The Parent They Knew and the “New” Parent:
Daughters’ Perceptions with Dementia of the Alzheimer Type

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Abstract: Psychosocial death is a significant dimension of the Dementia of the Alzheimer Type disease process but poorly studied. This paper explores three phases of psychosocial death that emerged from in-depth interviews with three daughters caring for a parent with this chronic illness. The phases discussed include 1) daughters creating a new relationship with their parent; 2) daughters grieving chronically throughout the illness; 3) daughters negotiating coherence between the parent that once was and the parent that exists now. Daughters’ narratives reveal that witnessing the deterioration of a mind was a burdensome grave learning process that encompassed many losses. These daughters lacked appropriate education and support. Future research in this area is required to develop strategies for informal caregivers that respond to this disease process.

Introduction

Understanding chronic dementia such as that of Dementia of the Alzheimer Type (DAT) demands recognition of its devastating consequences on individuals affected by this disease process, but equally demands recognition of its tremendous impacts on those who care for them (Albert & Drachman, 2000). I found in a previous study (Furlini, 1999) that despite trends in the literature demonstrating that caring for a person with DAT is stressful and difficult, little attention was paid to the lived experiences of informal caregivers, such as family members engaged with supporting them. The initial larger study that provided the framework for this paper captured the particular stories of three daughters who were in mid life that assumed a major supporting caregiving role in looking after a parent with DAT over a time that spanned from six to fifteen years.

One often crucial and overlooked aspect of this disease process that emerged from the original study was daughters’ lived experiences with the phenomenon of psychosocial death. The purpose of this paper will be to explore three phases related to psychosocial death that arose across the three daughters’ narratives meriting consideration. These three phases will include daughters’ processes creating a new relationship with their parent, secondly, of grieving perpetually throughout the illness, and lastly of negotiating coherence between the parent they knew and the “new” parent.

Review of the Literature

DAT disrupts the psychological and social fabric of persons affected by it as well as those around them. One of the most striking hidden complexities of the disease process maybe the experience of the loss of the person that once was. This disease process has been referred to as psychosocial death (Doka & Aber, 1989). Most forms of dementia such as that of DAT are chronic, and include a myriad of symptoms such as personality changes, disorientation, and behavioral manifestations (American Psychiatric Association, 1994). Persons affected by this
disease lose their ability to perform tasks of everyday living, as well as the ability to judge, reason, and communicate. The variant pathology of the disease process greatly influences how informal caregivers experience psychosocial death, but other important elements influence this experience as well.

Even in the early phases of the disease, there are changes and losses in relationships between informal caregivers and the person affected by DAT (Yale, 1991). Researchers (Collins, Liken, King, and Kokinakis, 1993) have reported that health care professionals are unable to recognize the losses in relationships that informal caregivers experience as a result of this disease process. The continued physical presence without a relationship or a changed one may be one of the most important aspects of informal caregivers’ experiences, but a review of the literature indicates that this issue remains mostly unexplored.

Researchers Bourgeois, Schultz, and Burgio, (1996), and Thompson and Briggs (2000) reviewed research on support and interventions for informal caregivers and concluded they demonstrated unclear and indeterminate results. Further, in most studies about informal caregivers the voices of these caregivers are omitted (Furlini, 1999). Thus, this suggests that researchers require a greater understanding of the interplay between informal caregivers and the DAT process. Studies by Ganzer and England (1994) and Collins, et al. (1993) have demonstrated the importance for health care professionals to attend to stories of family members who care for persons with DAT.

Daughters’ reflective stories were unique and shaped by the particular context of each daughter’s life. However, the common experience of psychosocial death cemented these stories together. My presence and personal caregiving history influenced the manner these women told me their stories, as well as the selection of the pieces they chose to tell (Furlini, 1999).

**Phases of Psychosocial Death**

The three phases of psychosocial death each stemmed from daughters’ inaccessibility to the parent that had existed prior to the illness. These phases were distinctive from one another, at times existed independently, and at times blended together in modulating, and varying forms. In the first phase daughters described the perceived losses in their relationships and how these relationships were continually reconstructed according to the nature and quality of the interaction between these women and their parents. The second phase refers to the chronic grieving processes these women endured accompanied by painful thoughts and emotions that ebbed and swelled in an ongoing process. Attempting to negotiate coherence is the third phase where daughters disclosed their culturally perceived ideologies about life, illness, and death that clashed with their realities of the disease process.

*Creating a new relationship with their parents.*

The human experience of loss of relationship between daughters and their ill parents was a central concern that emerged throughout the interviews. The connections that had defined the past relationship were continuously interrupted, and transformed, and unraveled. All three daughters described as frightening discerning between the effect of disease pathology and the preexisting character of the parent. These women engaged in a process of continually attempting to reconstruct the identities of their parents and the meaning of personhood.
The relational losses these daughters experienced corresponded to the unique context of the filial relationship that had existed prior to the illness. To appreciate the individuality of the losses some context of daughters’ prior filial relationship is provided. Lilliane, whose father was affected by DAT had a very close relationship with him. Sarah says that she perceived her relationship with her mother to be very close and described it as “enmeshed.” Marianna, on the other hand, did not have a close relationship with her father, and she had ambivalent and negative feelings about him.

Marianna’s prior relationship with her father was poor and difficult, and he had been uninvolved and emotionally unavailable to her as she grew up. He had deceived her mother, and treated her very badly during their marriage. Below Marianna described her experiences.

He was never there for me. What changed in my relationship now was I didn’t know him anymore, he was a different person. It’s very hard, very hard to express how this… how certain parts of his personality are so… highlighted, things just stand out more… and which I never saw in him before… and I never saw him helpless. He was always travelling, always did what he wanted to do, nobody stopped him. His personality changed so drastically that I couldn’t relate and I didn’t know if it was the real person. Then, there were things he used to say that make sense, you know, it was very confusing, very confusing. He calls my name sometimes, and he even said, “I love you,” when he never, never said this to me before. My mom says to him, “It’s too late, you should have said this before,” and I tell her he doesn’t understand. If I ask him, “How are you?” he says he’s fine, and I think, “you’re dying and you tell me you’re fine?” What kind of disease is this? I don’t even know what word to use. It’s overwhelming ... you tell me you’re fine? It just drives me crazy, I mean you don’t want to become crazy but you could easily. This new person that came from who knows where, telling me, pretending to be my dad because he looks like my dad, the face, the name... he’s telling me he cares for me, but he’s a stranger. I don’t know it just screws me up.

When Marrianna’s father told her he loved her, this contradicted her past losses in her filial relationship, and made her long for some resolution with him. She was constantly reminded that she was unable to connect with her father in the past and constantly reminded she could not connect with him in the present or in the future. The incongruity between Marianna’s losses in her past filial relationship, and her father’s continued physical presence, and his present verbalized expression of love together powerfully disturbed her. This aspect of the disease process magnified her losses and heightened her feelings of sadness and frustration.

Sarah described her loss in the relationship with her mother who had been obliged to raise Sarah and her sister without a father, and had struggled greatly to provide for them.

She had been really more than a mother, really, really a best friend, she was my confidant. I told her everything; there was nothing we couldn’t talk about. I lost my major support system in life. You know they say a person’s happiness is really dependant on their social network, on their support system, well, she was such a support for me personally, as a mother, as a friend, as a grandmother, she was phenomenal. When I felt my mother walk
into my house, my whole body relaxed. This woman could listen at nauseam to me, anytime of the day or night, she was there for me. I really lost… not to be ungrateful for having a husband or children, but I really felt like I lost half my life, like half my life. It’s horrible; it’s torture for nothing this disease. As far as I’m concerned, it doesn’t hold any meaning. The last six years of my mother’s life were not meaningful; she wasn’t able to share a thing. She just scared the hell out of herself and us. It’s changed so much of how I feel about life and about what life really is and what is truly meaningful in life, and it isn’t the physical presence … it’s the brain that makes the person present to us, that makes the relationship meaningful. It scared me so, and it’s changed the way I see life, it’s changed the way I see death. It’s a constant struggle, you don’t want your parent mistreated, but on the other side, you’re also struggling internally not wanting your parent to continue living this way. It’s important for others to be sensitized to the fact that they may be looking at it as a chronic illness but I am looking at it as a very slow and painful death and sometimes it’s just too painful. It’s too hard to go and visit someone who isn’t there. It’s the same thing as going to visit someone who’s out having tests, would you stay the whole time in the room if the patient wasn’t there? It looked like a bad imitation of my mother, and nobody was there, and all I could see in her eyes was horror, terror, fear, and confusion. It’s not like other diseases where even if they’re sick you can kiss them on the forehead and they feel safe knowing you’re around. There’s no reaching this person, and there is no consolation for her. I mean after a while you don’t want to visit a drowning person if you’re not going to be able to throw them a life raft.

Sarah tried to grasp at the meaning of the relationship that presently existed with her mother, and the tremendous pain this disease process had caused her.

Lillianne also experienced deep losses in her relationship with her father as a result of the disease’ destructive effects on her connection with her father. Her father had been a businessman and a scholar, and she felt his losses intensely.

The first loss I noticed was the loss of humor because we had shared the same sense of humor, and we used to, we used to not exactly banter, we used to sort of exchange things that we would know would please the other and make the other laugh. It was a very important loss because it was like a really intimate way of relating to one another. …As his daughter he was no longer the parent that you could seek advice from, and he could no longer play the role of parenting.

I remember during the illness we had this whole conversation and he thought I was this so and so person, who didn’t know his daughter. My father hadn’t recognized me, so he started to talk to me about his daughter Lillianne. So, he started to talk about how Lillianne was such a wonderful person, and he went on, and said some really nice things about me. It was really funny. And it was funny, but it was not funny. It was hair-raising because he didn’t know who I was. I couldn’t lean on him, but I felt this tremendous love for him. It’s very sad, terribly sad, I mean it’s this thing about mourning before the person dies. It’s definitely true, well true for me.
Lillianne’s experience served as a double-edged sword to remind her how much her father loved her, yet unable to engage in a reciprocal relationship with him.

Another disconcerting aspect of this disease process was parents’ fleeting moments of lucidity. Mirages of daughters’ parents past selves that surfaced and disappeared suddenly set these daughters up to destabilize them further. Daughters constantly vacillated precariously between feeling connected and destabilize with their parents. Despite the long duration of the illness these daughters did not reach a stage of acceptance of the losses in the relationship with their parents.

**Grieving Perpetually about the “Parent Lost.”**

These women tried to guard themselves against divulging their upsetting experiences during their interviews by on occasion deflecting questions about their relationships and feelings associated with their parents. Describing their experiences of psychosocial death was elusive, and laborious for them. Jones and Martinson (1992) state that the continued physical presence of a person affected by DAT may generate acute emotional dissonance for their caregivers. These women stated that they had repressed many of the emotions that accompanied their grief and they felt very isolated. These daughters’ lack of understanding about psychosocial death, and their accompanying losses were intensified by professionals’ lack of understanding about this issue. They often felt labeled as hysterical, untrustworthy, or mentally unstable, whereas their grief remained invisible, unacknowledged and unaddressed. Meagher (1989) states that when an individual is deprived of an opportunity to perform the tasks of grief work, the grief becomes disenfranchised.

Sarah gave some poignant insights into her feelings of grief and lack of closure.

One of the many horrible things about this disease is that it takes such a long time, … it happens so slowly. It’s so slow, and it takes so many years that by the time it’s over you’re robbed of even treasuring your memories because the memories you need to treasure are from so long ago, and so buried, and you’ve spent at least 10-15 years not wanting to think of them because you couldn’t bear what’s happening to your parent now. So when it’s over, you cannot grieve in a way that could be healing. There was no vacation from grief. Because you’re left with a shell, it’s like a photograph of somebody. You’re left with a photograph and in the end of Alzheimer’s, even the photograph disintegrates, and doesn’t even physically resemble that person anymore. So you are robbed of everything in the most slow, painful way you could possibly imagine. I mean just horrible, horrible, just to have to stand back and watch somebody you love being tortured, it’s double torture. The affect is gone, the facial expression is gone, the eyes are dead and for anyone who’s seeing someone dead with their eyes open that’s what it looks like. There’s nothing you can do and nobody wants to listen and there is no help and it can go on forever. I think what I’ve learned most of all was that really what you’re dealing with twenty-four hours a day, seven days a week without any vacation is grief. Nobody prepares you for that.

As DAT went unabated on for such extended lengths of time, daughters’ prolonged
unrelenting grief compounded over time, and they engaged in chronic grieving. For these women, their parents’ physical presence set up expectations that they would have opportunities to interact with their parents. Instead, their interactions with their parents’ were distorted, and their parents’ were not able to answer their needs. Collins et al. (1993) stress a need for early recognition of the grief experiences of informal caregivers of persons with dementia, and that the issues these caregivers confront are unique.

Negotiating Coherence between the parent daughters knew and the “new” parent.

Psychosocial death was a concept that was alien to these daughters yet evident in each of their lived experiences. As they questioned their personal belief and value systems, they asked themselves what defined a human being. These daughters reevaluated their personal expectations about the definition of life, about what it meant to be ill, and about the dying process. This disease process damaged daughters’ sense of coherence about their lives, and became a threat to their well being.

Culturally constructed definitions about human beings, illness, and death neglect the psychosocial death experience. As persons affected by DAT are slowly detaching from their psychic entities, it is not clear how society redefines or views the individual. DAT challenges cultural assumptions and expectations about how life’s processes about life, illness, and death will evolve. Ultimately, these cultural assumptions, expectations, and attitudes clashed with these daughters’ perceptions of the parent under their care, and their lived caregiving experiences associated with their parents’ disease. Further, other than the influences of the larger societal contexts in which they lived, each of these daughters’ were influenced by the unique cultural contexts specific to their situation and background.

Conclusion

The three phases of psychosocial death encompassed daughters’ direct and indirect losses, emotional outcomes, and larger societal issues. For researchers and professionals these phases present challenges and alternate possibilities for creating and offering education and support in regard to informal caregivers. These daughters related how they unconsciously deliberated new relationships with their ill parents throughout the course of the illness while being simultaneously unaware of the losses bound up with this disease process. Their experiences of loss were singularly about context because of the uniqueness of their unraveling relationships and disintegrating connections. A goal for those who attend to informal caregivers must be to recognize how this disease process insidiously and adversely affects relationships and past connections.

These women were in a state of constant mourning, and grieved chronically. The harmful cumulative effects of this ever-progressing disease process had detrimental effects on these women whose the right to grieve was hindered. Researchers and health care professionals who interact with informal caregivers may perceive informal caregivers as dysfunctional rather than as persons with little knowledge and support for learning to respond effectively and cope with distress and grief. Grief counseling education should be promoted for professionals and researchers that attend to these caregivers.

Differentiating between the illness and the person that existed prior to the illness was a
process that was difficult to label and ruptured daughters’ sense of coherence about their lives. Working out revised expectations about life, illness, and death processes was very difficult due to the nature of the disease process. Cultural and societal awareness of the psychosocial type of death experience is warranted. This can be accomplished by learning from informal caregivers’ perspectives to take into account both the larger and specific cultural frameworks in which they live.

From what can be garnered from these daughters’ testimonies is that they entered into a burdensome, educational and emotional learning experience. These daughters’ narratives provide access and necessary insight to uncovering and understanding the uniqueness and elusive qualities of these caregivers’ experiences that outsiders do not have. Researchers advocate including narrative work into research and practice contexts to educate professionals on how to intervene (Ellis & Bochner, 2000, Ganzer & England, 1994). Thus, as has been presented, narratives are an effective tool in research and clinical practice for developing strategies for informal caregivers that provide effective education and support programs. Ultimately, by addressing the needs and perceptions of informal caregivers with respect to losses corresponding to psychosocial death, societal awareness and inclusiveness of this type of death experience is advanced.

References
Disenfranchised grief (pp. 313-328). Toronto, Ont: Lexington Books.