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# Challenging Aspects of Bereavement and Grief in Older Adults with Dementia: A Case Series and Clinical Considerations

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#### **Abstract**

**Introduction:** Bereavement is commonly experienced among older adults and has been shown to predict adverse health outcomes and may be linked to cognitive impairment. There is a paucity of literature on the impact of bereavement on older adults with dementia, contrasting extensive research on how dementia carers cope with their grief.

**Methods:** 5 case studies of older adults with dementia and their bereavement reactions to losses are reported. The description of the phenomenology of bereavement distress in the case series help to shed light on its unique manifestations and how we can better understand this highly vulnerable group in their grief.

**Results:** Normal grief reactions of denial, anger, bargaining, depression and acceptance can be experienced in early dementia. As the disease progresses, persons with dementia (PWD) may be too cognitively impaired to experience and express their grief. A vague sense that something is wrong with inner distress may manifest as behavioural disturbances, for although cognition declines, feelings and states of emotional pain remain. PWD may not be aware of the loss or may confuse the present loss with earlier losses. Seemingly nonreactions of mourning were noted to be much more common than those found among persons with normal intellectual ability.

Conclusions: PWD and their families can be supported through the stages of grief by society and other support systems. Ethically, PWD have the right to grieve and mourn but the experiencing of acute grief and distress multiple times with 're-traumatization' when the truth is revealed each time may be considered cruel and insensitive. It may be understandable why some family members and care staff try to shield PWD from reality. There may be questions as to whether or not to tell, how to tell and how the revelation will impact on their psychological well-being as well as their caregivers. PWD need to be approached differently when they experience bereavement and loss. If the grief response of the PWD is not sufficiently understandable in the context of the loss, there is the risk of them being inadvertently excluded from their family's cycle of grief. Professional and family caregivers need to appreciate that PWD can be capable of grieving and we need to see how we can best support them and their loved ones in their grieving process.

## **Background**

Bereavement refers to 'the period after a loss during which grief is experienced and mourning occurs (American National Mental Health Association). It is commonly experienced among older adults, who are also more likely to have memory impairment and dementia. Bereavement has been shown to predict adverse health outcomes [1-6] and may be linked to cognitive impairment [7,8].

There are unique aspects of bereavement and grief in dementia which clinicians may fail to address in the care process. Disenfranchised grief refers to losses that are not appreciated by others. The individual has no perceived 'right' to mourn and the loss is not openly acknowledged [9]. In the early stage of dementia, both the person with dementia (PWD) and family carers may experience these losses. However, as the disease progresses, PWD may be too cognitively impaired to experience their losses and express their grief. A vague sense that something is wrong with inner distress may manifest as agitation and behavioural disturbances instead, for although cognition declines, feelings and states of emotional pain

remain [10]. They may not be aware of the loss or may confuse the present loss with earlier losses [11,12].

There have been a myriad of studies and research on how carers of PWD cope with grief and losses [13,14]. However, there is a paucity of literature on the impact of bereavement on older adults with dementia. The description of the phenomenology of the unique bereavement distress in the following case series serve to shed light on how we can better understand and support this highly vulnerable group in their grief.

## Case 1

Mrs P is an 88 year old Indian lady with moderately severe mixed vascular and Alzheimer's dementia (Mini-Mental State Examination (MMSE): 16/30). She was admitted for worsening of her behavioural and psychological symptoms 5 days after her husband passed away from pneumonia. They had been married for 65 years and had maintained a good relationship. They had no children and her husband had been the main caregiver after she was diagnosed with dementia 2

years ago. Mrs P had accepted news of her husband's death initially and had attended the funeral. However, the next day, she became agitated when she was unable to find her husband. She was noted to be confused with frequent crying spells and had poor sleep and appetite. Her niece was agreeable for the staff to reinforce news of her husband's death during her inpatient stay. Her niece would bring photos of the funeral to show her and Mrs P would cry and seemed to acknowledge her husband's death. However, she would forget at the next visit and would talk about returning to her husband at home. Mrs P was deemed unsuitable for grief counselling as she was unable to retain information about her husband's death. Her memantine was withdrawn as there were concerns amongst the treating team and her niece that being too alert and aware of events may be countertherapeutic. There was a discussion with her niece and staff about how Mrs P should be counselled if she were to ask for her husband. Consequently it was agreed that we would go along with Mrs P's insistence that her husband is still alive and is awaiting her return at home. She was continued with her antidepressant, Escitalopram and was discharged to the care of her niece. At home, her niece reported that Mrs P would still enquire the whereabouts of her husband but was able to be persuaded that he was at work. This stopped about 6 months after her discharge and her niece did not report any further behavioural issues at home.

#### Case 2

Mrs CSL is a 72 year old Chinese lady who was referred to the memory clinic for forgetfulness. She was diagnosed with early stage Alzheimer's dementia (MMSE: 22/30). She was fairly well maintained on an acetylcholinesterase inhibitor, Donepezil. Her family then reported the sudden loss of her son whilst on a business trip to China. Mrs CSL was able to express her grief over the son's death and would cry during the psychiatric consultations. Her daughter was open to a referral to the psychologist for grief counselling but Mrs CSL declined. She was able to open up to the psychiatrist during her visits and together with her daughter's support, did not manifest any significant worsening of function or cognition. Her latest MMSE 14 months after her son's death was 20/30.

#### Case 3

Mrs C is a 69 year old Indian widower who was referred for worsening of her mood and memory after she was informed that her son was robbed and killed overseas in India about 6 months ago. Dementia work-up including a neuropsychological evaluation was suggestive of Alzheimer's dementia in the early stage with MMSE of 21/30. Mrs C was thus initiated on Donepezil, an acetylcholinesterase inhibitor. However, Mrs C was clearly very much affected by the loss of her son and was noted to be tearful and angry for the first three visits. She would spontaneously talk about missing her son. She lamented that she had lost her husband to sudden illness and had singlehandedly brought up her 3 young children. Her daughter was initially reluctant for her to be referred to the psychologist for grief counselling as she noted that Mrs C would be worst after her consultations. It was apparent that her daughter was also traumatized by the sudden demise of her brother and would tear each time Mrs C broke down in the clinic. Mrs C was started on Sertraline, an antidepressant, but had to be discontinued on Donepezil as she was observed to be more irritable and agitated on the days when she was served with donepezil. Her daughter eventually agreed for the referral for grief counselling about 4 months later when she noted her mother to be less distressed when

talking about her deceased son. However Mrs C was noted to be vague and less focused on the loss of her son. Her daughter observed that she had deteriorated in her self-care with worsening memory function. Her MMSE had dropped significantly by 5 points to 16/30 over about 6 months and the psychologist opined that she would not benefit from grief work. She was not so distressed during her consultations thereafter but would repeatedly complain to her psychiatrist about her daughter being single, much to her daughter's frustration.

#### Case 4

Mrs TKC is an 85 year old Chinese lady with mixed dementia (MMSE: 14/30) of moderate severity. She was noted to have memory deterioration for several years but her family was unable to convince her to go for screening. She only agreed to see a doctor after she developed painful gouty arthritis of her left elbow. Her family declined cognitive enhancers as Mrs TKC has a propensity for side-effects of medications. She was otherwise manageable. Her children brought her to the clinic for an earlier appointment when her husband was admitted for a stroke. Her husband was her main caregiver. They enjoyed a fairly cordial relationship. She was found to have disrupted sleep pattern at night during her husband's absence. Mrs TKC was able to relate that her husband was ill and hospitalized. She stated that she was not worried as he was already so old and might be better for him to 'go' so he need not suffer. She was not keen to visit her husband in the hospital and her children also felt that it might be too stressful for her. Her children highlighted that she seemed unhappy that they were spending more time with her husband in the hospital than with her at home. They were somewhat upset that she seemed more concerned about who would be attending to her needs when her husband was ill. Mrs TKC was seen again about a month later in the clinic and her family revealed that her husband had passed away about a week ago in the hospital. Mrs TKC was noted to have taken the news well. One of her daughters moved in to care for her and there was no worsening of her behaviour or function noted.

## Case 5

Mr F is an 86 year old Caucasian man with moderately severe Alzheimer's dementia (MMSE 12/30) and is a resident of a nursing home for several years. The care staff had consulted me on whether he should be told about his son's demise from a cardiac event. His family members were undecided as to whether he should attend the son's funeral. Further exploration revealed that Mr F can be easily agitated, demanding and difficult with care staff. A family conference ensued and it was decided that Mr F was still able to keep track of his visitors and that they would have to tell him the truth if he were to enquire about his son's absence. He was eventually told of the news and also attended the funeral. Upon his return from the home leave, he was noted to be quiet and withdrawn for the next few days. The nursing staff did not encounter any difficulties in his care and reported that he was back to his usual self about a week later.

### Unique Aspects of Bereavement and Grief in Dementia

There may be similarities in experiences of normal grief versus grief in dementia. Normal grief reactions of denial, anger, bargaining, depression and acceptance can be experienced in early dementia [15,16] following the death of a loved one, as demonstrated in Cases 2 and 3. PWD and their families can be supported through the stages of grief by society and other support systems [9,17].

Mrs CSL (Case 2), in her early stage of dementia, was able to move through the stages of grief and come to some acceptance. The bereavement did not significantly affect her cognitive function even after the death anniversary of her son. She was able to achieve some stability of her cognitive function with Donepezil.

Although PWD when bereaved, responded with sadness, sometimes despair, and mental and physical inactivity, as in Mr F (Case 5), seemingly nonreactions of mourning were noted to be much more common than those found among persons with normal intellectual ability [10]. Table 1 summarizes the demographic, clinical variables and phenomenology of bereavement distress of the case series.

	Case 1	Case 2	Case 3	Case 4	Case 5
Age (years)	88	72	69	85	86
Gender	Female	Female	Female	Female	Male
Ethnicity	Indian	Chinese	Indian	Chinese	Caucasian
Dementia type/ severity	Mixed dementia/moderate	Alzheimer's dementia/ early	Alzheimer's dementia/ early	Mixed dementia/moderate	Alzheimer's dementia/ moderate
carer	Niece	Daughters	Daughters	Daughters	Children
Loss	Husband	Son	Son	Husband	Son
Grief reaction of PWD	Initial appreciation but searching and delusional belief that husband is still alive	Crying and sadness with eventual acceptance	Crying with anger initially; substituted with daughter's single status and loss of role as grandmother	No crying or apparent sadness; upset daughters with 'sense of threat' and who to take care of her needs	Initial withdrawal with inactivity but was back to his usual self after a week
Awareness of loss	Not maintained	Maintained	Not maintained	Maintained	Maintained
Impact on cognition	Worsened cognition	No significant impact	Worsened cognition	No significant impact	No significant impact
Impact on BPSD	Exacerbation of symptoms	No significant impact	Worsened cognition	No significant impact	No significant impact

**Table 1:** Summary of demographics and phenomenology of bereavement distress.

#### Lack of awareness of the loss

For more severe stages of dementia, awareness of the loss may not always be possible. The process of grieving may be impaired by cognitive deficits and learning failure and the bereaved person may be stuck at an early stage of grief [18]. For Mrs P (Case 1) in her moderate stage of severity, is it a denial of her husband's death which may be protective or was it an inability to be cognitively and emotionally aware of her loss?

#### Complicated bereavement reactions

Mrs P was likely to have manifested pathological bereavement reactions with searching behaviour and denial of loss with depressive and anxiety states [19]. She had behaved appropriately to the loss initially but was unable to retrieve the memory of her husband's death subsequently. It was alluded to in Vennen's paper that the bereaved may have a constant delusion that the deceased person is still alive [12].

Adverse impact on behaviour and cognition: The adverse psychological impact of bereavement on the elderly population cannot be underestimated [20,21]. This may be particularly the case in those with pre-existing cognitive impairment. Mrs P clearly manifested worsening of her behavioural and psychological symptoms of dementia (BPSD). There may also be an obvious worsening of cognition as illustrated in Mrs C (Case 3).

Re-traumatization and the dilemma of whether to tell: Ethically, PWD have the right to grieve and mourn [18] but the experiencing of acute grief and distress multiple times with 're-traumatization' when the truth is revealed each time may be considered cruel and insensitive [12,22]. It may be understandable why some family members and care staff try to shield PWD from reality. There may be questions as to whether or not to tell, how to tell and how the revelation will impact on their psychological well-being as well as their caregivers, as depicted by Mr F (Case 5).

Multiple losses and confusion of current loss for earlier losses: Mrs C (Case 3) had experienced various losses in her past viz. loss of her spouse, roles and control of her life. The traumatic loss of her son was clearly devastating and took a toll on her cognition. She was unfortunately intolerant of the side-effects of the cognitive enhancers. The resulting marked decline in her cognitive functioning may have eased her pain and suffering as she became less aware and focused on the loss of her son. PWD may confuse their current loss for earlier losses [11]. Mrs C appeared to have substituted the loss of her son for the loss of her role as a mother-in-law or grandmother when she shifted her worries and concerns to her daughter's singlehood. This phenomenon of metaphone, when the metaphorical loss changes from being the loss of the son to the loss of an object, was described [23]. The understanding of this phenomenon is important for the caregiver to pause before dismissing the repeated themes of loss of other objects or roles. Mrs C's daughter was initially frustrated and distressed by the rather sudden switch of attention from the loss of the son to her still remaining single. Understanding the different grieving mechanisms of her mother with dementia, she was able to be more patient and supportive.

Caregivers' potential alienation of the PWD from the family's grief: Caregivers need to be prepared that the response of PWD to the loss is generally less predictable and may sometimes be hurtful to family members [23]. In Case 4, Mrs TKC was more concerned about who would be attending to her needs than her husband's deteriorating medical condition. Her response was perceived by her children to be selfish and hurting. This 'self-threat' was described by Howard et al. [20] to reflect the PWD's perception of a threat to the 'self' with a shift of focus from the loss of the loved one to a more personal loss. For Mrs TKC, the loss of her husband also reflected the loss of a caregiving parent for her children. She was unable to be a model of grief for her children [24] and this may further alienate her from other family members.

#### **Clinical Considerations and Recommendations**

#### Understanding the unpredictability of bereavement reactions

Cognitive impairment may interfere with coping with the difficult task of mourning, particularly in the case of older adults with multiple losses [22]. Cognitive deficits interfere with the normal mechanisms for grief processing and bereavement adaptation [25] but PWD can still experience grief and sadness. Their bereavement reactions may be unpredictable and they may present with worsening BPSD [10,26]. Some PWD may not have perception of the loss. We need to be sensitive and to reserve judgement if they do not seem to grieve their loss [22].

#### Appropriate use of psychotropic agents

The indiscrete use of psychotropic agents and physical restraints to manage such behavioural disturbances has been prevalent unfortunately [27]. Other than subjecting PWD to the risks of increase morbidity and mortality associated with the use of antipsychotic agents [28,29], there is also the question of whether we are depriving them of their right to mourn [23]. There is obviously a role for antidepressants for those with prominent depressive and anxiety symptoms [30]. However, pharmacological management should not be the sole approach to support PWD.

## Bereavement support for the PWD

There is little research on how PWD cope with loss and sparse literature is available to guide grief counselling for PWD [31]. In the Harvard Bereavement Study, it was shown that in the grieving process, the ability of the bereaved to form new attachments and social connections is crucial. This will be an apparent challenge for many PWD. Difficulties communicating their distress may preclude PWD participating in bereavement support groups. Interventions for the bereaved PWD will be aimed at facilitating and maximizing learning and providing a supportive environment [32]. Facilitating paced learning in grief therapy will depend on repetitions of acts involved in the grief process and are usually carried out in response to behavioral disturbance or prolonged distress [32]. Spaced retrieval (SR) is a technique that helps PWD (moderate severity) with the learning and recall of new information [31]. A new piece of information is recalled again and again, with progressively longer intervals in between to allow PWD to process the loss rather than simply re-experience it as new information. With limited evidence to guide practice currently, it is

important to understand the premorbid personality and previous coping styles of PWD and to experiment and observe what works best for each individual.

## Bereavement support for the family caregiver

Family caregivers grapple with their own losses as they attempt to understand and comfort their loved ones with dementia. They will invariably question whether they should break the bad news, adopting a protective stance with fears that PWD will not understand or remember. There will also be concerns that PWD will behave inappropriately at the funeral. Family members thus need to be made aware that the PWD may be denied the opportunity to grieve, which already is particularly difficult due to their cognitive deficits. Empathic explanations need to be given to carers that PWD should be supported to grieve by every possible means e.g. by attending the funeral, visiting the grave or columbarium or visual reinforcement with photographs [18]. However, it may also be necessary to educate family caregivers to remove cues and reminders if PWD has difficulty processing the loss

#### Ethical considerations for the professional caregiver

There are many ethical dilemmas in working with PWD. Professional caregivers need to recognize and respond to the PWD's fears and anxieties about their illness and issues of death [18,33]. Care staffs need to be wary about using PWD's cognitive impairment to excuse their own difficulties in dealing with PWD's feelings of anxieties and uncertainties during the period of bereavement. The intuitive response to reassure the PWD that the deceased will come to visit to alleviate their distress can create ethical dilemmas for the professional caregiver [34]. The overarching principle for the professional career would be to respect the PWD's right to know and to mourn. However, this does not equate thrusting the awareness of loss upon them. Sometimes failure to learn may protect a person from recognizing their loss [18]. The family members' psychological and emotional state during this stressful time needs to be considered. The fears of the relatives must be recognized as they may interfere with the facilitation of grief and management of the PWD. In situations where there is an intention to cover up by the family, care staff needs to be careful not to impose their values on the relatives and the PWD. The clinical lead of the team needs to be sensitive to the different value systems of the multidisciplinary team members and to avoid antagonizing the family members. Relatives can often accept the explanation that PWD need to be helped to grieve in every possible way, and that it may be important that they attend the funeral and visit the grave [18].

Another ethical issue was encountered in the case of Mrs P (Case 1) when her niece raised the question as to whether her cognitive enhancer, memantine, should be withdrawn. She was concerned that it may be keeping her cognitively aware of her loss and resulting in more grief and suffering. Is it justifiable to withdraw her cognitive enhancers with no possibility of any meaningful discussions with Mrs P herself? Her niece was not appointed Mrs P's donee or deputy under the Mental Capacity Act Singapore [35] then. Again there is the question of removing Mrs P's right to grieve and mourn. Some care staff interpreted her niece's request to be unethical and there was some tension when her niece visited. The situation warranted reflection and understanding from the care staff about how family members often grapple with the loss. Criticisms about the care and feelings of anger may be displaced into the clinical setting. The divergence of views on what is best may cause further conflicts between family and professional caregiver [36]. After much discussion with her niece and amongst care staff, it was decided that her memantine will be ceased. It was highlighted during staff meetings that the reason for stopping the medication was that it had resulted in her being too alert and agitated, a recognized side-effect of memantine [37] and not so that Mrs P's cognitive decline would be inadvertently hastened.

#### **Conclusions**

Rando [38] emphasises that loss of cognition should not be seen to mean loss of ability to experience emotion. PWD need to be approached differently when they experience bereavement and loss. If the grief response of the PWD is not sufficiently understandable in the context of the loss, there is the risk of them being inadvertently excluded from their family's cycle of grief. Professional and family caregivers need to assume that PWD are capable of grieving and if not, we then need to see how we can best support them and their loved ones in their grieving process.

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