

Navigating Through Grief: The Unheard Story of Dementia Caregivers

Dr Alexander Manevich



NAVIGATING THROUGH GRIEF: THE UNHEARD STORY OF DEMENTIA CAREGIVERS

'Grief is the price we pay for love' (Queen Elizabeth II)

Grieving and mourning are natural and deeply personal responses to losing someone we care about. It is an experience that is known to most people and evokes a wide range of emotions ranging from sadness to anger. Often, grief is related to death, which may bring some closure. However, in some cases, people lose loved ones in ambiguous situations that do not allow for such closure. **Dr Alexander Manevich** at the Kinneret Academic College and the University of Haifa in Israel investigates this process in caregivers and family members of people living with cognitive decline and dementia.

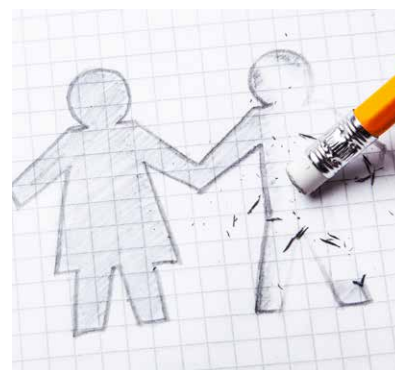
Losing Loved Ones While They Are Still Alive

Bereavement, mourning and grief are primarily recognised and understood as responses to the death of a loved one. However, in recent years, there has been a growing understanding that other life-altering events that do not directly involve death, can still leave family members bereft of an important relationship due to dramatic changes in a loved one. These changes can arise from a number of medical and psychological conditions, which are often ongoing in nature and without the opportunity for closure, resulting in the experience of 'Non-Death Interpersonal Loss' (NoDIL). In these situations, the physical presence of the 'altered' person coexists with the awareness that the essence of the person who had been there before is now 'gone'.

One example of NoDIL is when a loved one develops a disorder like dementia. Other examples include those affected

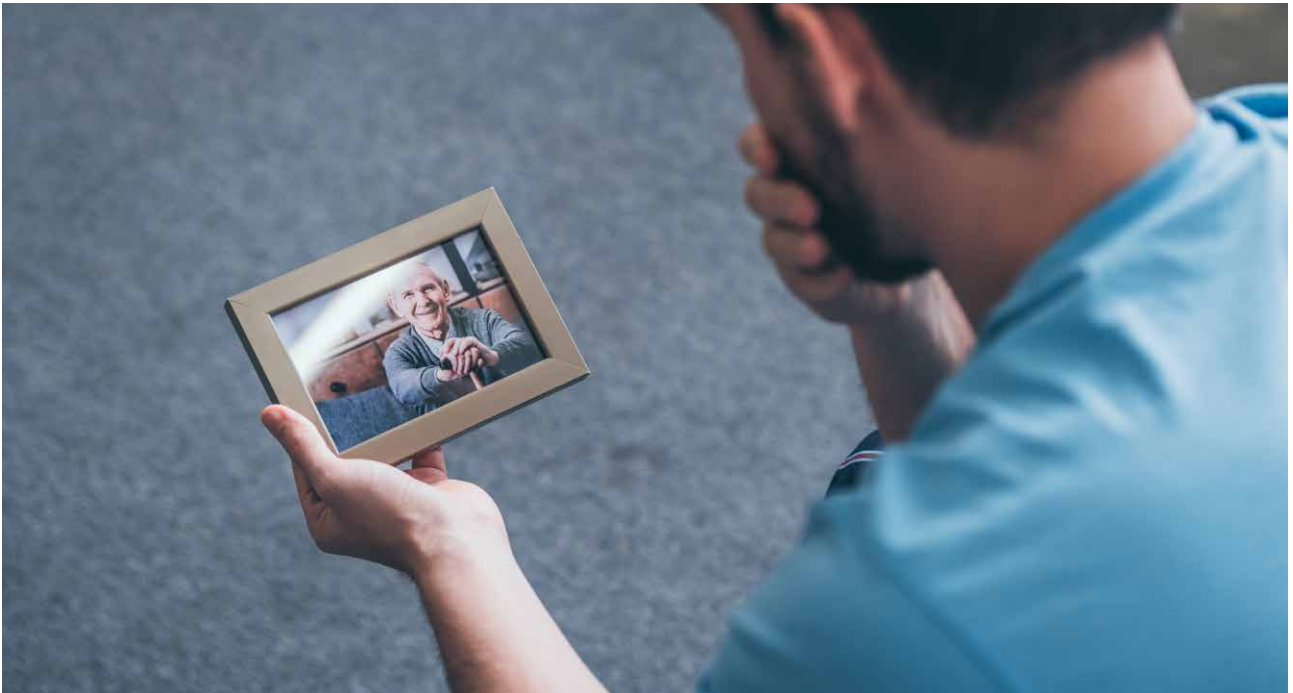
by traumatic brain injury, serious mental illness (such as schizophrenia) or disorders of consciousness. Unfortunately, grieving the loss of someone who is still physically with us can be an incredibly complex experience. An especially challenging aspect of this type of NoDIL is reaching a conclusion about what person their loved one was, is, and will become. Family members particularly struggle with facing this new reality and an uncertain future.

Dr Alexander Manevich at the Kinneret Academic College and the University of Haifa in Israel works with colleagues to pioneer a new understanding of this process. They believe that insight into this complex process of grief and mourning can help in the development of coping strategies and in offering more relevant professional help to families and caregivers of people living with cognitive decline and dementia.



Dementia: A Non-Death Life-Altering Situation

Life expectancy in the population is steadily rising, and with the rise of age comes a rise in chronic and life-endangering diseases. Dementia, especially Alzheimer's disease, is considered to be among the most painful and devastating diseases of old age. Dementia is a unifying term for a range of major neuro-cognitive disorders with diverse origins. They share the common characteristic of a decline in cognitive functions and the ability to live an independent life.



Experts estimate that the number of people living with dementia will increase from 57.4 million cases globally in 2019 to 152.8 million cases by 2050. This so-called ‘silent pandemic’ will have many consequences, not least on the patient support networks that provide much of the daily care – typically spouses and adult children.

The most common form of dementia is Alzheimer’s disease, characterised most prominently by impairments in memory, such as the inability to remember life events and even the faces of family members. Alzheimer’s disease progresses rapidly, and what starts as mild confusion and difficulties with memory slowly progresses into full dependence on caregivers.

Once patients are diagnosed with dementia, patients’ families and spouses have to rearrange their lives to accommodate the new caring responsibilities. Additionally, they have to learn how to effectively communicate in new ways and adapt to a new, different and potentially challenging relationship with their loved ones. Sadly, but not unexpectedly, difficulties with coping and adjusting to these new arrangements typically increase as the disease worsens.

Dr Manevich and his colleagues are eager to increase our understanding of the mourning that comes alongside a diagnosis of dementia within a family. They investigate different stages of family grief that can be experienced before the death of a loved one as well as into the period of bereavement.

The Continuing Bond in Sickness and in Death

Most previous studies have focused on the related stress and burden that caregivers experience. However, when it comes to pre-death grief (or anticipatory grief), there is a lot less research available. Dr Manevich and his colleagues are confronting

this omission in the literature by examining close family and caregivers’ responses to a loved one suffering from cognitive decline.

In previous research, caregivers often reported that they were grieving the loss of their loved ones even though the care recipient was still alive. What was very common across the caregivers’ responses was the loss of previously established roles in the relationship within the family and the loss of intimacy or interpersonal relations. At its most basic level, the relationships changed after diagnosis, and so did the bond between the family members and patients with dementia. Dr Manevich sought to understand this continuing bond in sickness and after death.

Many of the models that are used in clinical settings to help family members and caregivers with coping do not provide a sufficiently comprehensive perspective to account for the unique situation of grieving someone who is still alive and with whom the bond continues. The relationship is just very different. Therefore, in 2021, Professor Rubin, Dr Manevich and Professor Doron proposed a theoretical model (the Two-Track Model of Dementia Grief) that provides a virtual ‘map’ to assist in clinical assessment and research on the strengths and weaknesses of clients whose loved ones live with dementia.

This model incorporates specific characteristics of caring for a patient with dementia and the emotions that come with it. The team identified the gaps in current methodologies, and their new model now addresses previous limitations by considering ongoing interactions with the affected family member.

To gain a comprehensive picture, they considered the severity of cognitive decline, caregiving requirements, and related losses for caregivers. They also incorporated other psychological factors and backgrounds to get a full picture of



how caregivers functioned in everyday life. In their model, the researchers combined both the bio-psycho-social functioning of caregivers and family members as well as their relationships with their loved ones.

When exploring the family bond, the researchers were particularly interested in common memories, emotional closeness, positive and negative experiences, traumatic perceptions and conflicts. Gathering all this vital information helped Dr Manevich and his colleagues to understand the role of interpersonal relationships in the grieving process.

Using the Two-Track Model of Dementia Grief

The term Pre-Death Grief (PDG) associated with dementia caregiving refers to the caregiver's emotional and physical response to the perceived losses associated with their loved one. Family caregivers experience a variety of emotions (such as sorrow, anger, yearning and acceptance) that can wax and wane from the time of diagnosis to the end of life.

PDG is triggered by a number of processes. These include (a) caring for an ill person where the disappearance of their personality and personhood precedes physical death; (b) a protracted and uncertain disease course; (c) communication difficulties between the patient and caregivers; and (d) deterioration in relationship quality, new, unfamiliar and stressful family roles, and in addition, signification limitations in caregiver freedom. PDG is a significant risk factor for depression, anxiety, and prolonged grief disorder.

In 2023, Dr Manevich and his colleagues led an investigation into the experiences of healthy spouses caring for their partners with dementia using the Two-Track Model of Dementia Grief. They found that healthy spouses experience psychological reactions consistent with grief even in the early stages of the disease and associated decline in their loved one's cognitive ability. Alongside the disease progression, they found that spouses experience more distress and adverse bonds with their patient partners than they had before. Additionally, the research team found that these stages throughout the disease are significantly different in their characteristic to when their loved ones die, which evokes a more traditional form of grief.



Therefore, it is reasonable to assume that for those caregiving for a living spouse with cognitive decline, time may seem to be 'frozen', wherein the hard and sometimes cruel reality of dealing with the disease does not allow for the emotional and mental processing of it. With the formal event of death, however, there comes greater emotional availability to allow the bereaved to say goodbye, re-grieve, and bring the relationship to a balance in a more beneficial and integrated manner.

The trajectory of grief is profoundly individual. A common finding, however, relates to how grief impacts both the bio-psycho-social track and the relational track of the process. The bio-psycho-social track refers to the emotional, cognitive, and physical aspects of mourning. The relational track refers to the unique challenges that come with changes in relationships after a dementia diagnosis within a family.

Grief is incredibly complex in terms of how people live and function in the wake of loss, but also in the way they re-organise, remember and experience the relationship with the loved one they have lost. Dr Manevich and his colleagues knew that they needed to focus on both – how grieving families cope in terms of their overall functioning and also in terms of building and maintaining relationships.

Validation and Clinical Implications

Dr Manevich and his colleagues continue to devote their research to exploring the grieving process of those who are mourning a close one who is still alive but is fading away due to disease. Their theoretical model considers the bio-psycho-social factors affecting caregivers but also considers the continuing bond between the caregivers and patients.

In their future work, they aim to further validate these theories and their clinical potential. The team now hopes that the intervention can benefit from their findings on the importance of relationships and attachment style in the grieving process, with the ultimate goal of providing professional and tailored assistance to people who are coping with these 'transparent' and disenfranchised losses.



Meet the researcher

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Dr Alexander Manevich is a licensed psychologist and a senior faculty member, researcher, and lecturer at the Department of Psychology and the Department of Behavioral Sciences at Kinneret Academic College in Israel. Dr Manevich obtained his PhD in clinical psychology in 2021 at the University of Haifa, where he still holds a position as a principal research associate in the School of Psychological Sciences and the International Laboratory for the Study of Loss, Bereavement, and Human Resilience. Among other contributions, Dr Manevich has participated in multiple national and international seminars and conferences and in doing so, obtained several awards and prizes. The focus of his research is on loss, bereavement, palliative care, clinical geropsychology, and cognitive decline.

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FURTHER READING

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