

The experience of apathy in dementia: A qualitative study

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Abstract

Background: The presence of apathy is associated with less favourable outcomes in dementia, including more rapid functional and cognitive decline, greater disease severity and increased mortality. We aimed to explore and gain an understanding into how people with dementia experience apathy, and consequently suggest effective interventions to help them and their carers.

Method: 12 participants (6 dyads of 6 people with dementia and their family carers) were recruited from memory cafés, social groups, seminars and Patient and Public Involvement (PPI) meetings. People with dementia and their carers were interviewed separately and simultaneously. Quantitative data was collected using the following validated scales: Apathy Evaluation Scale (AES), short Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), Montreal Cognitive Assessment (MOCA), Cornell Scale for Depression in Dementia (CSSD) and Hospital Anxiety and Depression (HAD). The interviews were semi-structured, focusing on the subjective interpretation of apathy and impact on behaviour, habits, hobbies, relationships, mood and activities of daily living. Interviews were recorded and transcribed and analysed using interpretative phenomenological analysis (IPA) which generated codes and patterns, which were collated into themes.

Result: The participants with dementia had mild to moderate degrees of cognitive impairment, with a range between 9-22 (out of 30) on the MOCA. They reported moderate levels of apathy on the AES.

Four superordinate themes were identified, three of which highlighted the challenging aspects of apathy: *"Losing one's sense of self"*; *"Feeling like a burden"* and *"Hindered by invisible obstacles"*. One theme: *"What keeps me going"*, described the positive aspects of the individuals' efforts to overcome apathy and remain connected with the world and people around them.

Conclusion: This study is the first to illustrate and conceptualise the subjective experience of apathy in dementia, portraying it as a more complex and active phenomenon than the traditional view of apathy being simply negative and hopeless. Our study reveals a struggle against cognitive difficulties, fear of failure and invisible obstacles, with individuals desperate to remain connected, and appreciative of their carers' efforts to help them. Apathy and its effects warrant more attention from clinicians, researchers and others involved in dementia care.

Figure 1. The subjective experience of apathy in dementia, with superordinate (inner ring) and sub-themes (outer ring)

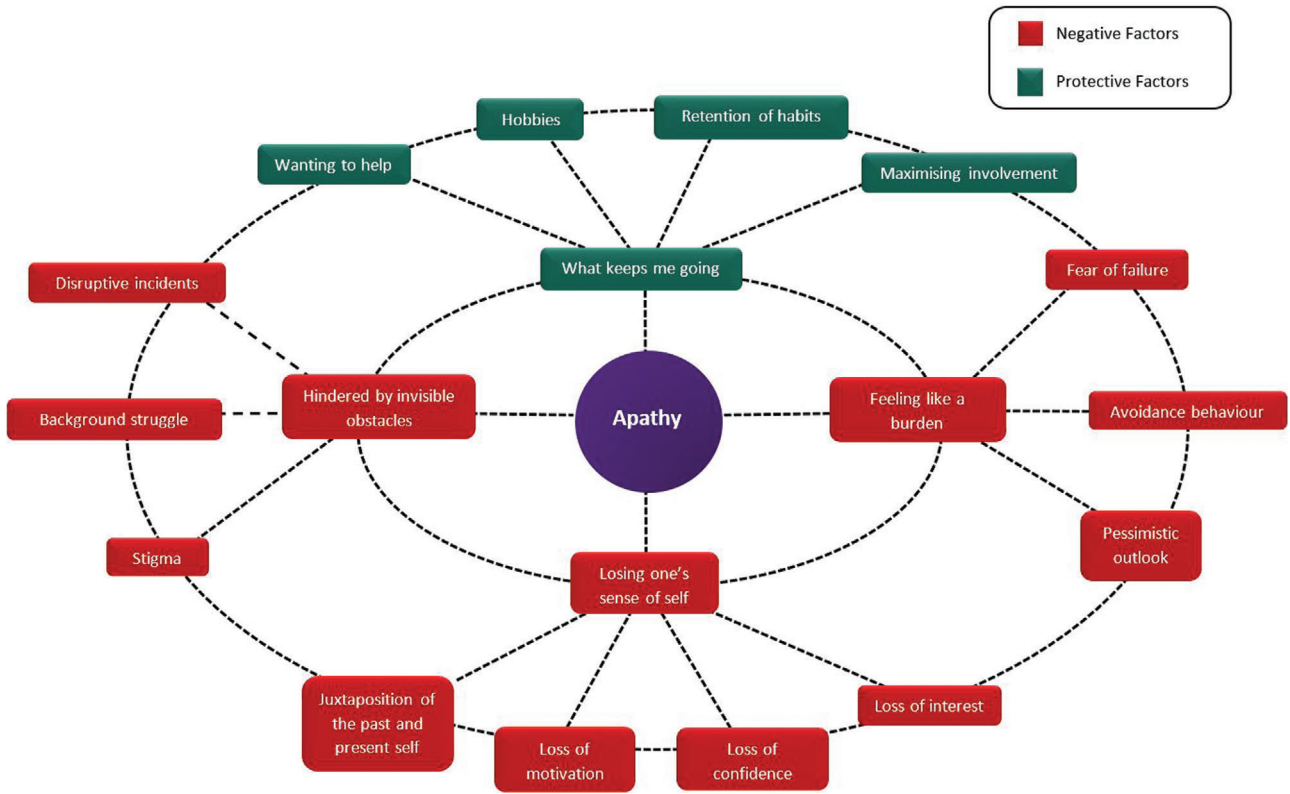


FIGURE 1

TABLE 1

Table 1. Summary of participant demographic and clinical data

Note: * = rated by carer, other ratings directly from person with dementia

	Dyad 1	Dyad 2	Dyad 3	Dyad 4	Dyad 5	Dyad 6	Mean (SD)
Pwd age	84	76	74	72	60	73	73.2 (7.1)
Pwd gender	F	M	M	M	M	M	-
Carer age	84	70	68	72	59	63	69.3 (7.9)
Carer gender	M	F	F	F	F	F	-
MOCA	11	9	18	22	18	15	15.5 (4.4)
*Short IQCODE	4.69	4.81	4.4	4.7	4.75	3.88	4.54 (0.32)
AES-Self	38	47	46	44	38	26	39.8 (7.1)
*AES- Informant	47	62	39	65	43	51	51.2 (9.5)
HAD Anxiety	0	2	16	8	14	2	7 (6.2)
HAD Depression	1	3	12	8	13	0	6.2 (5.1)
CSDD - self	1	1	15	3	26	8	9.0 (9.0)
*CSDD - informant	8	11	17	4	26	4	11.7 (7.8)

Pwd = person with dementia; MOCA = Montreal Cognitive Assessment; IQCODE = short Informant Questionnaire on Cognitive Decline in the Elderly; AES = Apathy Evaluation Scale; HAD = Hospital Anxiety and Depression scale; CSDD = Cornell Scale of Depression in Dementia

TABLE 2

Table 2. Superordinate themes, sub-themes and illustrative quotes

Superordinate themes	Sub-themes	
Losing one's sense of self	Juxtaposition of the past and present self	"I used to be quite a powerful bloke, quite muscly. I've never taken drugs or anything like that. I was able to lift quite a lot during the army and stuff like that. I was very powerful, but now I haven't got the strength to lift anything. It's like – I used to do a lot of boxing and stuff like that, but now I'm not" (pwd 05)
	Loss of interest in hobbies and activities	"I mean I am very conscious of the fact that I just cannot motivate myself to get involved in my hobbies" (pwd 03)
	Loss of motivation	"I used to love doing the job I did but then I started getting – I couldn't be bothered going to it" (pwd 05)
	Loss of confidence	"I'm not worthy. I can't do what I wanted to do...So, I feel like a failure. So, I just don't bother." (pwd 05)
Feeling like a burden	Fear of failure	"Now I don't want to be involved in other people's problems..I am afraid to get into other people's problems in case I get it wrong." (pwd 03) "Occasionally – I think I've let the wife down for one reason or another" (pwd 04)
	Avoidance Behaviour	I can do family meetings, but I wouldn't bother about anything that's going on in the neighbourhood. If I thought about it, I couldn't do anything about it so I try not to think about it, otherwise I'm worrying. (pwd 01)
	Pessimism	"I'm just scared what comes out of it, what the outcome nobody tells you or that type of thing." (pwd 05)
Hindered by invisible obstacles	Background struggle	"A swan going along a lake, all serene, lovely, but underneath his feet are in complete confusion flapping around just to keep it afloat" (pwd 03)
	Disruptive incidents	"I had started to do a painting and the telephone rang, I wouldn't know what to do. I wouldn't know whether to stop the painting and answer the phone, if I answered the phone I forget where I was on the painting and I just wouldn't carry on." (pwd 03)
	Stigma	"People tend to back away, they don't want to talk to me and I think that's not necessarily a bad reaction from me, it's ignorance, they don't understand it and they get the wrong impression" (pwd 03)
What keeps me going	Desire to help	"Yes, if I can help somebody, I will help somebody and I'd do that even if I didn't like the job I was doing but it was helping somebody." (pwd 06)
	Maximising involvement	"tried to teach my granddaughter how to do wood carving, that was great when I was trying to show her how to do it but I wouldn't get up and do it myself" (pwd 04)
	Hobbies	"Most of my activities are doing jigsaws....because you get lost with the brain on it and if I get back ache and that then I can leave it for a bit and then lie there and then get back up again and start again." (pwd 01)
	Retention of habits	"if it's something that is part of my life routine then I do them, I will probably do them without any forethought, I don't have to think I need to go and get my breakfast specifically, it might take me longer some days than others because I just can't be bothered to get out the chair, but they will get done." (pwd 03)