	Incompetency: feeling of dependence, failed				
	in achieving goals and irreplaceable loss				
	Negative support system Positive support system Self-competency				

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Difficulty in holistic well-being and sustainable living		Health-related physical issues: Sleep and appetite disturbance, somatic health issues, bodily noticeable changes and increased past
O	Social issues	somatic issues
		Health related psychological issues:
		persistent emotional pain, sensitive,
		flashbacks, hopelessness, feeling of guilty
		and psychological stress
		Social issues: decreased social activities,
		reduced social circle, resistance from
		activities and weak trust on others
		Financial issues: forced engagement,
		financial disengagement by others and
		disturbed financial management
Changes in		Responsibilities, express emotions alone, loss
personality		of interest, struggle to find comfort, difficulty
		dealing situations, loneliness and behavioral
		disturbances.

RESULTS

The data was obtained from people who were suffering from prolonged grief. After the interview, the data were first transcribed and then analyzed and interpreted in this section. The results, discussion, and conclusion are also reported here. The findings have been categorized into seven major themes. Major themes are then further broken down into subthemes and codes. **Difficulty in holistic well-being and sustainable living**

It involved those factors that contributed to a person's health after losing their loved ones. Three main domains were impaired, including health-related issues, financial issues, and social issues. Respondents talked about two health-related issues: the first was physical, and the second was psychological. All respondents reported that they were in persistent pain that did not recover or resolve even after years. They were hopeless about life and just passed their time. Respondents also reported that they suffered from stress that affected their health directly. The social circle was affected and reduced. Some of them talked about activities that they did with their loved ones, when they tried to do it without them, they had flashbacks or remembered memories with them, and avoided doing those activities. Some of them reported about disturbed financial management because all the authorities and responsibilities were taken care of by a person who was no more with them.

Encountering a Death Situation

The most frequent instant reaction to the following death is numbness, shock, denial, a sense of disbelief, or becoming quiet or devoid of feeling. Some of the respondents reported their reactions became shocked (dreadful), in denial (refusal and unacceptance), involved, devoid of feelings (emotionless), and emotional numbness (feeling emptiness).

Significant Attempts to Make up for the Loss

The grief affected lives positively or negatively. To come out from the grief they tried multiple attempts in which their self-competency/capability help out; shifting attitude toward work/activities (increase the activities where they can get relief from flashbacks), showed emotional relief through interaction (increases the gatherings and social circle) and started minimize pain in front of others (personal efforts to overcome the grief in front

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of others). Negative impact of grief on their Self incompetency/proficiency, feeling of dependence (dependent on others/family), failure to achieve goals (failure to achieve or accomplish their targeted goals and responsibilities), and irreplaceable loss (failing to come out from grief).

Perception of Current Life

Grief changed the perceptions of respondents about life. Life seemed a difficult challenge (low sense of acceptance) and Disappointment toward life (dissatisfaction with the future). The results show that prolonged grief hurts some respondents' perception and viewpoint toward life challenges and struggles. Some of the responses showed their unacceptance of their loss, which directly affects their functioning in personal, social, occupational, and other domains of life and will also affect their future goals.

DISCUSSION

The current investigation sought to examine the lived experiences of individuals diagnosed with Prolonged Grief Disorder (PGD) through the application of a thematic analysis methodology. The results unveiled a variety of prominent themes, subthemes, and codes that elucidate the intricate nature of PGD.

Nature of Death

The abrupt, unforeseen, and anticipated characteristics of death significantly influenced the grieving process. This observation aligns with prior empirical studies, which indicate that the contextual factors surrounding bereavement can markedly affect the grieving trajectory (Prigerson et al., 2009).

Perception about Current Life

Participants articulated that existence appeared arduous, demanding, and unsatisfactory following the bereavement. This observation corroborates findings from research that posits PGD can result in substantial distress and disruption in everyday functioning (Shear et al., 2011).

Support System

The support network, encompassing family and friends, was instrumental in either intensifying or mitigating the grieving experience. Constructive support systems, characterized by familial collaboration and robust interpersonal relationships, were linked to enhanced coping strategies. This conclusion is consistent with literature that underscores the significance of social support in the process of grief recovery (Cohen et al., 2015).

Difficulty in Holistic Well-being and Sustainable Living

Participants encountered considerable challenges in achieving holistic well-being and sustainable living, encompassing health-related complications, financial constraints, and social difficulties. These observations align with existing research that indicates PGD can profoundly affect an individual's comprehensive well-being (Lichtenthal et al., 2013).

Changes in Personality

The investigation also identified notable alterations in personality traits, including heightened responsibilities, challenges in emotional expression, and diminished interest in activities. These results correspond with research suggesting that PGD may precipitate enduring changes in personality and behavior (Bonanno et al., 2002).

LIMITATIONS AND FUTURE DIRECTIONS

This study has several limitations that should be considered when interpreting the findings. The small sample of seven participants limits generalizability. The study was conducted

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within a specific cultural context, while diagnostic criteria for PGD are largely based on Western models, which may not fully capture non-Western grief experiences. Future research should address these limitations by using larger and more diverse samples, incorporating mixed-methods approaches, and conducting longitudinal studies to examine the trajectory of grief. Cross-cultural research is needed to clarify cultural influences on PGD, and intervention-based studies could evaluate counseling strategies and support systems to inform evidence-based, culturally sensitive treatments.

CONCLUSION

This qualitative research examined the lived experiences of individuals with prolonged grief disorder (PGD), and revealed its wide-ranging impact on health, relationships, finances, and daily functioning. Findings showed that PGD extends beyond emotional pain, influencing physical and psychological well-being, disrupting social ties, and reshaping identity. While participants reported overwhelming distress, protective factors such as family support, religious practices, and personal coping efforts offered pathways toward resilience. The results emphasize the need to distinguish PGD from normal bereavement and related disorders to ensure accurate assessment and intervention. Greater societal awareness and culturally sensitive therapeutic approaches are essential to address the unique challenges of PGD. By offering qualitative insights, this study contributes to understanding the complexities of prolonged grief and underscores directions for future research and practice.

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