ASUME

Volunteering in Dementia

Family

Thirteen participants had experience of dementia among family and close friends and this was described as a reason for getting involved with volunteering in dementia care. Our secondary data analysis in particular noted the importance of family in the lives of those living with dementia. Secondary data analysis showed that among people with care needs, about 12% of them received care or support from volunteers. In this sense, volunteer care plays a role as important as care from siblings or other relatives (see Table below). We fit a set of logit models using receipt of different sources of help as dependent variables, where dementia is the variable of primary interest, controlling for age, gender, ethnicity, educational qualification, housing tenure, and equivalised household wealth. After controlling for the potential confounders listed above, people diagnosed with dementia are significantly more likely to receive help from their children and relatives. It indicates children and relatives are responsive to their parents' or relatives' dementia diagnosis and become more active in providing help with their daily activities. People with dementia are more likely to use formal care. However, there is no statistical evidence that dementia diagnosis is related to receiving help from volunteers.

PREVALENCE OF DIFFERENT TYPE OF CARE OR SUPPORT

Types	Percentage
Volunteers	58%
Receiving help from spouse	30%
Receiving help from children	12%
Receiving help from siblings or other relatives	12%
Receiving help from formal or informal volunteers	20%
Receiving formal care	58%

Knowledge of dementia and a wish to help this group of people often motivated people to take on a volunteering role and guided them towards roles involving people with dementia. However, only a few participants described themselves as former carers. Those who did, also saw this as a reason to take on a volunteering role.

> My mother had recently died and she had dementia so I was quite used to what would be going on. I said, oh well I've had plenty practice at that; I'll come and see what happens. (CVF13, Cumbria)

For those with direct experience of caring for a person with dementia there was recognition of the need to take some time following bereavement before taking on a volunteering role.

> My father died about four years ago now. I don't think I would have wanted to work with people with dementia immediately and solely. I mean, obviously I did, it was in my job but I think after a little bit of time lapsing it was something that I really did want to do. So yes, it gave me an interest and an understanding and how hard it is for carers in particular. (CVF03, Cumbria)

Most participants had a more distant experience such as knowing about family members and friends with dementia but no direct experience of caring. Their experience contributed to their motivation to volunteer and provided them with experience, knowledge and skills that would be helpful when working with people with dementia.

> I remember when I used to be younger my mum would maybe like pick me up from primary school and there would be someone in the car that was one of, I guess, her clients, [person with dementia] but you don't really call them that. I've always had some form of contact with dementia or with typically not what you should say, like, people with dementia. (SVM03, Stirlingshire)

For those with a direct experience of caring, this experience gave them knowledge and skills that enhanced their ability to take on volunteering roles with people with dementia.

> Well I've lived with somebody with dementia for at least five years and also since she went in a home. And I'd sort of got used to dealing with people in the home - they all had dementia - and so I got used to sort of dealing and speaking and knowing the sort of things that people would like. So I'd sort of got used to dealing with elderly people that had memory problems. (CVF13, Cumbria)

The findings also indicated that volunteering in dementia care was very much about supporting both the carers and the person with dementia. The experience people had with dementia reinforced the perception that the carers' role is extremely challenging and supporting this was a clear attraction into volunteering in this area.

A caveat to this, however, is that some volunteers had also experienced negative responses from wider family. There was the perception that volunteering activities could also instigate feelings of guilt in others. For example, when family members reacted to a volunteer who was visiting a client perhaps on more occasions than they were:

> So I've arrived a couple of times, and I can see the resentment in their faces. What are you doing? Why are you calling? Why are you bothering? It's a guilt factor, that you're going there more often than they are. They resent that. They don't look at it that it's beneficial for the person. So therefore you've got to be sensitive and step back and say oh, it's all right, I'll come another day, and walk away with your tail between your legs and think, oh, done it again (SVM01, Stirlingshire).

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