

# Attitudes Towards Changing Care Needs and Experiences of Social Care for People Aged 95 years and Older Living At Home: A Population-Based Study

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## Research article

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# Abstract

**Background:** The 'oldest old' are amongst the largest recipients of social care services and informal care, yet they are under-represented in research and service-user experience surveys. The aim of this study was to understand experiences of receiving social care from formal services and informal carers amongst very old people living in the community.

**Method:** Framework analysis of qualitative data from 36 interviews with community-dwelling people aged 95-101 (n=24) and/or their relatives/carers participating in the UK population-based Cambridge City over-75s Cohort (CC75C) study.

**Results:** Fifty-eight percent lived alone, 75% were disabled, and 42% moderately or severely cognitively impaired. Sixty-seven percent had contact with formal care services and 85% with relatives at least weekly. Informal care mainly supported instrumental activities of daily living, though substituted for, and complemented, formal care at low and higher disability levels respectively. Impractical service delivery and lack of awareness of social care processes and entitlements caused unnecessary distress. Lack of meaningful social interaction, difficulties with bathing and management of continence were key areas of unmet need. Poor continuity of service and frequent changes of formal carers posed a threat to older people's autonomy, dignity and safety.

**Conclusions:** This study revealed a rich complexity of older old care recipients' responses and attitudes not adequately captured in national surveys. As the urgent need to review social care provision receives more attention, there are valuable opportunities to incorporate the views of older old people into service design and delivery, honouring policy directives for person-centred care and improved quality of life.

## Key Messages

- Very old people are generally accepting of their changing care needs and satisfied with frequency of input from social care services
- Remaining at home and avoiding care home admission is an absolute priority for many
- Older people and families experience great difficulties with the logistics and administration of accessing and sustaining care support
- Inconsistency and unpredictability of care staff allocation and their arrival times cause considerable worry and pose threats to older people's autonomy, dignity and safety
- Care workers and their visits are valued for the assistance provided, but lack of time and continuity impedes meaningful social interaction and opportunities to build relationships

## Background

More people are living into older old age and very old age-groups are now the fastest growing sections of the population, across low and middle income countries and the developed world (1, 2). Worldwide the

number of persons aged 80 years or over is projected to triple by 2050 from 143 million to 426 million(1) and the UK has seen a 30% rise over the last 20 years in numbers of people aged 85 or older(3).

The oldest old are most likely to use health and social services to support their increasing care needs(4). Formal social care encompasses a range of services such as care assistants, meal delivery and home cleaning, delivered by contracted, trained and licensed professionals. Informal care includes emotional and practical support provided, typically by family and friends, without formal training, contracts or wage arrangements in place. With well over half a million people (584,024) in the UK aged 90 or older in 2018, planning for the health and social care of the oldest old is an important priority(5). Service-user involvement and person-centred care are core values within UK social care policy and design, yet the oldest old age group are often under-represented in research and service-user experience surveys. Understanding the views, preferences and experiences of the oldest old regarding their care is essential to delivering person-centred care and designing empowering services. Research in this area has been scant(6–12).

The landscape of how we provide care in an ageing society is constantly evolving and there is concern that the current systems are unsustainable(4, 5). The formal care sector is facing growing pressures in supporting rising numbers of older people to continue living at home(13), with increasingly complex co-morbidity(14–16). The number of family and friends providing informal care in an unpaid supportive role is also increasing, with many carers themselves aged 65 or older(15, 17, 18). Changes over recent decades have led to a shift away from state provision of services towards a market based economy, encouraging individuals to utilise personal budgets to procure care directly from a range of for-profit organisations(19). However, in contrast to the consumerist discourse of increasing user choice, 80% of older people request their personal budget be managed by their local authority, who use it to pay for council commissioned services(20–22). This reflects the importance of appropriate methods of consultation to meet consumer needs. Current national surveys typically adopt top-down approaches, setting questions around policy incentives(23). Open-ended questions better reflect the priorities of service-users themselves(24).

Using a rare qualitative data resource from interviews with a representative population aged 95 or older living at home, this study addressed three aims: 1) to describe the nature of their formal and informal care provision, 2) to examine to what extent they accepted their changing care needs, and 3) to understand their experiences of care being delivered in their homes through formal social services.

## Methods

Qualitative analysis of cross-sectional data from a mixed methods population-based cohort study.

### Cohort methods

The Cambridge City over-75 s Cohort (CC75C) study is a longitudinal population-based study that started in 1985 and ran until 2013, with follow-up ending when the last participant died. Methods have been

previously described(25, 26) (<http://www.cc75c.group.cam.ac.uk>) but are briefly summarised here. The initial survey (n = 2,610 aged  $\geq$  75) enrolled 95% of patients who were approached through general practices geographically- and socially-representative of the total population of Cambridge. Nine further follow-up surveys conducted every few years maintained high response rates, continuing to include participants in all care settings. Data collection via structured interview (see <http://www.cc75c.group.cam.ac.uk/documentation/questionnaires>) included measures of cognition, activities, health and wellbeing. Participants re-consented following ethical approval granted from the Cambridge Research Ethics Committee for each survey. In 2007 (survey Year 21, n = 44 of 48 surviving participants all aged at least 95), qualitative methods were introduced in order to better capture participants' experiences of ageing, with open-ended topic-guided interviews supplementing quantitative measures in the core survey. These additional qualitative methods have been previously described(11) (see also topic guide: <http://www.cc75c.group.cam.ac.uk/documentation/additional-data-collection-formats/>). Interviews were conducted by three experienced interviewers in the older participants' usual residence, audio-recorded and transcribed. Proxy informants (usually relatives) were also interviewed for further contextual data and their insights into the study participants' experiences. All interview data were anonymised.

## Data sources

This paper reports findings from analysis of all qualitative data for participants who were community-dwelling at the time (n = 24). These comprised 36 interviews contributed by 21 CC75C study participants and 21 proxy informants (13 participant-proxy pairs interviewed separately, four interviewed jointly, one married couple interviewed together with their daughter, two participants interviewed alone and three proxy informants interviewed alone).

## Data analysis

Descriptive statistics summarising quantitative data from core survey measures were used to characterise the sample and their social care support. Summary disability scores were assigned based on six core Activities of Daily Living (ADLs)(27): two instrumental ADLs (cooking and housework) and four personal ADLs (bathing, dressing, getting to the toilet on time and grooming), categorised as 'no ADL disability', 'instrumental-ADL disability only' or 'instrumental-ADL and personal-ADL disability. Physical Health Scores (PHS; range 0–9, missing for n = 4) were calculated based on how many of nine common physical symptoms (poor vision, poor hearing, arthritis, back pain, chest pain, shortness of breath, limb weakness, unsteadiness on feet and tendency to fall) were reported to have affected participants' day-to-day routines in the last month, adapted from previous research with this cohort(28). Depressive Symptom Scores (DSS, range 0–11, missing for n = 6) were derived from the 'Mood' section of the Cambridge Diagnostic Examination for the Elderly (CamDEX)(29) with DSS > 5 categorised as depressed(30). Cognitive impairment, measured by the Mini-Mental State Examination (MMSE)(31), was categorised as mild (score 22–25), moderate (score 18–21) or severe (MMSE score 0–17 or known dementia diagnosis).

Framework analysis was used to analyse qualitative data thematically(32) working from primary coding to more complex themes and connections as the data were charted into a framework matrix. Each transcript was read, re-read and analysed for themes relating to experiences of formal care, and sub-themes were identified. As the analysis progressed, the themes and subthemes were revised and developed. The thematic analysis was carried out by JB and RD with additional input from JF in the later interpretive stages. All three analysts hold clinical qualifications, and JB has additional prior experience as a social care worker.

## Results

### Characteristics of the sample

Of the 24 older people living in the community who comprised the sample, 10 lived alone in their own homes, four lived alone in sheltered housing and 10 cohabited. Of the 10 who cohabited, five lived with children/in-laws, three lived with their spouse, one lived with a sibling and one lived with a paid carer. Table 1 shows the socio-demographic and health characteristics of participants separately for individuals who were living alone (including in sheltered housing) and those cohabiting. As would be expected in such an old population, the majority were women and widowed and levels of disability and physical problems were high. More than a third had moderate or severe cognitive impairment, lower in this community-dwelling sample than would be found in an age matched population-based sample including care home residents. Contact with family members was daily for a third of the sample and at least weekly for 83% (n = 20). Overall, participants were satisfied with frequency of family contact though many expressed that they would like to have more. All reported that they felt they could rely on their family to take care of them.

Table 1  
 Characteristics of participants (n = 24)

	Living alone		Cohabiting	
	n = 14		n = 10	
Age	97.0 (1.5)		97.6 (1.9)	
Mean (SD)	96.6 (1.6)		96.7 (2.8)	
Median (IQR)	95.4–100		95.5–101.4	
Range				
	<i>n</i>	(%)	<i>n</i>	(%)
Sex	3	(21)	2	(20)
Men	11	(79)	8	(80)
Women				
Marital status	0	(0)	3	(30)
Married	14	(100)	7	(70)
Widowed				
Education	10	(71)	6	(60)
Left school aged ≤ 14	4	(29)	4	(40)
Left school aged ≥ 15				
Social class	7	(50)	5	(50)
Manual	7	(50)	5	(50)
Non-manual				
Has relatives nearby	11	(67)	10	(100)
Has friends locally*	10/12	(83)	7	(70)
Relatives visit ≥ 1 x week	12	(86)	10	(100)
Satisfied with family contact†	7	(50)	5/6	(83)
Disability‡	1	(14)	2	(20)
No ADL disability	1	(14)	2	(20)
IADL disability only	12	(86)	6	(60)
IADL and PADL disability				

	Living alone		Cohabiting	
	n = 14		n = 10	
Cognitive impairment§	7	(50)	4	(40)
Cognition intact	1	(7)	2	(20)
Mild impairment	4	(29)	2	(20)
Moderate impairment	2	(14)	2	(20)
Severe impairment				
Physical frailty (PHS ≥ 4)	8/11	(73)	6	(60)
Depression (DSS ≥ 5)¶	4/13	(31)	1/5	(20)
Notes:				
* Data missing on whether any friends locally for n = 2 (both living alone)				
† Data missing on satisfaction with family contact for n = 4 (all cohabiting)				
‡ ADL = Activities of Daily Living				
IADL = Instrumental Activities of Daily Living				
PADL = Personal Activities of Daily Living				
§ Cognition intact = Mini-Mental State Examination (MMSE) scores 26–30				
Mild impairment = MMSE 22–25				
Moderate impairment = MMSE 18–21				
Severe impairment = MMSE 0–17 or, if unable to complete the MMSE, dementia diagnosis from the Cambridge Diagnostic Examination for the Elderly (CamDEX) assessments				
No Physical Health Score calculated for n = 3 due to missing data (all living alone)				
¶ No Depressive Symptoms Score calculated for n = 6 due to missing data (1 living alone, 5 cohabiting)				

[Insert Table 1 here]

## The nature of care delivery

Table 2 shows the distribution of formal care service use. One third of participants received no formal services. Frequency of contact was not recorded for all services, but of the 10 who received help from care workers the majority received care daily (80%, n = 8). Most participants (17/21 who responded) were satisfied with the amount of support they received from community services.

Table 2  
Distribution of formal care services

	Living alone		Cohabiting	
	n = 14		n = 10	
	<i>n</i>	(%)	<i>n</i>	(%)
No formal services	3	(21)	5	(50)
Care worker	7	(50)	3	(30)
Home help*	2	(14)	0	
Community nurse*	3	(21)	3	(30)
Private domestic	5	(36)	2	(20)
Meal delivery*	6	(43)	0	
Day centres	1	(7)	1	(10)
Notes:				
* Data missing for n = 1 participant living alone				

*[Insert Table 2 here]*

Figure 1 shows the number and proportion of participants with informal carers and formal care services supporting them in six key ADLs, in relation to their level of ADL disability (see Methods). The majority of participants required ADL assistance, formally or informally, with many using a combination of the two. Formal carers provided the majority of assistance in the community for all ADLs except housework (Fig. 2). Relative to other ADLs, informal carers mainly supported instrumental ADLs. Informal care substituted for and complemented formal care at low and higher disability levels respectively.

**[Insert Figs. 1 and 2 here]**

## Attitudes towards changing care needs

Older participants' attitudes towards their changing care needs as they grew older were varied. A large proportion of respondents appeared accepting of their changing needs, acknowledging it as an inevitable part of getting older:

*"I'm annoyed that I can't do the things, but now old age is what it's all about, isn't it? You come down a level. You're not keeping up top or going higher. So you just accept, you know, what comes" (ID1 95-year-old woman living alone)*

“After all, you know, it’s like a car that’s running down, isn’t it? There are bound to be bits that aren’t functioning quite as well as they used to” (*ID2 96-year-old man living alone*)

Although many older participants wished that they could still do more for themselves, there was an acknowledgement of their limitations in their physical and cognitive abilities. For example, one respondent who lived in sheltered housing had been keen to maintain her financial independence but realised she would “just have to let it go by” due to her failing eyesight and dexterity, meaning she could no longer read bank statements or enter PIN codes (*ID3 95-year-old woman in sheltered housing*).

Regarding plans for the future if their care needs changed, few had made plans but viewed going into a care home as inevitable in the absence of other options:

“I haven’t thought many times, but it would have to be...what would it be? In a home? What do people do when they can’t stay in a flat?...You know more about that sort of thing that I do. What do people do?” (*ID4 100-year-old woman living alone*)

Though some acknowledged they would rather be in a care home than put additional pressure on their families, in general, the idea of moving into a home was resisted as people were keen to remain in their existing environment. One terminally ill man had asked his GP to promise that he could remain at home. Another respondent who had no family and “nobody in the world” was typical when he said:

“Well, I’m gonna stay here as long as possible. I hope I can stay here for the rest of my days. That’s what I’m hoping for anyway. I know there are facilities if you can’t, but there’s no place like home” (*ID5 97-year-old man living alone*)

## **Acceptance of formal care**

Older participants were largely accepting of their need for assistance from formal care providers. Though some were initially resistant, they went on to enjoy the limited social contact afforded by daily visits from care staff. Some proxies noted that participants were less willing to receive increased care input from their family members as they were worried about being a burden on them:

“I stayed over one night just to see exactly what happened in the morning. When she woke up I helped her onto the commode but after that she didn’t want me to help her get dressed or anything. She said “you’ve all done enough now. I’m getting help now so let’s wait for them to come”. So she stayed in bed and, you know, they didn’t come until quarter to eleven” (*daughter of ID6, 97-year-old woman living alone*)

## **Experience of formal care services**

### **Difficulty accessing services**

Family members were frequently required to arrange care services, often at short notice and with little guidance. Formal care agencies on the lists provided by Social Services were often unavailable and

proxies had to rely on word-of-mouth from other community members and colleagues to find alternative sources of private support, often within pressured time-frames causing much anxiety:

“We felt we were very much on our own. It was this one. The self-funding, you go and do it yourself. They... I mean she more or less said that they wouldn't be able to help us. We got a booklet sent, you know, for in the area. That was it. We had to do it. And obviously the sooner the better 'cos she was taking up a place in [an acute hospital]”.

*(daughter of ID7, 96-year-old woman in sheltered housing)*

## **Timing of services, communication and consistency of care workers**

Lack of control over time slots and punctuality were the major concerns raised by almost every respondent and proxy who had current or previous interactions with formal care services. Formal carers often arrived very late in the mornings to get respondents washed and dressed, were delayed at lunch time and conversely often came very early in the evenings to put respondents to bed. This had widespread implications for the respondents' health, well-being and quality of life. From a basic physical needs perspective, respondents reported being incredibly hungry and “busting” to go to the toilet upon the arrival of carers in the morning (ID8, 99-year-old woman living alone). When breakfast was only provided at 11am, respondents were often not hungry for their lunch when it arrived an hour or two later (ID9, 97-year-old woman living alone). One respondent developed a sore, aching spine and joints from having to lie in bed for almost 16 hours each night from 6 pm to 10am; she had also become clinically dehydrated from deliberately restricting her fluid intake to avoid needing to go to the toilet during the 16 hours she was confined to bed nightly (ID6, 97-year-old woman living alone). From an emotional well-being perspective, being put to bed early was described as an isolating and lonely experience:

“...they see me to my bed, pull my covers up and then they go off. So I'm alone... That's the only time in the day I don't like at all...” *(ID13 100-year-old woman living alone)*

People were seldom notified if carers were running late or unavailable, and were often left to ring agencies to follow-up on carer-workers' availability, with relatives filling in at the last minute. Older participants and proxies were concerned by the lack of continuity of carer staff provided by care agencies; only one participant was unperturbed by this. Older participants would often not know which carer they were expecting and would have to open their doors to unexpected strangers. If respondents preferred certain carers over others, they had no choice as to who arrived at their door:

“No, no. You never know who is coming. That's another thing which I think, for old people, is very baffling. But on the other hand it's better than no-one...Well, we do get the same ones but you never know which. And [lowering her voice] some are much better than others.” *(ID10, wife of 101-year-old man living with her)*

Another area of concern was the amount of time allocated for the formal carers to perform care tasks. Formal carers were reportedly allocated 15–30 minutes per service user, which did not include travel time to the service user's house:

Yeah. The problem is with these carers is that half an hour with them getting here and going upstairs and getting her ready to wash, half an hour is not long enough, is it really.

*(ID11, son of 96-year-old woman living with him)*

Participants reported this limited time allocation left formal carers rushing their roles, often forgetting to complete tasks such as making beds, cleaning the kitchen after use or emptying commodes and rubbish bins.

## **Impact on autonomy**

For those who had relatively low levels of disability and were mobile, autonomy was well preserved and augmented by formal care services, which allowed them to remain living safely within the community. On the other hand, for more disabled individuals – while their macro-level choice of 'where' to live may have been facilitated by the provision of formal services in the community – autonomy over their micro-level choices of 'how' to live, such as bathing, dressing, eating and toileting routines, was frequently compromised due to the unreliable timing of care. In the following exchange a respondent was describing one of the worst things about being her age:

Respondent: "Well, you can't go to the toilet when you want unless you do it in your pants."

Interviewer: "Because you have to wait for carers?"

Respondent: "Yes, or you can't do it when they come. You want to, but you'd break your neck before they get here."

Interviewer: "And that must be extremely difficult."

Respondent: "It is"

*(ID8 99-year-old woman living alone)*

## **Impact on dignity**

There were instances where the formal care services failed to maintain the dignity of the service-users, particularly around personal care and toileting. The unpredictable timing of care in the community often left older people embarrassed. This was a daughter describing the events when her mother's care worker was delayed:

One time she just couldn't hold on and it was very upsetting. She never used to have accidents, she was always so clean, and she was apologising and apologising to the girl who came. She felt so ashamed,

but of course it shouldn't have happened

*(Daughter of ID6 97-year-old woman living alone)*

## **Relationships with formal carers**

Despite the limitations, respondents were grateful for their care workers, acknowledging the difficulties in their role:

"I'm very thankful for people what have helped me. I have... I am really. It's a difficult thing for people to take on invalids and things like that, you know, 'cos I know they do these things.... And things are done for me, you know. I can't do them myself, but things are done for me, which I'm very grateful for. And I'm very lucky to, you know, have them.

*(ID1 95-year-old woman living alone)*

There was sympathy for the plight of care workers, and older participants and proxies displayed concern for carers, describing them as "abused" by the system and its limited resources. Many older participants in the community were very conscious about the scarcity of resources and felt they should not call on Social Services unless there was a desperate need. They did not want to be an unnecessary burden on the system if they could potentially manage alone:

I don't want to bother them if I don't need them. They've got plenty to do with all the others...without doing people what don't need them. They've got plenty to do.

*(ID12, 96-year-old woman living with her husband)*

## **Discussion**

This is the first study of its kind with such an aged surviving cohort from a population-based sample. The analysis has identified the role that formal social services play in providing the most personal and intimate care to the oldest members of our society, and the supportive function that family members fulfil regarding the more practical aspects of daily life, which combine to enable them to continue living at home. The participants' drive to remain at home seemed to be underpinned by the desire both to stay within their own familiar environment and to avoid moving to an institutional setting. The participants described the complexity of their interactions with community care service systems, detailing frustrations with the logistics of accessing and co-ordinating care on the one hand, and their appreciation of the individuals who provide the care on the other. The impact that the limited scope, inflexible nature and frequent unpredictability of the formal care system had on dignity and autonomy was, at times, quite stark. Of particular note was the interaction between formal care services and continence needs, with the erratic timings, frequency and duration of visits leading to particular distress in this area. Concerns about safety, both personal and about their property, also featured.

Our findings show how important informal carers are in helping people with instrumental activities of daily living, such as cooking and cleaning, thereby supporting people remaining in their own homes. The older participants in our study were grateful for the help they received from family members and, in line with findings from Sweden, hinted at the worry about becoming a burden on family members(33). However, concerns about the future supply of unpaid, usually family, carers are widely acknowledged. Although care by spouses or partners is likely to increase as rising male life expectancy leads to fewer widows(34), care by adult children is likely to decline, due largely to their distant location from their aged parents, or economic factors such as women remaining in the workforce longer. It is estimated there will be a shortfall of 160,000 family care-givers by 2032(35). While technological advances may help to provide and facilitate some aspects of care in the future, the social interaction afforded by even a brief visit may well be difficult to replicate.

Findings from Scotland showed care services did not engage socially with older people(36). In our study participants usually valued their formal carers and sometimes valued relationships with them for the social interaction their visits provided, albeit limited. Most preferred continuity of carers where possible and others have identified benefits beyond social interaction that such continuity can bring, such as helping carer-workers to understand the individual and how they like tasks done, leading to more person-centred care(37). However, the hurried nature of formal care interactions leaves few opportunities to develop these relationships with increasingly limited time apportioned to each service user. Findings from interviews with older people in Finland suggest that the busyness of care workers and short time slots extends across borders(38) .

Participants in this study mostly exhibited strong views that they would like to remain in their homes and avoid institutionalised care. This is perhaps unsurprising given that many people who live in long-term care facilities do not want to be living there and that decisions to move into care are heavily influenced by others and often do not reflect the choice of older people themselves(39, 40) or are only brought on by crisis events(41). Nicholson et al found similar importance attached to remaining at home by their frail older interviewees(42) which was explained in terms of maintaining feelings of control. Home was seen to provide an anchorage in older people's lives, a connection with their past, as their health deteriorated and care needs increased. This resonates with findings in our study and perhaps goes some way to explaining the conundrum that, while the participants were often compromised due to the lack of personalisation and communication difficulties experienced with care agencies, there was a general acceptance of these difficulties and a near total lack of impetus to challenge the system. With their voices so silent, it remains incumbent on others to raise the alarm and ensure that their dignity is upheld as they live out their final years.

## **Strengths and limitations**

This study provides insights from a group of people infrequently heard from in research studies. The rarity of access to such an aged cohort render these findings of particular importance. These are compelling findings given their level of validity as a result of the trust that had been developed over more

than twenty years participation in this long-running study at the time of these interviews. All secondary analyses draw on the strengths of longitudinal research but, given generational and social changes, results reinforce the need for further detailed investigation in contemporary aged cohorts. Moreover, although this study included a representative sample from a population-based cohort, all participants were white British, reflecting the relative lack of ethnic diversity in the older population in the study location.

## **Conclusion**

The older participants in this research study have now all died, yet their experiences remain pertinent as the UK undergoes a shift in health and social care policy. Future policy must be planned, and the impacts examined, at both a macro and micro level, as failure to do so could see the continued erosion of morale and dignity in the most vulnerable members of our society.

### **List of abbreviations**

CC75C Cambridge City over-75 s Cohort study

ADLs Activities of Daily Living

IADLs Instrumental Activities of Daily Living

PADLs Personal Activities of Daily Living

PHS Physical Health Score

DSS Depressive Symptom Score

CamDEX Cambridge Diagnostic Examination for the Elderly

MMSE Mini-Mental State Examination

### **Declarations**

## **Declarations**

### **Ethics approval and consent to participate**

Each CC75C study phase was approved by Cambridge Research Ethics Committee (relevant reference numbers: 06\_Q0108\_87 and 08\_H0308\_3) and participants' and proxy informants' consent was re-sought at each new survey and for the informant interviews after participants had died. Consent was obtained from the next of kin for interviews or assessments with any participant with dementia.

### **Consent for publication**

Not applicable

### **Availability of data and materials**

The anonymised datasets analysed during the current study are available from the corresponding author on reasonable request through the CC75C study data sharing request procedures.

### **Competing interests**

None of the authors have any competing interests.

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### **Authors' contributions**

JF, CB, SB and MF devised the study and obtained fieldwork funding and further funding with JB. JF collected data with acknowledged co-fieldworkers below. JF and MF cleaned the data, devised coding frameworks with SB and conducted initial coding. RD, JB and JF further coded the data, conducted the analyses and together wrote the first draft. CB, FS, MF and SB have contributed to conceptual discussions throughout the research process and to re-drafting the manuscript. JB, RD and JF prepared the final manuscript, which all authors have read and approved. JB and RD are joint first authors and guarantors for the paper.

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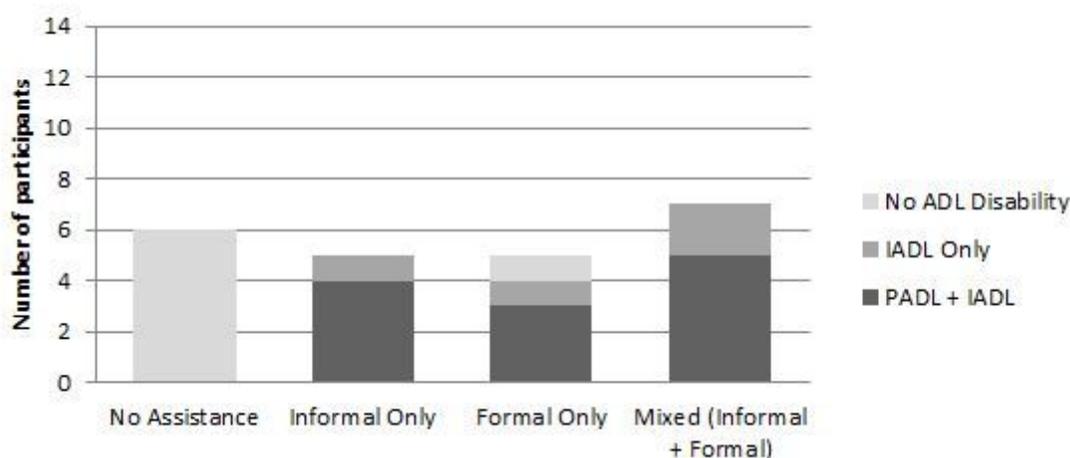
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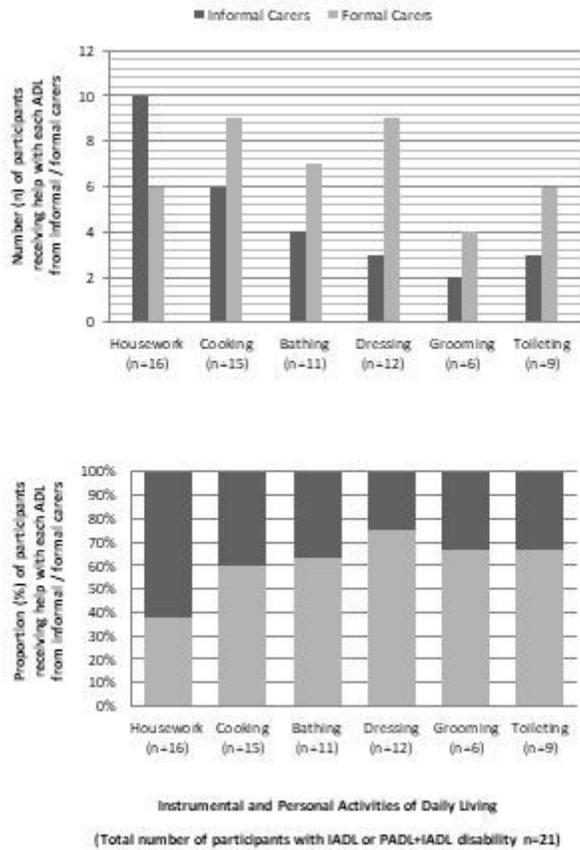
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## Figures



**Figure 1**

Combinations of informal care and formal care services providing support with six core activities of daily living (ADLs), by summary disability score categories [see Fig 1\_Attitudes-experiences-care.docx] Notes: IADL: Instrumental Activities of Daily Living PADL: Personal Activities of Daily Living Legend: Three-quarters of the study's participants received support with either instrumental or personal activities of daily living, or both, from a combination of informal carers and formal care services.



**Figure 2**

Number and proportion of participants receiving help from informal/formal carers with six core activities of daily living Notes: IADL: Instrumental Activities of Daily Living PADL: Personal Activities of Daily Living Legend: Care staff from formal care services were the main providers of assistance with all daily activities, particularly personal activities.