Moral Injury in Care Partners of People with Dementia: A Psychodynamic Perspective

I'm here to talk about moral injury in the care partners of people living with dementia. My approach to this subject is influenced by my lived experience as a carer for my dad, who has mild to moderate Alzheimer's Disease, and my work as an adult psychodynamic psychotherapist. Part of my work is in Salford and Trafford Age UK, where we have a small team offering supportive counselling to family carers of care partners of people with dementia. Our goal as a service is to stay with care partners on their emotional journey, as long as they want us to, as opposed to offering a time-limited intervention. The service model is based on the New York University Caregiver Intervention that was established by Mary Mittelman in the late 1990s.

My presentation will be in 4 parts. I'll say a few words about (1) dementia, (2) moral injury from a psychodynamic perspective and how it relates to the notion of the ego ideal, (3) offer a couple of composite case studies as examples and (4) sum up by situating the position of care partners of PWD within a broader societal context.

Dementia is an umbrella term for a neuro-degenerative syndrome that over time causes increasingly severe intellectual and sensory impairment. It is the largest contributor to disability and the need for care among older adults and it has now overtaken heart disease as the leading cause of death in the UK. In benign relational environments in which their needs are met, people with dementia can live well despite their disabilities, but in suboptimal and unsafe environments, their vulnerabilities are hugely exacerbated.

Informal care partners provide most of the care for people with mild or moderate dementia who are living at home. Caring for someone with dementia can be rewarding, but it is often very challenging. For example, when a spouse or child is recast as a parent due to the person with dementia's neurological decline, or when the person with dementia becomes exceptionally confused towards the end of the day, a phenomena, known as sundowning. The protracted and progressive nature of dementia can lead to cumulative moral distress, as care partners can find themselves in increasingly turbulent and morally challenging situations. It is not easy to feel like a good person when we encounter another person's increasing or absolute dependency. 40% of family carers of people with dementia have clinically significant depression or anxiety. This is a higher level of mental ill-health than family members caring for people with other chronic conditions (Hopkinson et al. 2019). Like military veterans and others exposed to trauma, they are affected by moral injury. They carry a moral burden that almost everybody can relate to, but few seem to really see or understand.

A Psychodynamic Perspective

From a psychodynamic perspective, a crucial element of a care partner's sense of moral injury is their relationship to their ego ideal, the dream or vision of how they want to be. Our ego ideal incorporates the internalised set of ideals and aspirations that guide our behaviour towards what we perceive as being the right thing to do, both at a conscious and unconscious level. From the point of view of virtue ethics, we could call this our salient concern. For example, we may want to be someone who always tells the truth and keeps our promises. This is an ideal that can be a source of pride, or alternatively, it can be a source of deep shame if we find ourselves speaking unpalatable truths or transgressing the ideal, even when we have the intention to do so. **A healthy ego ideal evolves over the course of life as we gain new experiences and mature in the ability to adjust to challenging situations** (Sedlak, 2019). However, when there is a significant gap between our ideals and the reality of the way we live our lives, we can respond in self-critical and self-destructive ways. As care partners unconsciously defend themselves against feelings of guilt and self-reproach for their perceived moral failings, shame and suppressed grievances can foster a state of mind, which has a quality of moral masochism, as they hold on with a martyr-like identification to their caring role. Stefano Bolognini former President of the International Psychoanalytic Association has suggested that these narcissistic tendencies may be being fuelled by the individualist ideologies that pervade modern consumerist cultures. Increasing numbers of the patients he works with have difficulty and reluctance in accepting their basic dependence on others. The belief that we can do it all by ourselves is a myth. Like the myths of institutional infallibility and the idea that it's all our fault that Aaron Fuller and Christopher Bowen talked about yesterday, the belief that we can do it all by ourselves is a myth that may cause us to come crashing down when we are confronted by the vagaries of dementia.

Vignette 1: The critical parent

Fiona cares for her husband, Dave, who has mild to moderate Alzheimer's. She recognises Dave's desire to maintain his independence and the frustration he feels when she curtails his independence. But sometimes, she has no option but to intervene by restricting his autonomy. For example, by hiding the ladders to prevent him going on to the garage roof. Dave's aggressive response when he finds the ladders bears scant resemblance to the man, she has shared her married life with. Fiona's distress and anxiety stir up echoes of her father.

<<He was a bully, very controlling.>>

Throughout their long relationship, Dave and Fiona have rarely fallen out, but the ego ideal of them being the 'perfect couple' that has sustained her throughout her adult life is being eroded. Emotional wounds are reopening, as Fiona is racked by feelings of guilt as she considers whether the point has been reached where Dave may need to move to a care home. This is a life-altering decision which they have never seriously discussed.

<<I've always told him that putting him into a care home is absolutely out of the question. He's my world, without him I'd be in no man's land.>>

Vignette 2 Hidden resentments

Bodhi’s mum has moderately severe vascular dementia. She diligently cares for her mum with apparent good humour, reassuring her counsellor that, <<*Things are not too bad.*>> Her resentments break through, however, when Bodhi speaks of an incident that occurred when she took her mum out to a cafe.

<< *Outside the café, she was hitting, grabbing hold of me, and pinching. I said, Stop it now. This woman was standing by the window waving her finger at me. I said, ‘Excuse me. Have you got a problem? She’s got dementia.’*>>

Outwardly, Bodhi bears her sense of moral injury with quiet fortitude, sustained by gratitude for what her mum has given her and a desire to do what she feels is right, which aligns with her Hindu heritage, in which caring for one’s elderly parents is an important value. As the only female sibling in the family, Bodhi has taken on the ego ideal of being the essential caregiver in the family unit. This ideal has contributed to her sense of being a worthy person. However, the cruel impact of losing the warm and supportive mum that she had loved and adjusting to her mum’s almost total dependency upon her is a heavy emotional load to carry. Bodhi’s calm exterior belies feelings of protest that are difficult to voice and for which there are no easy answers. Bodhi feels especially resentful towards her four brothers, who say that they value what she does for her mum but lend very little to practical support themselves.

Vignette 3 Betrayal

Unlike Bodhi, Declan has no extended family network. He is a reclusive man in his 50s who lives with his mum, Dorothy, who has moderate to severe Lewy Body dementia. Dorothy spends most of her time in bed. Declan discloses to his counsellor that his problematic drinking has escalated and that he has been ignoring his mum's calls for help, by turning up his music so that he cannot hear her. There is a regressive aspect to Declan's no-entry defence, as he externalises his anger.

<<*We've had our gas and electric bills pushed up to £250 / month. And we've got to get a roofer in to fix a leak in the bathroom. It's one bloody thing after another.*>>

Declan's capacity to care has reached breaking point. His ego is too fragile to bear the hatred he feels toward her and the situation in which he finds himself. He is consumed by a sense of shame for not being the person he once was—or believes he ought to be. His excessive drinking and cutting himself off from his mum by playing his music are a means of dissociating from his intense ambivalence. His counsellor lets Declan know that she must follow safeguarding procedures and inform her line manager and adult social services of her concerns, but she knows that he will experience this as a betrayal.

Discussion

Much of the focus on moral injury focuses on the impact catastrophic decisions and events. These vignettes point to something that operates on a more day to day level, the powerful transference that care partners of people with dementia can be exposed to and how hard it can be to tolerate the absolute dependence of others (Winnicott, 1949). The intense and complex emotional attachments involved can make moral injury in care partners of people with dementia, very intimate and self-directed, as they contribute to internalized blame and self-reproach. While their experiences were all unique, recurring themes emerge in the vignettes—feelings of guilt, shame, resentment, and emotional exhaustion— stemming from the tension between the care partners' ego ideals and the realities of caregiving. For Fiona and Bodhi, moral injury involved feelings of acute distress about failing to meet their caregiving ideals. However, they continued to sustain the emotional resources that were necessary to maintain their caregiving roles and find meaning in their filial relationships. For Declan, the situation was more extreme. His story clearly highlights how moral injury can push a care partner of someone with dementia towards detachment and neglect.

The containing presence of a counsellor who can lend valuable support, may reduce their sense of isolation and bolster the emotional resources of care partners of people with dementia. Three key aspects of this support can be identified.

Active Listening – Care partners of people with dementia have a need to feel heard and understood. They often have a craving for their experience to be validated. For many, social isolation has a significant impact on their mental health. Their relationships can feel increasingly onesided. And friends and family who are aware of their struggles are often reluctant to visit, as they feel awkward or unsure of how to interact with the person with dementia. Progress has been made in destigmatising dementia, but there is still a long way to go.

Emotional Holding – It is important that care partners are held themselves in an emotional sense if they are to contain the fragmentation, persecutory states of mind and complex grief associated with dementia. This grief can take the forms of anticipatory grief, ambiguous loss, disenfranchised grief and dying with dementia (McEvoy et al., 2024). Ambiguous loss is particularly difficult to tolerate and resists closure due to the paradox of the fluctuating presence and absence of the loved one with dementia, which is unstable over time (Boss, 1999).

Symbolic Linking – One of the most destructive aspects of emotional loss is the disruptive impact it has upon the ability to link the present with the past and to envisage a meaningful future. Care partners who are exhausted and emotionally overwhelmed are often filled with a crushing sense of self-reproach as they see no future beyond the present. They can feel incredibly guilty about wishing the person with dementia's life away. Within this context, symbolic linking can help change their narrative as it opens up space for mourning and more mundane but equally important aspect of practical problem solving.

Concluding Remarks

David Smith was asking what the mechanisms are for the repair of moral injury. For care partners of people with dementia, this may be the provision of adequate assistance and a transitional space that affords the capacity for self-reflection before it is erased by the scale of their moral injury. It would be a mistake to look at the impact of moral injury on care partners in isolation. The internalized expectations that contribute to moral injury intersect with familial conflicts and broader sources of epistemic injustice. In the UK, The Care Act of 2014 entitles carers to an assessment of their needs, but for all too many carers, adequate support is not forthcoming. People with dementia are diagnosed in memory clinics, where their care needs are assessed—but they are frequently left to manage on their own until a crisis occurs. Many care partners of people with dementia also live in relative poverty. Barriers to accessing support through systems such as direct payments for funding social care can create differential gradients where those in need of the most support get the least. Their challenges are frequently relegated to the private sphere and rendered invisible (Muller, 2019). Counselling is an invaluable source of support for some, but ultimately, addressing moral injury requires more than individual psychological interventions; it also requires a substantial strengthening of the communal social support systems. If this is to happen, there may need to be a broader transformation in how we value and resource caregiving work.

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