The Role of Volunteers in Dementia Care

Dr Vikki McCall
Dr Louise McCabe
Dr Alasdair Rutherford
Dr Feifei Bu
Dr Mike Wilson
& Shirley Law (DSDC)

#DARG17
The Role of Volunteers in Dementia Care

Our project will provide new knowledge and understanding of the role played by volunteers in the lives of people with dementia and produce practical guidelines and advice that will help:

• People living with dementia,

• Those who volunteers with people living with dementia,

• The housing services and care organisations that support them.
The Role of Volunteers in Dementia Care

1. What role do volunteers play in the social networks of people with dementia?
2. What is the perceived impact of volunteering in dementia care settings?
3. Who are volunteers in dementia care settings and what activities do they engage in?
4. What attracts volunteers to support those living with dementia?
5. What are the experiences of volunteers in dementia care?
Housing and Dementia Care

Housing policy puts clear emphasis on “shifting the balance of care” and “ensuring an appropriate balance of housing provision, across all housing tenures, and a range of housing sizes and types, including extra care, sheltered and mainstream housing”
The Role of Volunteers in Dementia Care

To investigate these questions we have conducted an exploratory study using a mixed methods approach.
Volunteering in Dementia

Attract
- Skills
- Experience
- Pathways
- Interests
- Family

Sustain
- Training
- Development
- Support
- Management
- Peer-support

Understand
- Impact
- Integration
- Personalisation
- Challenges

Motivate
- Enjoyability
- Self-development
- Altruism
- Social interaction
- Trust

Environment
- Community
- Home
- Services
- Social networks
- Learning
I think the biggest challenge is getting people (other than those who have some experience of dementia) interested initially. Difficulty getting diversity of volunteers (Organisational survey, 2016).
<table>
<thead>
<tr>
<th>Rank</th>
<th>Volunteering to support people living with dementia, their family members or carers</th>
<th>Volunteering in other roles</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Communication skills</td>
<td>Enthusiasm</td>
</tr>
<tr>
<td>2</td>
<td>Reliability</td>
<td>Communication skills</td>
</tr>
<tr>
<td>3</td>
<td>Emotional skills (maturity)</td>
<td>Reliability</td>
</tr>
<tr>
<td>4</td>
<td>Enthusiasm</td>
<td>Availability</td>
</tr>
<tr>
<td>5</td>
<td>Experience of dementia</td>
<td>Emotional skills (maturity)</td>
</tr>
<tr>
<td>6</td>
<td>Flexibility</td>
<td>Flexibility</td>
</tr>
<tr>
<td>7</td>
<td>Availability</td>
<td>Relevant wider work experience</td>
</tr>
<tr>
<td>8</td>
<td>Relevant wider work experience</td>
<td>Experience of dementia</td>
</tr>
<tr>
<td>9</td>
<td>Experience as a carer</td>
<td>Previous experience of volunteering</td>
</tr>
<tr>
<td>10</td>
<td>Previous experience of volunteering</td>
<td>Experience as a carer</td>
</tr>
</tbody>
</table>
Volunteering with those living with dementia was equally about volunteering for the carers.

“that’s one of the reasons I volunteered because I realised I’ve had it more looking after mum. And, so, since then I have always supported West Cumbria carers, because it struck me, the carers need a break” (Volunteer, 73, female, Cumbria).

Many volunteers had previous experience of dementia or had been carers themselves. This was often seen as an essential skill in how they help and support other carers through volunteering.
<table>
<thead>
<tr>
<th>Activities</th>
<th>From spouse</th>
<th>From children</th>
<th>From relatives</th>
<th>From volunteers</th>
<th>From formal care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with moving</td>
<td>61.68%</td>
<td>32.79%</td>
<td>12.07%</td>
<td>12.07%</td>
<td>22.51%</td>
</tr>
<tr>
<td>Washing or dressing</td>
<td>63.77%</td>
<td>33.41%</td>
<td>12.43%</td>
<td>10.08%</td>
<td>30.95%</td>
</tr>
<tr>
<td>Preparing a meal or eating</td>
<td>53.12%</td>
<td>40.64%</td>
<td>17.10%</td>
<td>12.07%</td>
<td>39.03%</td>
</tr>
<tr>
<td>Shopping or doing house work</td>
<td>47.49%</td>
<td>38.27%</td>
<td>15.92%</td>
<td>15.85%</td>
<td>30.31%</td>
</tr>
<tr>
<td>Using phone or managing money</td>
<td>53.58%</td>
<td>37.41%</td>
<td>16.63%</td>
<td>12.93%</td>
<td>39.03%</td>
</tr>
<tr>
<td>Taking medication</td>
<td>52.63%</td>
<td>38.06%</td>
<td>18.22%</td>
<td>8.91%</td>
<td>51.42%</td>
</tr>
<tr>
<td>Other activities</td>
<td>73.52%</td>
<td>21.69%</td>
<td>5.84%</td>
<td>6.39%</td>
<td>3.65%</td>
</tr>
</tbody>
</table>
“You get to know people. We’re like an extended family. I used to say that when I worked. I said, you’re like a family to them and you become part of them, really”. (Volunteer, female, Cumbria)

“So you think, well, you’ve done your bit for them in society and help them through the stage of it” (Volunteer, female, Cumbria)

I’ve always been a caring person. Even from being this high I used to go to the neighbours and make the old lady who was 80 odd her toast and I’d take it up to bed to her and I was only four”. (Volunteer, female, Cumbria)
Where do volunteers in your organisation undertake their work? (Please tick all boxes that apply)

- Service-user’s own home: 45 (15.9%)
- Community setting – semi-public (such as a community or church hall): 45 (15.9%)
- Care home: 42 (14.8%)
- Community setting – public (such as a café or shopping centre): 39 (13.8%)
- Day care centre: 30 (10.6%)
- Office-based or head office: 25 (8.8%)
- Sheltered housing complex: 20 (7.1%)
- Hospital ward: 15 (5.3%)
- Other: 10 (3.5%)
- Hospice: 5 (1.8%)
- Day hospital: 4 (1.4%)
- Volunteer’s own home: 3 (1.1%)
Conclusions

The project so far has highlighted the key gaps in knowledge and the currently unintegrated areas of volunteering, housing and dementia care.

Findings from the literature and quantitative analysis point to the importance of different care spaces on the experiences of volunteers and those living with dementia.

Those living with dementia receive more help from family carers but not necessarily from formal volunteers. This may present both opportunities and challenges for different care organisations.

Volunteer agencies may begin to think about a more rounded volunteering package that includes not only those living with dementia but those around them as well.
Contact us

Vikki.mccall@stir.ac.uk

@vikki_mccall

@HousingStirUni

Tel: +44 (0) 1786 467698