

GUEST EDITORIAL

Suffering with dementia: the other side of “living well”

Introduction

In this editorial, we challenge the current understanding of “Living Well with Dementia.” Such discourse introduces the possibility of not living well with the condition or even of “living badly with dementia.” Numerous words might be relevant here – grief, pain, anguish, depression – but in this editorial we consciously use the word “suffering.” This term is used for two reasons; one, because it captures the attributes of other more limited words, and, two because the language of “suffering” is contentious, making it suitable for debate. We speak of suffering, not to deny the positive aspects of life with dementia or to concentrate just on the negative, but to redress the balance that is disturbed by a relentlessly positive view of living with the condition. Our aim is to promote a more realistic understanding of the dementia experience, one based on actualities and evidence rather than presumption and sentiment.

Defining suffering

Suffering is hard to define and acknowledge because it is an intensely personal experience and thus varies hugely. Health sociologists define suffering as “the unspeakable, as opposed to what can be spoken; it remains in darkness, eluding illumination” (Frank, 2001, p. 245). “It is an experience common to us all, yet can only be known uniquely as our own” (Wilkinson, 2005). For this editorial, it is important to note that the language of suffering is different from that of “sufferer,” see [Box 1](#).

Causes of suffering for people with dementia

People can and do live well with dementia (DeBoer *et al.*, 2007; Department of Health, 2013). However, this portrays only a limited picture. There are some very low points in everyone’s journey through dementia; for instance, the impact of receiving a diagnosis, and the gradual loss of capacity that follows. Like any life-limiting condition, having dementia will involve suffering on at least some occasions. Some of this will be due to the nature of the illness where moments of

Box 1 Distinguishing between “dementia sufferers” and “dementia suffering”

Speaking of “suffering” does not mean that we condone use of the term “dementia sufferer”. Using the phrase “dementia sufferer” does nothing more than label and offend people, as Keith Oliver explains “I don’t see myself as a sufferer but I do suffer from dementia. I find dementia extremely challenging and frustrating but I am not a sufferer because if I become a sufferer that’s how I’m defined and that’s how I’m treated”. Obviously, it is not right to define a person simply by the diagnosis they have, whatever condition they might have.

realization or insight can lead to feelings of despair or fear. In other circumstances, gaps in memory or misperceptions may lead to frightening experiences. There may be a general sense of life being out of control or at least being regulated by others. This may be distressing and cause suffering.

Other forms of suffering may not necessarily result directly from dementia itself but stem from the quality of care or services that are provided and how caregivers themselves deal with the effects of dementia. For example, people with dementia may feel isolated, depressed or marginalized, as their social networks shrink due to the fear and stigma that surrounds this condition (Alzheimer’s Society, 2013a). In hospitals and care homes, people with dementia may suffer from terrible boredom, lack of access to nature and the outdoors, lack of pain relief, malnourishment, dehydration, abuse or mistreatment (Care Quality Commission, 2013; Alzheimer’s Society, 2013b; Alzheimer’s Disease International, 2014; Peisah *et al.*, 2014). Some individuals diagnosed with dementia may even choose to take their own lives because the future looks too bleak (Wilkinson, 2015). This is what happened to Lore Windemuth-Wolfson’s husband. All of which suggests that people with dementia are at risk of social suffering – that is, because of the social climate and circumstances in which people are treated by others, individuals begin to feel “superfluous” (Wilkinson, 2005).

Recognizing dementia suffering

The current policy emphasis in England and other countries on living well with dementia has been accompanied by a shift in research away from a focus on loss to one of maintaining and promoting personhood (see, for example, Hyden *et al.*, 2014). But in this attempt to forge a positive approach to a terminal disease, there is a risk that the suffering, especially the social suffering, experienced by people with dementia is denied. Certainly in David Cameron's Prime Minister's Challenge on Dementia, the emphasis is on the "light" at the end of the tunnel rather than the tunnel itself; the possibility that people living with dementia suffer is rarely acknowledged (Department of Health, 2013). Yet, as previously indicated, research on quality of care, nutrition and pain management indicate large amounts of suffering for people living with dementia, some of it at the hands of health and social care professionals.

There are several reasons why it is important to recognize dementia suffering. First, from a legal perspective, only when the substantial and long-term *negative* effects of the condition are recognized, can a person with dementia establish that they are disabled, as defined by the Equality Act 2010 (our emphasis). This is particularly important for people with dementia still in employment, as reasonable adjustments only have to be made for people legally defined as disabled (Edgeell *et al.*, 2016). Second, humanitarily, we must recognize and acknowledge that people with dementia and their families are suffering to varying degrees, in different ways, on different levels physically, emotionally, and existentially. For example, reflecting on when he was first diagnosed, for Keith Oliver accepting the condition was a very important part of alleviating some of the anguish a diagnosis of dementia brings with it. Like he says:

I knew from very early on that there was no cure, I knew very early on that it was going to be challenging and if I looked too far ahead I was going to get frightened. So I wanted to take some kind of control over this disease. I wanted to do things like Lasting Power of Attorney and I thought it was important that we did my wife's as well. So it was a shared thing...However, as time has moved on the nature of suffering has changed it has become more emotional...I'm scared of losing support and that becomes frustrating.

Understanding and recognizing dementia suffering is important then, as it not only acknowledges the distress an individual and family are experiencing, but also calls for change and social action.

Ways to alleviate suffering

By acknowledging social suffering in the dementia community, questions such as follows are raised about what can be done to alleviate it: What mechanisms are in place to allay peoples' fears? What opportunities do people with dementia and their families have to express emotional pain and despair, or suicidal thoughts? And what alternative forms of therapy or support might help? One way to begin to alleviate suffering is to acknowledge the pressure a heavy accent in policy and practice on "living well with dementia" can place on individuals and families. As Keith Oliver reflects, "this living well with dementia is very important and it is something we aspire to...but it's not easy. It can become almost a rod for your own back that you feel you're failing to live well with dementia therefore you're a failure." Thus, we suggest, that while the discourse of "living well" is important, the term itself and some of its specific meanings can adversely affect well-being.

Second, healthcare professionals need to have an understanding that dementia is more than memory difficulties; there can be sensory challenges and difficulties when interacting with others, about which something can be done (Jones *et al.*, 2006). As Keith Oliver remarks, "where I feel supported, valued and included, and able to relate to people and people relating to me; I go away from that feeling well." Clearly, Kitwood's ideas about valuing and getting to know the person are still very salient (Kitwood, 1997). Therefore, to gain a clearer picture of what dementia is and how it affects the lives of those living with it, we need to take more time to listen to people with dementia and their families. Specifically, we need to find out how and whether people are in pain or distress and what support they need. For it is only in a space where multiple perspectives are acknowledged that people can speak of the full range of experiences – including emotional, physical, existential, and social pain.

Conclusion

The current policy emphasis on "living well with dementia" is welcome and long overdue, but it denies suffering. Furthermore, it implies that no further thinking or resourcing is required because all we need to do is aspire or hope for people to "live well" with dementia. Insights from the sociology of suffering literature remind us that all illnesses inevitably involve suffering, and that we must work towards recognizing, understanding, and alleviating this.

Conflict of interest

None.

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