The struggle of apathy in dementia

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Most people will recognise a sense of apathy within them, at some point during their lives, and this may present to a greater or lesser extent depending on the individual and the context. When people are asked about what apathy is, what it means, or how it might feel, generally they can provide an insight, suggesting it is something broadly universal to the human experience. We might consider apathy to be a lack of motivation, a feeling of not being bothered, or a desire to do something coupled completely with a desire not to do that same thing. For most people though, apathy can be overcome, and it represents a fleeting problem that does not impact on day-to-day life. For people with dementia, apathy is an important problem because it is recognised anecdotally, clinically and in research to be common (Selbæk et al., 2013; Zhao et al., 2016), persistent (van der Linde et al., 2017), and difficult to live with for both the person with dementia and those close to them (Feast et al., 2016). Follow-up studies suggest that apathy is associated with worse health and social outcomes (Breitve et al., 2018).

Apathy is already recognised clinically, but typically under another guise as a symptom of something else rather than in its own right. It is strongly associated with disorders of mood and is an important symptom of depression. However, apathy can occur without depression (and vice versa), and in dementia apathy and dementia are poorly correlated (Levy et al., 1998) and have different trajectories with different biomarker patterns over time (Banning et al., 2021), so they are clearly different entities. Apathy is also closely related with anosognosia and lack of insight, with more severe apathy being associated with less awareness into a person's cognitive and functional limitations (Horning et al., 2014). This is observed even in early dementia (Azocar et al, 2021), and is most marked in people with frontotemporal dementia or Alzheimer's disease with frontal lobar involvement (Tondelli et al, 2021).

Apathy has become an important topic in dementia research. The number of published papers with keywords apathy and dementia has grown exponentially over the last three decades, with over 2000 papers listed under these two headings in PubMed, growing from just one paper in 1987 to over 150 in 2020. Apathy is considered to be an outcome of neurological changes, and imaging research shows a relationship with various neural processes and an association with pathology in certain brain regions, such as the dorsal anterior cingulate cortex and the ventral striatum (LeHeron et al., 2018), which is consistent across different disorders associated with apathy. This has led to a predominantly biological approach to apathy research and exploration potential pharmacological remedies, with limited success to date (Harrison et al., 2016; Ruthirakuhan et al., 2018), although apathy remains an important target for future drug trials (Mortby et al., 2021). Several scales to measure the severity of apathy are available, for example the Apathy Evaluation Scale (Marin et al., 1991), the Lille Apathy Rating Scale (LARS) (Sockeel et al., 2006) and the brief Dimensional Apathy Scale (Radakovic et al., 2020).

However, there is more to apathy than simply neurological changes or mood problems. Apathy does not happen in a vacuum, and consequently considering the role of psychological, social, and environmental factors is important to provide a holistic understanding. Perhaps not surprisingly, not much work has been done on the subjective experience of having apathy. What does it feel like? What factors act as barriers and facilitators? What do carers experience and how do they try to deal with caring for someone with dementia and apathy? What can we learn that will help with improving practice and care?

Our recent work (Baber et al., 2021; Chang et al., 2021) involved a qualitative study to explore these questions. Semi-structured interviews with six people with dementia and six carers (five men and one woman with mild to moderate dementia, and their spouses) were conducted separately to allow for independent accounts. In order to capture the everyday experience of apathy, all participants were recruited through non-clinical contacts, such as community support groups, and were living at home. The participants were recruited as volunteers, not as a clinic sample. They were not selected as having severe apathy, but it was evident from the interviews that at least some degree of apathy was experienced by all of them. Quantitative measures showed a mild to moderate level of apathy across the participants. An interpretative phenomenological approach was taken to analyse the data to explore and develop an account of how the participants made sense of their experience of apathy, and what they thought was happening to themselves or their spouses.

Analysis of the interviews with people with dementia identified four themes, and three themes were identified from the interviews with carers (see Table 1). The analyses were completed separately for the two groups of participants in order to retain independent voices and avoid positioning either group of participants as ‘correct ’or not, and are published elsewhere (Baber et al., 2021; Chang et al., 2021). This editorial positions the findings next to each other for the first time, and demonstrates how the different insights complement each other.

Firstly, our findings suggest that there is a strong emotional element to the experience of apathy for both parties. People with dementia spoke of a fear of failure, aware that their present did not quite match up to their past, and attributes such as hobbies that make them who they are no longer felt part of their identity, leading to a loss in confidence. This perhaps stopped our participants with dementia from wanting to undertake activities and outings in a bid to maintain their sense of self as a constant amongst the experience of cognitive and functional changes. This is consistent with previously published literature, which has described, for example, the existential threat to the person’s self-esteem (Cheston et al., 2015) and how people with dementia attempt to present a preserved, rather than damaged, image of themselves to the world (Birt et al., 2020). We did not specifically examine the topic of insight, but it was clear that all the participants had some awareness of the limitations in their levels of motivation and activity, even if they underestimated the degree of impairment compared with the views of their carers. This is consistent with existing literature around insight and early dementia (Azocar et al., 2021).

Carers experienced feelings of guilt around employing strategies and deception to help their spouse engage with activities congruent to their sense of self, knowing that it was in their spouses ’best interests but feeling uneasy at having to make use of such means. A tension existed between the background struggle experienced by people with dementia, invisible to others but representing a strong inner yearning to do something, and frustration felt by carers in the face of an increasing need to pick up new roles, tasks, and provide a great deal of encouragement to their spouses when presented with avoidance behaviour and changes in abilities.

However, positive elements for both groups were clearly expressed. People with dementia reflected on what kept them going, including maintaining hobbies and habits, and how other people helped to involve in activities and choices. Carers spoke of constantly being on the lookout for activities or opportunities to reignite the ‘spark ’in their spouses, but reflected on the importance of time for themselves and support networks to talk to.

Taken together, these findings suggest that despite the behaviour of apathy, people with dementia have a tremendous need and desire to connect with others, but this is made extremely challenging by an unremitting, unseen internal struggle that can hinder them from initiating or continuing with activities or connections. One participant described how, despite the apparently serene progress of a swan across a lake, the bird’s feet are paddling frantically under the water to keep it afloat.

On the other side, carers use a variety of strategies to connect with and maintain a level of activity for their spouses or other family members, and this is shrouded in a concern that they may be acting malevolently through bypassing traditional social negotiations or explicit consent. In consequence, this may lead to a gap in communication, where both parties perhaps do not perceive how hard the other is trying, and people with dementia thoroughly value their spouses ’efforts to get them to do things even if they do not express it. If carers only knew how much their strategies were welcomed it might release them from the burden of guilt created by the belief that they had tricked their spouses into participating in activities that in fact they enjoy.

We conclude that not only is apathy worthy of more attention in research and practice, but also that carers and people with dementia would benefit from more information and education about the importance of apathy and how to approach it effectively. As a society we are now familiar with the role of memory in dementia, and approach it formally through assessments, and informally through support services such as memory cafes. The same conversation around apathy is yet to exist, yet our findings suggest that the experience of apathy is just as pervasive and impactful as is memory impairment. The public message about memory and dementia has certainly been successful but probably now more attention on non-memory symptoms is needed (Aldus et al., 2019).

In addition, apathy is not simply a lost cause as there is evidence that psychosocial interventions can be beneficial (Theleritis et al., 2018), which is mirrored in several anecdotal comments from our own study. Therefore, we advocate for a greater recognition of this important and currently overlooked phenomenon by opening up the conversation and calling for development of measures that capture the experience more holistically, so that support might be provided. It is perhaps time that our research and practice community put aside our own apathy on this topic and got to work.

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Table 1: comparison of experience of apathy themes from interviews with people with dementia and their spouse carers

(Data from Baber et al. (2021) and Chang et al. (2021))

People with dementia		**Carers**	
Themes	**Subthemes**	**Themes**	**Subthemes**
Losing one's sense of self	Juxtaposition of the past and present self	**Balancing conflicting emotions**	Feelings of guilt
	Loss of interest in hobbies and activities		Endurance
	Loss of motivation		Frustration with lack of insight
	Loss of confidence		
Feeling like a burden	Fear of failure	**New roles imposed by caring**	Additional responsibilities
	Avoidance behaviour		Reigniting "the spark" by promoting interests
	Pessimism		
Hindered by invisible obstacles	Background struggle	**Having a life of one's own**	Pursuing own hobbies and interests
	Disruptive incidents		Finding people to talk to
	Stigma		
What keeps me going	Desire to help		
	Maximising involvement		
	Hobbies		
	Retention of habits		