



The Reservoir of Goodwill: Conceptualising a Community Care Model for Later Life Care

RESEARCH

YVETTE MOREY 

SARA SPEAR 

ALAN TAPP 

JULIA VERNE 

STELLA WARREN 

AMY BEARDMORE 

*Author affiliations can be found in the back matter of this article



ABSTRACT

Context: Concerns about an ageing population with long-term care needs putting strain on health and social care systems have prompted interest in community care models for later life care, as already exist in palliative and end-of-life care.

Objectives: To identify existing later life care and support within communities, willingness to participate in a community care model, and barriers and enablers to such a model.

Methods: We adopted a qualitative approach, involving in-depth interviews and focus groups with 39 participants aged 70–91 years old. Data were transcribed, and a deductive thematic analysis conducted.

Findings: Most participants were involved in help-giving within their local community, with friends, neighbours, and nearby residents. However, whilst participants were willing to receive home care from volunteers in the community, they considered it inappropriate for volunteers to provide personal care, and perceived considerable barriers to enacting a community care model.

Limitations: This study does not aim to be representative of the population aged over 70 in England, and instead presents an in-depth exploration of the views and experiences of a small sample of this group.

Implications: There is currently a broad but shallow reservoir of goodwill towards caring within the community. Later life community care relies heavily on a core of family and friends, and there will continue to be increasing demand for professional care services to fill the gaps where this core does not exist, and where medical and personal care needs exceed what can be supported by informal carers.

CORRESPONDING AUTHOR:

Sara Spear

St Mary's University
Twickenham, UK

sara.spear@stmarys.ac.uk

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CONTEXT

Global population ageing, often combined with growth in complex care needs, means that long-term care costs are rising across the world (Clark et al., 2017; Kaley & Sidhu, 2010; Kelly, 2015; Roquebert & Tenand, 2024). This is challenging the financial sustainability of countries' long-term care systems, including in England (Duell et al., 2021; Lemmon, 2020; Verity et al., 2024). Governments are therefore interested in moving care into community settings (Morgan et al., 2016) with policies aimed at decreasing the use of formal, paid (publicly financed) long-term care, and increasing the provision of informal care, which is mostly provided by people within an individual's social network (Duell et al., 2021). Caring activities have been broadly divided in the literature into personal care (such as bathing, toileting, dressing, and helping with eating), and home care (such as shopping, housework, picking up prescriptions, and paying bills) (Duell, et al., 2021; Lemmon, 2020).

Questions have been posed as to whether, and to what extent, formal care and informal care are substitutes for each other, or are complementary. If informal care can substitute paid care, then this can decrease the overall costs of care, which is favourable to governments and local authorities (Duell et al., 2021; Lemmon, 2020). The evidence so far is mixed; Duell et al. (2021) analysed administrative data from the Netherlands and found that having at least one daughter living at home increased the amount of paid care used, whilst having at least one daughter living on her own, or having a healthy partner, decreased the amount of paid care. A healthy partner was associated with a 19% decrease in use of formal paid care, compared to having no partner. Lemmon (2020) analysed similar data from Scotland and found that the presence of an unpaid carer was associated with an average increase of one hour and 14 minutes of paid care per week. Lemmon (2020) poses that this may be due to unpaid carers advocating for paid care on behalf of the cared for, but also that this paid care could support unpaid carers, and enable them to continue caring for longer. Lemmon (2020) raises that the existence of a complementary relationship could mean that individuals who do not have an unpaid carer are more likely to have unmet care needs.

Studies have identified that later life care is often provided by a close family member. Spijker et al. (2022) discuss that in Spain, care is usually provided by a spouse or adult daughter. In Ute et al.'s (2017) study of older migrants in Luxembourg, participants expected their children to be involved in their care, although not to provide hands on care themselves. Similarly, von Saenger et al. (2023) found that a third of older parents in Sweden received some practical care from their adult children, such as food shopping or cleaning. Lethin et al. (2019) note the important role of wider family

members in supporting the informal carers of people with dementia, by sharing tasks and appointments, and providing a space to talk about their life and problems. Arbel et al. (2023) though, in their study on the 'oldest-old' caregivers of people with dementia, found that the carers received only sporadic assistance from other family members. Most caregivers had therefore used publicly funded and/or private services to provide additional support.

It is recognised that informal family carers are at risk of suffering physical and psychological problems from providing care, including exacerbating their own health conditions, and suffering distress and depression (Lethin et al., 2019; von Saenger et al., 2023). Steinsheim et al. (2023) report that dementia is one of the leading causes of old age care requirements, and that the burden this places on the informal care giver can lead to decreased quality of life for both the care giver and receiver. Morgan et al. (2016) draw attention to gendered expectations of care, with women more likely to be carers than men, and to provide personal care, whereas men are more likely to provide instrumental (home) care. Spijker et al. (2022) note that in Southern European countries, including Spain, old age care has traditionally been provided by spouses and adult daughters. However, there is now an increasing deficit in family care, due to more women participating in the workforce, below-replacement fertility, and increased life expectancy (Spijker et al., 2022).

Considering the constraints of both family and paid care, there is increasing interest in models of care which extend into the wider community. This can be seen in the palliative care field, with the growth in compassionate communities (Bakelants et al., 2023; Librada-Flores et al. 2020), and as illustrated in Abel et al.'s (2013) 'circles of care' community-centred care model.

COMMUNITY APPROACHES IN PALLIATIVE AND END-OF-LIFE CARE

The compassionate cities and compassionate communities approaches to palliative and end-of-life care were pioneered by Kellehear (2005; 2013). These community-based approaches aim to foster capacity-building around dying, death, and bereavement, and enable support among community members for individuals at the end-of-life (Dumont et al., 2022). They rely heavily on volunteers, who are generally healthcare professionals who provide initial help with setting up networks of care, or local members of the community who have been involved in helping family members or close others with end-of-life care (Abel et al., 2018; Poulos et al., 2017). In recent years, many compassionate communities have been developed that show the benefits for people at the end-of-life, their families, volunteers, and healthcare professionals, as well as highlighting the challenges of this approach (Dumont et al., 2022). Liu et al. (2022) report on a compassionate community in Taipei,

which was found to strengthen social connectedness, particularly for the most vulnerable people, and bridge gaps between asking for/accepting and providing help within the community, and between community members and health and social care providers. The project was driven by the city government and hospital, and involved multiple government agencies, community leaders, non-governmental organisations (NGOs), students, and volunteers (Liu et al., 2022). This illustrates the complexity and variety of stakeholders involved in setting up and maintaining a community approach to care, and emphasises the importance of support from local authorities and health and social care providers, as well as community buy-in.

Aoun et al. (2022) and Aoun et al. (2023) report on the Compassionate Communities Connectors programme in Australia, where trained volunteers ('connectors') helped people with terminal illnesses ('clients') to build supportive relationships in their communities. Patients and families valued the connector as an advocate for their needs, who increased their social connectedness, and relieved pressure on the family. Healthcare providers saw the value of the programme in reducing social isolation, filling a gap in service provision, and building the capacity of the healthcare service (Aoun et al., 2023). The connectors did, however, acknowledge challenges; some clients were unwilling to involve friends in what they saw as their 'private' life, or to extend their networks (Aoun et al., 2022). In their review of the literature on compassionate community initiatives, Dumont et al. (2022) express concerns that patients, families, and community members are most often engaged as target audiences, rather than partners, in programme design and implementation, and found that local culture and social attitudes acted as a common barrier to implementing initiatives. Despite this implied importance of culture in community care, Dumont et al. (2022) found a lack of compassionate community initiatives aimed at marginalised groups. Finally, they note that less attention has been paid to policy development than to local education and awareness programmes, despite the former having potential for more wide-reaching impact.

The interconnections between a dying person, communities, service delivery organisations, and policy, are illustrated in Abel et al.'s (2013) 'circles of care' model of community-centred end-of-life care. The model depicts a person with an illness surrounded by an inner network, outer network, communities, service delivery organisations, and policy development. These spheres are intended to intertwine to provide end-of-life care that benefits patients and communities, with communities caring for the dying, and service delivery organisations providing support where needed, within a cohesive policy framework (Abel et al., 2013). Of particular interest for us here are the inner and outer networks,

and communities, which Abel et al. (2013) define as follows; the inner networks are 'close family members and friends... who provide intimate and direct hands-on care, companionship and support.' The outer networks are 'less close family members, friends and neighbours who may respond to requests for help. The type of tasks that the outer network can do may relate to the sometimes mundane practicalities of living but generally relate to activities outside the home.' Communities are more loosely defined and may include, 'networks within a neighbourhood...someone who lives nearby...a family member may know the person involved via someone else' (Abel et al., 2013, p. 386). Given the increasing demand for later life care, extending community-based approaches from palliative care into later life care has the potential to reduce pressure on both formal, paid, care systems, and informal, unpaid, care provided by family members. This study therefore explores the potential of a community-centred approach to later life care, based on Abel et al.'s (2013) 'circles of care' model. Specifically, we investigate existing later life care and support, perceptions of a community care model for later life, and the barriers and enablers of such a model, from the perspective of individuals in later life.

METHODS

STUDY DESIGN

A qualitative, phenomenological, approach was adopted, to gain insight into people's subjective experiences and understanding of later life care. This followed from an interpretivist paradigm, seeking to make sense of reality by understanding individuals' beliefs and motivations within a particular setting.

SAMPLING AND RECRUITMENT

In order to gain the views of people in later life living in England, the primary inclusion criterion for our study was age, with a minimum age of 70 required for participation. Thereafter quota sampling was used to reflect key demographic aspects of this population that may intersect with care needs, namely: gender, location (rural/suburban), and socioeconomic status. Quotas for socioeconomic status were determined based on the National Readership Survey (NRS) (n.d.) social grade classification, focusing on social grades B (intermediate managerial, administrative, and professional) to D (semi-skilled and unskilled manual workers), as this comprises 86% of the population.

We worked with a fieldwork company to recruit participants for the qualitative research, and they used their network of local recruiters within the North West and South West of England to recruit members of the public in accordance with our criteria. These regions were selected to gain a breadth of views within England, and

also for feasibility within the budget and timescales of the funder. Participants were recruited by word of mouth, and by flyers containing information about the purpose and requirements of the study in local community venues, with contact details for the local recruiter. Potential participants were then provided with the full participant information sheet by the local recruiter, and were invited to choose whether they wished to participate in an interview, or in a focus group with other people in their local community. In accordance with National Institute for Health and Care Research guidelines for recompensing members of the public involved with research (NIHR, 2023), participants were paid £20–30 to cover their time and expenses, for their involvement in the interview or focus group.

ETHICAL APPROVAL

Ethical approval for the research was granted by the Faculty of Business and Law Research Ethics Committee at the University of the West of England, Bristol (FBL.18.10.014 Tapp). Potential interviewees received information on the study via the participant information sheet, and again from the researcher before data collection commenced, including that participation was voluntary, that they had the right to withdraw from the study up to two weeks after the interview or focus group took place, and that their data would be anonymised, with nothing reported that could be used to identify an individual. Verbal and written informed consent was gained from all participants before data collection commenced.

DATA COLLECTION AND ANALYSIS

Data was collected via semi-structured interviews and focus groups, which enabled us to gain in-depth responses from individuals, as well as insights evoked by discussion amongst peers of a similar age and location. The sensitive nature of the topic and the age of the participants meant that their comfort was a priority, and collecting data via two methods meant that potential participants were able to choose how they felt most comfortable engaging with the research. The interviews and focus groups were carried out within the same period of data collection, and were scheduled according to participant availability. All the interviews and focus groups took place in the home of the interviewee, or the home of one of the focus group participants. This again assisted in ensuring participants felt comfortable during the data collection, and so were more likely to speak freely. A moderator's guide was created for the interviews and focus groups, based on the community care literature and the research objectives, which were; 1) to identify existing later life care and support within communities, 2) to understand willingness to participate in a later life community care model, and 3) to explore barriers and enablers to such a model (see Supplementary information one for the

moderator guides). The guide funnelled participants through a set of topics with the aim of identifying existing levels of later life community care and who was involved in delivering this care, perceptions of a community care model for later life including willingness to provide and receive care within this model, and barriers and enablers of a community care model.

The data collection was carried out by two of the authors, who shared characteristics with the study population, specifically socio-economic status (between social grade B and D), and location (living in rural or suburban West of England). The two researchers were female and although at least 20 years younger than the study population, had experience of later life care through their own relatives and friends. The researchers believed that their characteristics facilitated the discussions of later life care in the interviews and focus groups, and found that participants spoke freely about their experiences and wishes.

Interviews and focus groups were audio-recorded and transcribed verbatim. Transcripts were imported into NVivo 11 to facilitate the management and analysis of the data. A deductive thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006) was carried out, with codes agreed by all members of the research team prior to the start of the analysis, and recorded in a coding manual. A deductive approach was appropriate given the extensive literature on later life care and community care, including Abel et al.'s (2013) 'circles of care' model and our particular interest in the inner and outer networks and communities sphere in this model. The researchers reviewed the coded data in order to develop themes and sub-themes, and both the coded data and themes were discussed and agreed by the research team at key points in the analysis of the data. This allowed for an iterative process, involving initial reading of the data, analysis, discussion, reflection, and then further analysis and discussion, which enhanced the credibility of the findings.

FINDINGS

Thirty-nine people between 70–91 years of age took part in the study. In-depth interviews were carried out with 20 of these participants, and the remaining 19 took part in one of four focus groups. Once we had collected data from these 39 people, we were content that data saturation point had been reached, and no further participants were recruited. There were more female participants than male (25 compared to 14), and 24 participants were in suburban locations versus 15 in rural locations. The majority of participants were in socio-economic groups C1/C2 (23), with 10 in group B, and 6 in group D. Interviews lasted around 60 minutes, and focus groups lasted around 90 minutes. Each focus group had four to five participants, which was appropriate given participants' ages and the sensitivity of the subject.

The achieved sample is represented in Table 1 below.

CATEGORY	NO. OF PARTICIPANTS
Age	
70–79	30
80–89	8
90–99	1
Total	39
Gender	
Male	14
Female	25
Total	39
Location	
Suburban	24
Rural	15
Total	39
Socioeconomic status	
B (Intermediate managerial, administrative and professional)	10
C1/C2 (Supervisory, clerical and junior managerial, administrative and professional/Skilled manual workers)	23
D (Semi-skilled and unskilled manual workers)	6
Total	39

Table 1 Demographics of achieved sample.

The data was deductively coded and themes and sub-themes were developed in relation to later life care and the potential for a community model of care, as illustrated in Figure 1.

We investigated differences in the data according to demographic traits as part of the analysis, and found no differences according to location (rural/suburban) or socioeconomic status. This may be due to the socioeconomic groups sampled (B–D), which are in the middle of the range, and so have fewer potential differences than the extremes at either end of the range (being A – higher managerial, administrative and professional, and E – casual and lowest grade workers, unemployed with state benefits only [NRS, n.d.]). Similarly, differences between rural and suburban participants may have been less apparent than between urban and rural populations. There were some differences in responses between male and female participants, and these are discussed as part of the findings. The findings are presented here according to the main themes developed; existing care and support within the community, future care needs, willingness to participate in a community care model, and barriers and enablers to a community care model.

EXISTING CARE AND SUPPORT WITHIN THE COMMUNITY

Many participants had received support from neighbours and friends, and described examples of this help:

I had to have an operation on my foot and for at least two days I wasn't supposed to walk on it. My neighbour that side used to bring me a cup of tea and piece of cake every afternoon [...] So we are very caring in this close, we keep an eye on one another without interfering. (Female, 73)

I've got a fantastic young neighbour, she's a diabetes nurse, and she knocks every other night to see if we need anything, and 'Are we all right?'. (Female, 86)

Most participants were also involved in help-giving for friends and local residents, which varied in frequency from occasional visits to a daily commitment:

I have got a friend, I mean he is 80 (...) I go down his house sometimes and makes sure he is all right (...) He appreciates that. And I say, 'Well, you are a mate of mine, I have known you for years.' (Male, 74)

I go to the old lady up the road three times a day so that her carer can go and do some shopping or stuff that she wants to do. (Female, 83)

These were generally home care tasks, or providing companionship, and were seen as being a good friend or neighbour. Participants were keen to emphasise though that they were not intruding in providing this help:

I am not a nosy neighbour, don't get me wrong, but her house was there and mine here so you couldn't not help. (Female, 72)

Engaging in caring in the community therefore involves an awareness and balancing of familiarity versus over-familiarity, and neighbourliness rather than intrusion.

FUTURE CARE NEEDS

Participants were conscious of the likelihood of increasing care needs in their later life, but dealt with the uncertain prospect of this in different ways. Only one participant had already made practical preparations:

I didn't want to move really because I loved it there, but the boys said, 'Well mother, you are not going to be able to stay here always so it's better to move while you are active than it is to move when you have got to move somewhere.'

Introduction

We are considering ways to help people stay in their homes, or where they are currently living, for longer, rather than having to go into a nursing home, care home or hospital. What are your thoughts on staying in your home versus going somewhere else?

Receiving help

Who would you currently call upon to help you, if your family and friends weren't available? Prompt for neighbours, someone from a faith group.

Would you be open to having people from the community, who weren't family or friends, helping you, if that meant you could stay in your home for longer?

What sort of things would you be happy for someone you didn't know to help you with? Prompt for household chores, cleaning, making the beds, washing and drying clothes, ironing, shopping, transport, preparing meals. How about more personal things, like personal care, hygiene, toileting, for example?

Is there anything that you wouldn't accept help with?

Giving help

Have you ever done any volunteering to help others in the community? Would you consider it?

Is there anything that you wouldn't be prepared to help other people with?

Do you think that people from the community helping others should be paid, or should this be a voluntary service?

What might motivate people to give this help? Could you think of anything that would be an incentive? For example, one of the ideas is that people could earn hours that someone could then give back to them if they needed it, do you think this would work?

Future planning

Do you have any concerns or worries for yourself in the future?

Have you discussed with family or friends what might happen if you need to go into a care home?

If you felt like you needed any information about assistance at home, or moving into an assisted living situation, where do you think you would go to find that information?

Would you like the information to be available in any other places? For example, the library? Charity shops? GP practice? A freephone number to call?

Figure 1 Example interview questions.

[...] I have got a toilet and hand basin downstairs and then upstairs I have now got this walk-in shower. The boys got onto [company]. They were very good, they sent a man and explained what I might need. So, they put in what I might need rather than what I need now. (Female, 83)

Some preferred not to think about it:

I try to put things like that to the back of my mind really and enjoy the day for what it is rather than think about what might happen [...] We just live for today and hope that tomorrow is going to be fine as well. (Male, 75)

I haven't thought about those things. I know it's going to come but not yet. (Female, 73)

Whilst participants were all aged 70 plus, they still perceived later life care as something that was not an immediate concern, and could be dealt with in the future.

Some participants were confident that they could rely on care and support from family members – this was particularly notable amongst female participants, especially those who had female relatives in a caring profession:

If I had to have personal care, I am sure my granddaughter, who is a nurse, would do it. (Female, 83)

I would call on my daughter who's a doctor, because she has seen it all anyway and she wouldn't worry about it. And the same with [my daughter] the nurse, I would call on her because she's seen it all. In fact, I have called on her before because I had a burn on my foot, and she had to come in and dress it. (Female, 72)

Our daughter [who had worked in a care role] would do it and probably [son's] wife. One of our granddaughters-in-law she is a social worker, or training to be a social worker, so I am sure she would. (Female, 83)

Male participants were more likely to express the opposite view though:

I don't think any man would like his daughter to come in and clean him and etc, etc. It would be most embarrassing for him, it would be most embarrassing for her [...] I think a stranger is a better position to look after you than a close relative, especially a daughter. (Male, 76)

You can't rely on family in the main, because I've got two daughters, they've got grandchildren, their priority in life is work and their children, not coming up and looking after me. I'm not saying they wouldn't, but I don't think it's fair to ask them, they've got a full life as it is. (Male, 77)

Many participants were conflicted about receiving care from family, because of the burden this could place upon them:

I had about 3 or 4 operations, my son is always there for me, he keeps the house running, he walks the dog, he does the shopping, but I don't like him having to help me. (Male, 80)

If anything happened then my daughter would sort it out, she said, 'Come and live with us.' So that's, you know, like most people do don't they, they go and live with their children. But I am not the sort of person that would like to feel as if I was imposing on them. [...] I would sooner live with her than go in a home, to be honest, because once you are in a home, they say you never come out [...] I wouldn't want her to think she is looking after me and think 'I can't do anything because our dad's not very well,' or anything like that. I would hate that. (Male, 74)

The desire for family support versus reluctance to become a burden presented an unresolved tension for participants, particularly as paid options for care were perceived unfavourably.

Participants were critical of paid carers coming into the home, based on their own and other's experiences:

I got this lady who was from an agency [...] and she came of a morning, 15 minutes! And in those 15 minutes the first thing she did when she came through the door was make a cup of tea, make herself some toast, put the telly on in the bedroom, sit there and eat her toast and drink her tea, and then for the last few minutes that were left of the 15 minutes she would rub some cream on my legs. That was that. For that I paid £1500 until I stopped it. (Male, 70)

The problem at present is that the carers have only got 10–15 minutes [...] I mean, there's no point in coming into a household and expect to make sure everything's all right in 10 to 15 minutes. (Male, 71)

The least favoured scenario was to go into residential care, and fears about care homes were widely discussed, for example:

I'd rather be dead than end up in one of these homes [...] I tell them I'm not going into a care home. (Female, 83)

I don't think there is a lot of care going on today [in a care home]. There are so many people, they just don't have the staff [...] once you are in a home, I know what it's like, they have got nothing to do and they are so bored, they want to die, a lot of people. (Male, 74)

You hear so much about these nursing homes where you get in and there are all these people sat around doing nothing. I couldn't stand that. (Female, 72)

Residential care was seen as inevitable in some circumstances, however:

I think [you can stay at home] as long as you have got your marbles. I think if I suddenly went doolally and started to become aggressive and things like that [...] I think those people have to go into a home, because you just can't cope with them, quite honestly. (Male, 73)

I hope that I will be able to stay at home. But if the time came and I was ill and it was too inconvenient or too troublesome for the children to look after me, then I would have to [go into a care home]. (Female, 80)

In light of participants' reluctance to move into residential care, they were willing to consider a community care model, if it would enable them to stay in their own home for longer.

I don't know how bad you would have to be [to accept help from volunteers] but oh yeah, you would prefer that, to be in your own home. (Female, 74)

If the day should come, of course we would accept [help from volunteers]. (Male, 91)

The details of help that participants would be willing to receive is discussed in the next section.

WILLINGNESS TO PARTICIPATE IN A COMMUNITY CARE MODEL

Participants felt that volunteers would be well placed to provide them with home care, but were clear that they would not want them to provide personal care:

Wouldn't mind people popping and getting me a loaf of bread or milk or something like that and

popping in for a chat, I'd like that, but if it got any deeper, I would want professional people to come in and do things for me. (Male, 77)

To have someone drop in that you know, just to keep an eye on you, and when things are getting a bit grim in the house, for example, if you can't manage cleaning [...] I think it's a good idea. It would be good to have neighbours to come in just to see how you are from day to day, that to me is more beneficial than a 10, 15 minute visit from a carer. I mean, the carers are essential for things like personal care, I think that's an essential part of the carers job and it's not something which friends would want to do, or you would want friends to do. (Female, 77)

[Personal care] I would prefer it to be a professional because if I am at the stage where I need that, then in my mind I would need a professional rather than a volunteer, however helpful. I am not sure it would be fair on them unless they were, you know, a retired nurse or something like that. (Female, 75)

Similarly, participants were willing to consider providing home care to strangers, but generally would not countenance providing personal care. There were differences in the types of home care that male versus female participants felt they could provide:

There are some things I would do, and some things my wife would say I was incapable of doing, like household chores, cleaning [...] I think the social side would be good [...] I wouldn't be comfortable going into someone else's home and doing [personal care]. (Male, 73)

Clothes washing and drying, no thanks, it's not a man's thing, I just wouldn't want to know at all. Shopping, that's not a problem. Transport, I would quite like to do that [...] Preparing meals, no I wouldn't fancy that. Personal care and hygiene, help in the bathroom, toilets, again I personally wouldn't want to do that as a volunteer. Not at all. (Male, 70)

I wouldn't want to clean people or the mucky things like that. I wouldn't volunteer to do that. I could take people to the hospital, take them to wherever they wanted to go. (Male, 75)

Clothes washing and drying, ironing, that's no problem. Shopping, I could do that. Transport, I wouldn't like that one. Preparing meals, I would be fine with. (Female, 73)

Male participants were most comfortable with providing transport and companionship, where female participants were agreeable to tasks like cleaning, washing, and preparing meals. The gendered differences are unsurprising given participants' ages, and traditional roles for men and women in this generation.

BARRIERS TO A COMMUNITY CARE MODEL

Despite hypothetical willingness to provide and receive care in accordance with a community care model, participants were sceptical that this would work in practice. Some discussed the lack of connection with their community:

They are very nice all the way round, but I haven't got a neighbour that if I took ill I could ring and say, 'Please can you come and help'. (Female, 80)

People have got such busy lives and that. It's not that they are not interested, but they just concentrate on their own families. Perhaps some would like to help, but I don't think they have got the time and that now, not the younger ones. There is always something to do, something going on with their own lives. (Female, 72)

Participants identified barriers to their own involvement in volunteering, including caring responsibilities within their own families, and lack of time due to work and leisure commitments:

With my husband like this, that is my main responsibility. So, to go outside the home and offer help, I wouldn't have the strength, I just wouldn't. (Female, 75)

I do the school run. I wouldn't want it to interfere with that, because my daughter would come first, if you see what I mean. And if she needed me to babysit or, like, the school holidays are coming up, I will have the children then and they have got to come first. So, I don't know whether I am the right person to do it. (Female, 73)

I need to work because we never had a pension, basically we invested all our money in the farm, so we didn't take out a pension. We have a very small one, it gives us a couple of grand a year. If I want a reasonable life I still have to work. (Male, 73)

I have got quite a hectic life. We go out quite a lot, go on holiday quite a lot. We are very fortunate to be able to do that. And we have got a good social life, we don't have time to help people out. (Male, 75)

Participants elaborated on their inability to provide personal care (as noted in the previous section), due to lack of skills and experience in this area, or their own physical limitations:

I think at this stage in our lives, we wouldn't really be able to really do that [...] in my opinion you've got to have somebody who knows what they're doing, or you could do more harm than good. (Female, 81)

I know older people are very frail, I would be a little bit nervous about lifting and helping them with things like that. I wouldn't be too good myself because I suffer with my back. I wouldn't want to do that without some sort of professional help. (Male, 75)

Reluctance to provide personal care was common for both male and female participants, recognising their own health conditions and limited ability to lift and move people requiring care, but also reflecting a general unwillingness to be involved in these intimate tasks.

Participants noted difficulties in sustaining commitment from volunteers:

If you're asked to do it unpaid, it might last for a couple of weeks, 'Oh yeah, this is great,' and then gradually it will fade, 'I've got better things to do'. (Female, 71)

I wouldn't want to commit to anything that I could do regularly because it wouldn't be fair to somebody to say, 'Well, I will come today but I am not sure when I will be here again'. (Female, 73)

Alongside barriers to volunteering in a community care model, we also explored potential enablers.

ENABLERS OF A COMMUNITY CARE MODEL

The majority of participants dismissed either financial means of incentivising people in a community care model, or a system where you could 'bank' hours, and that volunteering would bring its own intrinsic rewards:

I think if you are going to do it [volunteer], you will do it because you want to do it, not because you want someone to do something back for you [...] some people might take advantage of that sort of situation and get more out of it than they put in. (Male, 75)

I would hate to think in the future people get paid to do it. I would think it's got to be voluntary, because if your heart's in it, then you do a better job. (Male, 70)

Would I feel better with myself if I did it? I probably would [...] That's probably the advantage of helping someone, it's the social thing, you do meet someone. (Male, 73)

Participants generally agreed though that a volunteer's expenses should be covered:

If they have got expenses, petrol expenses or something, then they probably should get that paid back. (Male, 75)

To be a volunteer you don't expect any incentive to do it, but you shouldn't be out of pocket. What you are giving is your free time and help. I don't think a lot of people would want to spend too much of their own money. (Male, 70)

This indicates that funds to at least cover volunteers' out of pocket expenses may be necessary to enable a community care model, either from the recipient of the care, or from an organising body.

Participants were concerned about the potential for harm to older people, and believed that monitoring volunteers was necessary in a community care model. This was due in part to having seen stories of older people being taken advantage of in the media.

I would want to be assured that [volunteers] have been very carefully vetted, because you read in the paper very frequently about care workers being cruel, stealing. There are some unscrupulous people about, you hear these stories, they definitely have to have a CRB [Criminal Records Bureau] check. (Female, 70)

Monitoring was also discussed in terms of protecting the volunteers themselves:

You've got to be so careful these days, haven't you [...] The public will be putting themselves open to all kinds of accusations. (Male, 74)

The problem is, if you get [...] someone a bit obnoxious, saying, 'I saw you, did you go in my purse?' People would be frightened of being accused of doing something. (Female, 76)

Carrying out Disclosure and Barring Service (DBS) checks (formerly CRB checks), or similar checks in other jurisdictions, would provide some reassurance of the suitability of volunteers to work with older people. A community care model would therefore be enabled by putting in place oversight from an organisation or group of individuals, who could facilitate the payment of expenses and carry out checks on volunteers.

DISCUSSION

This study found that most participants were involved in help-giving within their local community, with friends, neighbours, and nearby residents. However, whilst participants were willing to receive home care from volunteers in the community, they considered it inappropriate for volunteers to provide personal care, and perceived considerable barriers to enacting the community care model illustrated in Abel et al.'s (2013) 'circles of care'. Whilst the model exists for later life care insofar as it is based on giving help to people with whom one has a level of relational and/or physical closeness (e.g. the inner and outer networks in the 'circles of care'), it becomes more tenuous when envisioning help-giving between individuals without this connection (in the community sphere of the model).

Many participants already received, or expected to receive, care from family members, supporting studies such as Ute et al. (2017) and von Saenger et al. (2023). However, participants were also aware of the pressure this placed on family, as acknowledged by Lethin et al. (2019), Morgan et al. (2016), and von Saenger et al. (2023). They were also reluctant to have friends or neighbours involved in personal care tasks, which aligns with the findings of Aoun et al. (2022).

The reluctance of participants to help strangers, or commit to a regular caring schedule, makes the creation of a network of community volunteers, who are eventually trained, and security checked, as envisioned in the 'communities' sphere of the 'circles of care' model (Abel et al., 2013; 2018), unlikely in practice. Additionally, the breadth of caring tasks which may be undertaken by a volunteer network is likely to be limited to home care, as defined by Duell et al. (2021) and Lemmon (2020), such as shopping and housework. Whilst many individuals have experience of providing personal care for close family members (such as bathing, toileting, and dressing), they are reluctant to provide this type of care for strangers. This contrasts to the hopes that those who have cared for family members will be willing to share their knowledge and provide the same care for others in their community, as proposed by Abel et al. (2013; 2018) and Horsfall et al. (2012).

This prompts us to look again at the 'circles of care' model (Abel et al., 2013) in the context of later life care, specifically the first three circles surrounding the individual which comprise community-centred care; inner networks, outer networks, and community. The findings in this study show the need for a more nuanced view of the different levels of care within these networks, influenced by familiarity and proximity. We conceptualise this as the Ecology of Later Life Community Care Model in Figure 2.

The ecological metaphor is appropriate given the interconnectedness and interdependence between levels of community care. The informal, irregular, timebound, and limited nature of care (specifically home

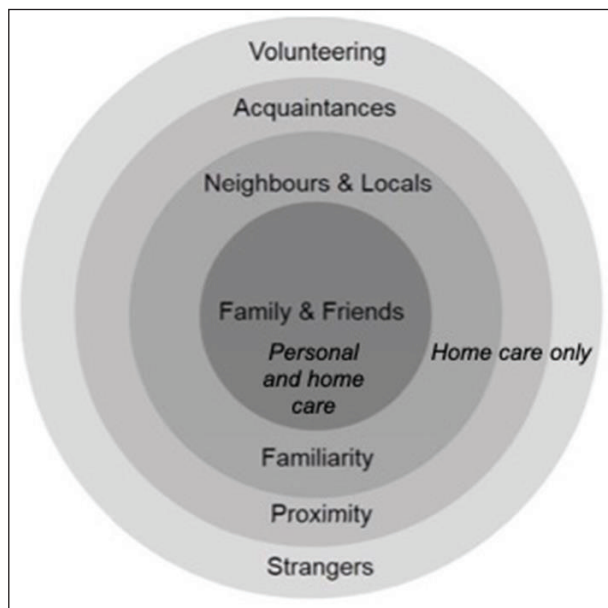


Figure 2 Ecology of Later Life Community Care Model.

care only) that members of the intermediate and outer levels are willing to provide, means that an inner core of family and friends willing to consistently provide regular personal and home care is necessary for the community care model to function. Relational ties based on either familiarity or proximity affect the help-giving that individuals are willing to provide at different levels of the model; familial help-giving is provided for people known well e.g. neighbours and local residents, proximal help-giving is provided for people recognised as living in the area, and volunteering is then help-giving provided to strangers. A possible tension exists in that the more an individual is involved in help-giving to a family member or close friend as part of an inner core, the less likely they may be to engage in help-giving to strangers as a volunteer, due to the time and commitment this involves.

Although certain tasks (and particularly personal care) reside with the inner core, the wider levels provide a valuable function by reducing some of the burden of home care tasks on family and friends, which could otherwise make caring for a relative or friend untenable. This is noted in the dementia literature, such as by Lethin et al. (2019), as it is particularly vital where care needs may continue over a lengthy period of time. In cases where this inner core does not exist for an individual though, the reservoir of goodwill that exists within the community is unlikely to be deep enough to fill this gap. This will limit the feasibility of the community care model for many people, who will instead require professional care services. In addition to this, the reality of medical and personal care needs in later life mean that whilst many people would prefer to remain in their own home, residential care may be the only option. This makes improving current realities and narratives around care homes imperative, to give older people greater peace of mind regarding the potential scenarios for long-term care.

STRENGTHS AND LIMITATIONS

The qualitative nature of this study and the sampling method used means that it does not aim to be representative of the population aged over 70 in England, and instead presents an in-depth exploration of the views and experiences of a small sample of this group. Whilst the aim of the method is not generalisability, the findings do still have implications for other geographic and health and social care settings grappling with increasing later life care needs and costs.

The study identified differences according to gender, but the socioeconomic and location sampling criteria did not show differences between groups – an expanded criteria to include participants in the highest and lowest socioeconomic groups, and in urban locations, could have brought further insights. We also did not include ethnicity or cultural or religious background in the sampling criteria or data collection. Future research investigating the impact of these factors on experiences of and wishes for later life care would therefore be valuable. This study did not involve the public in the design of the research, and utilising an Advisory Group with members of the public, to help develop the interview and focus group guide, could have improved the quality of insights from the data collection. Future research should consider the UK Standards for Public Involvement (NIHR, n.d.), or similar, to support collaboration with the public.

CONCLUSIONS AND POLICY IMPLICATIONS

Community-centred approaches have risen as a potential solution to meeting end-of-life care needs in an ageing population, as illustrated in Abel et al.'s (2013) 'circles of care' model. We have explored how the 'circles of care' model could be extended to later life care, by investigating existing care and support in the community, and willingness to participate in a community care model, through receiving/giving help. We found evidence of a broad but shallow reservoir of goodwill towards help-giving within the community, which necessitates revisiting the 'circles of care' model for the context of later life care. We propose the 'ecology of later life care' model, to illustrate the reliance on a core of family and friends as a basis for community-centred care, supported by help-giving from the wider community which is bounded according to familiarity and proximity.

Further to this, policy support will be necessary to drive community-centred later life care, through mobilising collaboration between government agencies/local authorities, health and social care providers, and community organisations to create connections between individuals and people outside their current networks, as can be seen in examples of compassionate communities (such as Aoun et al., 2022; 2023; Liu et al., 2022). These

organisations will be needed to provide the funding support and monitoring that is proposed as necessary to enable a community care model. Policy should also recognise and support the role of professional care services, who will continue to be placed under increasing demand to fill the gaps where the core of family and friends does not exist, and where medical and personal care needs exceed what can be supported by informal carers.

ADDITIONAL FILE

The additional file for this article can be found as follows:

- **Supplementary Information 1.** Figure 1: Data analysis – developing themes. DOI: <https://doi.org/10.31389/jltc.345.s1>

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The authors have no competing interests to declare.

AUTHOR AFFILIATIONS

- Yvette Morey**  orcid.org/0000-0003-1302-4901
University of the West of England, UK
- Sara Spear**  orcid.org/0000-0002-1693-9018
St Mary's University Twickenham, UK
- Alan Tapp**  orcid.org/0000-0002-7951-9264
University of the West of England, UK
- Julia Verne**  orcid.org/0000-0001-5213-5562
UK Health Security Agency, UK
- Stella Warren**  orcid.org/0000-0002-6303-4123
University of the West of England, UK
- Amy Beardmore**  orcid.org/0000-0002-7492-2521
University of the West of England, UK

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