Social Research Methods to Support Involvement of Community Dwelling Older Adults With Complex Needs in Assessment of Their Care Related Quality of Life

Lyn Phillipson (✉ lphillip@uow.edu.au)

University of Wollongong <https://orcid.org/0000-0003-2173-0291>

Ann-Marie Towers

University of Kent at Canterbury: University of Kent

James Caiels

University of Kent

Louisa Smith

University of Wollongong

Research article

Keywords: aging, social policy, dementia, long term care

Posted Date: December 1st, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-113429/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Background: Determining whether the needs and preferences of older adults are being met by new 'ageing in place' and 'consumer directed' care policies presents methodological challenges.

Methods: This study explored how a cascading methodology, offering different supports as needed, promoted assessment of care related quality of life that was inclusive of home care services users with cognitive and physical disabilities. Multiple tools from the Adult Social Care Outcomes Toolkit (ASCOT) were tested in a sample of older adults living at home in one geographic region in NSW (Australia).

Results: Both physical assistance, emotional support and an 'Easy Read' format facilitated the inclusion of those with greater physical and cognitive impairments. Importantly, their inclusion identified their greater unmet needs in seven out of eight quality of life domains.

Conclusion: The adoption of more inclusive social research methodologies is critical to understanding if shifts in aged and social care policies support quality of life for the most vulnerable.

Plain English Summary

It is important that we find ways to engage and involve all older people in evaluating public programs that affect their lives. This includes older people with physical disabilities and cognitive disabilities (such as dementia) who may need supports to live at home. In a lot of countries, governments have changed the way they support older people to live at home longer. Many countries, including Australia, have decided that giving older people their own budget to purchase their own supports, from a service provider of their choice. However, because it can be hard to engage and involve older people with different disabilities in service evaluation and research we are unclear about the extent to which these consumer-directed care models are meeting their needs. In this paper, we argue that in order to include older people with different kinds of disabilities you need to offer a number of different kinds of support. While we started with a general survey to assess needs, we offered a range of tools and supports as the older person demonstrated a need for them to assess their care-related quality of life. This allowed us to involve a greater diversity of older people, and changed what we found out about how older people's care needs were being met. Because of this, we argue that government and aged care agencies must implement more flexible and inclusive methods to support the assessment of quality of life in users of long term care. This is critical to evaluate the extent to which social and health policy and programs are meeting care needs, especially of the most vulnerable service users.

Introduction

With the global aging of the population it is becoming increasingly important that we find ways to engage and involve all older people in evaluating public programs that affect their lives. However, involvement and engagement can present challenges with large numbers of older people living with chronic and degenerative conditions, including dementia (1).

One key area that could benefit from greater involvement is the evaluation of aged care policies and programs which emphasise aging in place at home, with long-term care services delivered in community settings (2, 3). Reforms in aged and disability care in many countries have supported the introduction of consumer directed care (CDC) models on the basis that they can improve autonomy and choice for service users (4-7). However, the evidence surrounding the effectiveness of CDC models is mixed (7-9), especially with regards to supporting vulnerable service users such as those with dementia, mental health issues, financial or social disadvantage and/or low literacy (6, 10-14).

Related to these mixed service evaluations are the research methods used to evaluate service-related outcomes, especially given the complexity and vulnerability of the users of aged and disability care supports. Previous research has highlighted significant challenges with establishing reliable methods to collect care outcome data for people ageing with cognitive and communication impairments. For example, the cognitive impairments inherent with dementia present challenges for recruitment (15); managing consent (16); and with engagement in research processes (16, 17). Impairments can also make results difficult to interpret due to vagueness in speech, decreased vocabulary, poor reasoning of verbal information, confabulations or 'pseudo-reminiscences', perseverations, and confused word associations (18, 19).

There is however, a growing recognition that, with the right support, people with dementia are capable of expressing their views, needs and concerns (20, 21). It is recognised that understanding the experiences of people with dementia is important for evidence-based program and service delivery (17, 22, 23). This is especially so in a CDC aged care market where the success of programs must be understood through the rubric of meeting peoples' preferences and needs.

There is a need for methodological innovation to support the development of valid, accessible and reliable assessment approaches for use with older populations living with cognitive and communication impairments. For people with dementia, new tools have been developed to support assessment of health related quality of life e.g. (24) and social care-related quality of life (25). However, it remains unclear how, when and with whom to use different these approaches and formats, or the types of assistance which may be required to support a cohesive (manageable, meaningful and comprehensible) approach.

This study outlines the value of alternative methods to promote assessment of care-related outcomes inclusive of the voice of the most vulnerable service users. In this study, we trialled the use of two alternative questionnaire formats within a cascading inclusive methodology that offered assistance and support as it was required. The aim was to understand what supports older service users with varying degrees of cognitive and physical impairments needed to participate in reporting their own care-related outcomes, and the value of this reporting to illuminate the service use experiences of this vulnerable cohort.

Methods

This project was conducted from June 2017 to February 2018, with ethics approval from the University of Wollongong (HE16/236). It explored the usefulness of two ASCOT questionnaire formats administered with support 'as needed' to promote self-reporting of care-related quality of life outcomes. Research questions included:

- Does the use of alternative questionnaire formats enable direct report of outcomes from service users who would usually rely on proxy reporting (e.g. those with greater cognitive or physical impairments)?
- What types of support do participants require for each of the two different questionnaire formats?
- Are the findings useful to inform understandings of care-related quality of life for community dwelling people with complex needs receiving supports?
- Are some service users unable to be supported to report against their own outcomes using the proposed methods (i.e. is there a need for further innovation to promote comprehensive assessment for this cohort)?

Assessment of current Social Care Related Quality of Life (ScRQoL)

The Adult Social Care Outcomes Toolkit (ASCOT) is a valid and reliable measure focused on areas of quality of life that can be attributed to care services – Social Care Related Quality of Life (SCRQoL) (26). The eight domains cover core or lower order domains including personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, feeling safe and also higher order domains, including social participation, occupation and control over daily life. The eighth domain, dignity, asks respondents to consider how treatment by care staff makes them feel (26). These domains are directly relevant to the goals of the CDC HCP in Australia the country in which this study was conducted (DOH, 2007).

For each domain of ASCOT, there is one item with four response options, relating to four conceptual outcome states (ideal state, no unmet needs, some unmet needs and high unmet needs). ASCOT has been used extensively to assess care related outcomes in community dwelling service using populations in the UK (27-29), Europe (30-32) and more recently in the Australian older population (33-36). Despite its high validity and reliability, barriers exist to engaging sections of the aged and disabled cohort to report on their own outcomes (37, 38). As such, it is important to better understand the value of utilising different formats and degrees of support to better represent the direct perspective of clients with cognitive and communication impairments.

This study explored the utility of two versions of ASCOT (ASCOT SCT4 and ASCOT-ER) to promote the inclusion of a greater number of service users to self-report their current SCRQoL. The ASCOT SCT4 is a standard, self-complete questionnaire, designed to assess current SCRQoL in the context of receiving care-related services (26). The ASCOT-ER is a modified version of the ASCOT SCT4, initially developed for use with people with autism and intellectual disability (39), and adapted for use with older people with cognitive impairment (25). The Easy Read format uses black and white illustrations and plain text to

convey the meaning of each of the ASCOT social care related quality of life domains. The selection of one of four response options is supported by a visual scale and text based response categories. See Figure 1 for an example comparing the ASCOT SCT4 vs Easy Read 4 level format.

Figure 1. ASCOT 'Food and Drink' domain, ASCOT-ER Pictures, Stem and Response options (top), SCT4 version (below)

Recruitment and procedure

The study was conducted in collaboration with a service provider for community dwelling older people with complex needs through the Australian government funded Home Care Packages (HCP) Program (40). Inclusion criteria were current receipt of HCP supports by this service provider and being resident in the Illawarra-Shoalhaven region of NSW (Australia).

The service provider made initial contact with n=299 potentially eligible participants through a mailed out research information pack. The pack included a letter from the provider encouraging participation in the research. It contained a plain language information flyer which outlined the aims of the research and what would be involved for those who were willing to take part. Potential participants were advised, if they consented to take part, a researcher would make arrangements to come to their home to discuss their experiences and test two different questionnaire formats. The flyer included a photograph of the lead researcher to create a personal connection with potential participants, and invited them to make contact via phone, email or mail if they were willing to participate.

In response, sixty three (n=63) potential participants (or their carers) made contact by phone or email. The first author answered their questions and provided more information about the study. This included advising them that they would be sent a self-complete questionnaire (the ASCOT SCT4), but if they could not complete it on their own they could do it with support when they met with the researcher face-to-face. At this point in the process, fourteen (n=14) participants either declined or were deemed ineligible to take part due to not meeting the inclusion criteria. One participant, whose carer had initiated the phone contact, was deemed unsuitable for participation due to their advanced dementia and was identified at this point as needing alternative methods to assess their outcomes. Appointments were made with forty-eight (n=48) participants. Participants were mailed an ASCOT SCT4, an additional plain language Research Information Sheet and a Consent Form.

On commencement of the research interview, all participants were required to verbally confirm their understanding of the research project and provide written consent. Three were unable to do this satisfactorily, despite showing an interest and willingness to take part. In these cases, verbal and written consent was also obtained from a family carer/guardian for their participation.

Demographic, functional and cognitive data was then collected directly from participants in a supported interview format. This included: age, language spoken other than English, gender, carer status, carer co-residence, education level, self-reported diagnosis of dementia, monthly family finances and level of

Home Care Package. Cognitive status was screened using the Mini-Cog® (a score of < 3 was used as an indication of cognitive impairment) (41, 42). General functional ability was assessed using the Home and Community Care (HACC) functional screener. This tool has a maximum total score of 16, with a lower score indicating more difficulty managing with daily activities of living (43, 44).

The cascading methodology

The research interviews conducted within this study acted as both a way of collecting data about the experience of completing either version of the ASCOT questionnaire and, providing support and assistance to those who needed it to ensure their participation in the study was 'manageable'. Whether or not the participants were able to self-complete the ASCOT SCT4 directed the way the method cascaded during the research interview. If participants were able to independently complete the ASCOT SCT4, they were subsequently interviewed about their responses. If assistance to complete the ASCOT SCT4 was required on the basis of visual or physical impairment, this was provided by the researcher. However, if assistance was required due to the comprehensibility of the questionnaire, they were instead provided with the Easy Read format (ASCOT-ER). Assistance was again provided on an 'as needed' basis, but this time included support for comprehensibility, as well as to aid the focus and/or orientation of participants to promote complete responses for each domain if required.

Detailed field notes were also taken by the researcher regarding the types of assistance and support required by all participants to complete the ASCOT SCT4 or ASCOT-ER questionnaires.

Data Analysis

All interviews were audio recorded and transcribed. Transcripts and field notes were placed in NVivo 11 and deductively analysed, using the framework for research cohesiveness to identify the supports that were required to support a manageable, meaningful and comprehensible assessment experience for the participants (Phillipson, Smith, et al, 2019). Participants were classified as either being 'independent' or 'assisted' for three parts in the research process: 1. Replying (as part of the recruitment process) 2. Providing consent and 3. Completing of the ASCOT questionnaire. This was further analysed to identify whether the assistance was required to 'manage' the demands of the process (e.g. holding a pen, writing or talking on the phone, maintaining focus on topic, prompting to complete responses for each domain) or related to 'comprehensibility' (e.g. ability to make sense of the domain through the text explanation or the pictorial).

Statistical analysis

All demographic, functional and cognitive data collected were entered into a spreadsheet and analysed using Statistical Package for Social Sciences (SPSS 24) (SPSS, 2016). Univariate analysis was conducted on demographic and functional data to identify if there were significant differences ($p < 0.05$) between the characteristics of those able to complete the ASCOT SCT4 vs the ASCOT-ER formats. Tests for normality were conducted to confirm homogeneity of variance (SPSS 2016). With regards to the

continuous variables, only age (in years) was normally distributed – and this was analysed using a t-test. All other continuous variables (e.g. HACC and Mini-Cog) utilised Kruskal Wallis. Tests of normality of categorical variables revealed a lack of homogeneity for all variables. As such, Fisher's exact test was utilised to analyse statistical differences between all categorical variables in the different groups.

Calculating current Social Care Related Quality of Life (SCRQoL). Participant responses were recorded during the interview and then manually entered into an ASCOT Excel Spreadsheet for each outcome state per domain. These excel spreadsheets convert raw scores (1=Ideal state; 2=No needs; 3= Some needs; 4= High needs; -9 = No response) into weighted scores to reflect English population preferences (Australian preference weights do not yet exist). The spreadsheets use an algorithm to calculate an overall score ranging from -0.17 to 1.00. Scores of one represent the 'ideal' outcomes across all eight domains and a score of zero represents a state of quality of life that is equivalent, according to the general population, to 'being dead'. Negative scores indicate a state worse than death (45).

The ASCOT-ER differs from other questionnaires in the toolkit by asking two separate questions in the 'Safety' domain. This allows participants to distinguish between safety in the home and that experienced in the local area. To enable the calculation of an overall current SCRQoL score using the weighted preferences, and comparability with the other ASCOT measures, in this study, the 'Safety' score indicating the highest unmet need for each participant was utilised.

Results

Overall, there were 63/299 responses to the mailed research invitation (21% response rate). However, n=15/63 of these chose not to take part in the study. 14/15 of these responses were family carers advising ineligibility (e.g. due to the participant being in hospital or admitted to residential care). One other response, also from a carer, confirmed that the HCP recipient was immobile and non-verbal. As such, this participant was identified as needing alternative methods to assess their outcomes.

In total forty-eight (n=48) respondents agreed to participate. Five did not complete the study requirements due to sickness (n=1), unwillingness to trial alternative research methods (n=2) or identification of the need for other assessment methods during the research trial (n=2).

Figure 2. Study flowchart

Demographic Characteristics of Participants

Overall, demographic, functional and current SCRQoL data were obtained from n=43 participants. The demographic characteristics of those able to rate their current SCRQoL through completion of either the ASCOT SCT4 or the ASCOT-ER are displayed in Table 1. Participants in the study were mostly: old (Mean age 84.2 years), female (69%), supported by a family carer (67%; 23% co-resident); had more than a high school education (53%), and reported adequate financial circumstances (usually had some money left over at the end of each month) (65%). People who spoke a language other than English (LOTE) were not

well represented and less than 25% of respondents were receiving the highest level of care package (Level 4).

Table 1. Characteristics of participants using ASCOT SCT4 vs ER

Demographics	Total <i>n</i> = 43	SCT4 <i>n</i> = 35	ER <i>n</i> = 8	<i>P</i> value
Age, mean (SD)	84.27(7.1)	83.56 (7.2)	87.38(6.17)	0.000*
Gender, Female <i>n</i> (%)	28 (65%)	24 (69%)	4 (50%)	.121
LOTE, yes <i>n</i> (%)	1 (2%)	1 (3%)	0 (0%)	1.000
Carer, yes, <i>n</i> (%)	29 (67%)	22 (63%)	7 (88%)	0.099
Co-resident, yes, <i>n</i> (%)	10 (23%)	8 (12%)	2 (29%)	0.166
Dementia, yes, <i>n</i> (%)	3 (7%)	1 (3%)	2 (25)	0.032
Education, > highschool, <i>n</i> (%)	24 (56%)	21 (60%)	3 (37.5)	0.571
Finances, some left over, <i>n</i> (%)	28 (65%)	22 (63%)	6 (75)	0.229
Mini-cog, mean (SD)	4.03 (1.44)	4.55 (0.88)	2 (1.41)	<0.001*
HACC, mean (SD)	11.79(2.74)	23.38 (2.24)	9.38 (3.07)	0.018*
Package Level, <i>n</i> (%) 1	1 (2%)	1	0	-
2	27 (63%)	21	6	-
3	5 (12%)	4	1	-
4	10 (23%)	9	1	-

Value of support to make assessment more manageable for all service users

Overall, 35/48 participants made an attempt to complete the ASCOT-SC4 self-complete survey. Of those, 24/35 were able to complete the SC4 independently. For the other 11/35, participants requested physical assistance due to functional impairment (e.g. visual, physical, fatigue). Others also requested support due to a reported lack of confidence, or a desire to clarify the meaning of some questions before choosing a response.

For those 12/48 who were unable or unwilling to attempt completion of the ASCOT-SCT4, 8/12 were successfully assisted by the researcher to complete the Easy Read format, 2/8 were unable to complete even with assistance, and 2/8 declined to make an attempt even with support.

For those eight participants who were aided by the Easy Read format, success was associated with the researcher providing support for orientation, focus, comprehension and completion of the questionnaire. This support was mostly initiated by the researcher on the basis of an assessed need. Rarely was this support directly requested by the participants.

Finally, there were 3 participants who were unable to be supported to use the Easy Read format. One participant was identified when their carer replied to the research invitation, and two others were unable to be successfully supported during the trial.

See Table 2 for details of needs for assistance and support for successful completion during the various stages of the research and assessment process.

Value of Easy Read format to make assessment more comprehensible

The flowchart in Figure 2 of the cascading inclusive methodology shows how it allowed for more people with cognitive impairment to complete the questionnaire than if the study relied only on the standard questionnaire format (ASCOT SCT4).

Table 2. Need for assistance/support for recruitment and data collection

Tool	Recruitment	Consent	Completion	Comments
SCT4	10/35	0/35	11/35	Assistance mainly to promote ‘Manageability’ of the processes e.g. Visual, hearing, writing. Also some due to anxiety, confidence, loss of interest or fatigue
ER	4/8	3/8	8/8	Assistance mainly to promote ‘Comprehensibility’ e.g. Support for orientation, focus, comprehension, meaning-making.

Statistical analysis showed significant differences in the profile of those who were able to be supported to complete the ASCOT SCT4 vs the ASCOT-ER. That is, those who could not complete that the ASCOT SCT4 but were successfully supported to complete the ER format to rate their current SCRQoL were not only older ($p<0.000$) but also both more cognitively ($p < 0.001$) and functionally impaired ($p=0.018$).

Whilst the size of the study prohibited statistical analysis of differences, comparisons of descriptive data indicate there were also some differences in the self-reporting of met and unmet needs across the eight domains for the two groups (ASCOT SCT4 vs ASCOT-ER). For the ASCOT-ER group, scores in seven of the eight domains, and their overall current SCRQoL scores, were lower than those who were able to complete the ASCOT SCT4 (see Table 3 for details). The two domains where self-reported needs were higher for the ASCOT-ER group than for the ASCOT SCT4 group were ‘Personal cleanliness and comfort’ and ‘Social participation’. The exception was for ‘dignity in care’, with the ER group indicating more ‘ideal’ and ‘no

needs' states than the ASCOT SCT4 group i.e. those with more cognitive and functional impairment rated the kindness and respect with which they were treated by care staff as in a mostly 'ideal state'. For both groups, self-reported need in the 'social' and 'occupational' domains were the highest.

Table 3. Comparisons of current SCRQoL for participants (ASCOT SCT4 vs ASCOT-ER)

Average SCRQoL % of the total	SCT4	ER	Difference
Accommodation	91.43	83.33	8.1
Personal Cleanliness	93.33	70.83	22.5
Food & Drink	97.14	87.5	9.64
Safety	81.9	75	6.9
Social	73.33	62.5	10.83
Occupation	68.57	62.5	6.07
Control	77.14	75	2.14
Dignity	88.57	100	-11.43
Overall SCRQoL (%)	0.86	0.79	0.07

Discussion

There is a growing emphasis on supporting aging in place through the provision of long term care in community settings through consumer directed care models. To evaluate the outcomes associated with this policy change, there is a need for valid and reliable assessments which are inclusive of the voice of all service users. However, this presents numerous challenges when programs are supporting vulnerable populations with multiple co-morbidities, including those aging with cognitive and communication impairments.

This study specifically explored the value of a cascading inclusive methodology, where increasing supports were introduced as needed by participants as a way of promoting the cohesiveness (comprehensibility, manageability and meaning) of assessment of social care related quality of life (SCRQoL). Specifically, it explored the value of two alternative formats of the ASCOT (ASCOT SCT4 and ASCOT-ER) and degrees of functional support needed to assess SCRQoL in older people with complex needs who were recipients of a Home Care Package (HCP) in a region of NSW, Australia.

Value of Easy Read format to promote comprehensible and meaningful assessment

Overall, the use of an Easy Read format (ASCOT-ER) contributed to supporting people with greater levels of cognitive and functional impairment to rate their current SCRQoL. The pictorials used within the questionnaire supported the comprehensibility and meaningfulness of the questionnaire - promoting greater engagement and meaningful self-reflection on care domains. This is consistent with the results from a study which used a cognitive interviewing protocol to adapt the questionnaire for use within this cohort (25). It is also consistent with other research which has highlighted the value of visual methods and aids within research with people with dementia to promote their engagement (46). The use of ER principles is mandatory in the NHS for all health information resources, to ensure that all service users have access to health information in an accessible form (47). Results from this study suggest the benefits of tailored ER in the design of evaluation tools to promote the inclusion of the voice of older people living in community settings with cognitive and communication impairments. Given they are a primary target audience for programs, these types of formats should be seen as mandatory, rather than as exceptional, in evaluation of home based support programs.

Value of support to promote more manageable assessment

In this study, the successful completion of the ASCOT questionnaires in both formats (ASCOT SCT4 or ER) benefitted from the support of the interviewer. The cascading inclusive methodology provided value to participants who needed support for physical and/or cognitive reasons. In addition, unlike other inclusive methods which propose a one-sized fits all adjustment (such as an Easy Read format for all participants), the cascading inclusive methodology adjusts according to need. For example, almost a third who completed the ASCOT SCT4 benefitted from assistance to make their participation more 'manageable'. This was mostly due to physical impairment (e.g. vision, physical limitations, fatigue) though some also reported a lack of confidence, or a desire to clarify the meaning of some questions before choosing a response. In contrast, for those requiring the ER format, assistance was required by all participants and was frequently more intensive, including support to maintain orientation, focus, comprehension and completion of the questionnaire.

The need to adapt methods and provide support for people with dementia to participate in research is established (48, 49). Adaptation is useful, specifically for older people with cognitive impairment to promote meaningfulness in the context of their life stage (25). This study reinforces that whilst the ER format was useful to improve 'comprehensibility' of the domains, administration of the questionnaire within a supported interview protocol was essential to ensure engagement with the questionnaire was 'manageable'(25). Whilst preliminary, the early findings from this study show that support is necessary for use of the ASCOT-ER with this cohort.

Insights and the value of a cohesive social research methodology

Despite the challenges, the use of multiple questionnaire formats and a cascading inclusive methodology was useful to highlight better self-rated outcomes in lower order domains and more needs in higher order domains for all HCP users. This is similar to results from other studies using ASCOT, including the

ACCOM study in Australia (50) and also from studies of long term care users in the community in the UK (9).

Due to the utility of the ASCOT-ER administered in a supported interview format, this study is the first to collect self-reported care-related quality of life outcomes in community dwelling older people with cognitive impairment. This group would either normally be excluded, or have a proxy respond on their behalf. It is important to note that these participants reported consistently poorer outcomes across 7 out of 8 domains. They also reported better outcomes for the eighth domain - 'dignity in care'. This could suggest an area of greater benefit within this domain for this cohort or reflect the value of the different type and intensity of care that people with higher needs were receiving. Whilst only a small scale study, these results merit further investigation to maximise insight into the value of aged care support programs for this vulnerable cohort.

Limitations

This study was conducted for the purposes of understanding the methods that may be required to assess self-reported community care outcomes in a vulnerable aging cohort. It was conducted in a small sample of HCP users from a service provider in a single geographical region. As such, the results obtained about their SCRQoL may not be representative of the population of the provider, the region, or the broader HCP population. The study was also very time intensive and the researchers required dedicated training to provide the needed supports. This may limit future transferability of some of these methods beyond the research environment. Future research is therefore required to apply these innovative methods to assess outcomes in a representative sample of service providers and users in different types of geographical locations.

We had limited success in assessing the outcomes of people with more moderate or advanced dementia. This suggests there is still further need for methodological innovation to promote their inclusion in research and assessment. One approach which may have merit is the multi-methods ASCOT CH3 – adapted to promote greater inclusion of the voice of older people with cognitive and communication impairment living in institutional/care home settings (51) but has not yet been feasible in a community setting.

The use of a mail out invitation to take part in the research was also not useful in supporting participation in HCP users who speak languages other than English, those without the support of an informal carer and those with more moderate and advanced dementia. As such, alternative methods for recruitment are needed to overcome the challenges of recruiting people with dementia for social research, even when using multiple methods (15).

Future research should focus on supporting larger scale research in a representative population. It should also consider the value of training service providers to adapt cascading supportive approaches to support their use of assessment tools as part of routine care planning and service evaluation. Finally, further

methodological innovation is needed to ensure the preferences and needs of those living in community settings with more moderate and advanced impairments are understood and met.

Conclusion

Overall, this study highlights the value of a cascading inclusive methodology which has methods and supports that adjust to the cognitive and physical needs of community-dwelling older people with complex needs. Offering people with cognitive and physical impairments a range of methods and supports to meet their needs allowed us to include the direct perspective of vulnerable people in reporting on their own needs. This is crucial if we are to evaluate the success of programs and policy changes that aim to support older people living with cognitive and/or communication impairments as one of their primary target groups.

Abbreviations

Consumer Directed Care (CDC)

Adult Social Care Outcomes Toolkit (ASCOT)

Social Care Related Quality of Life (SCRQoL)

ASCOT Self - Complete Tool (SC4)

ASCOT Easy Read (ASCOT-ER)

United Kingdom (UK)

Home Care Packages (HCP)

Declarations

Ethics approval and consent to participate

All participants were required to verbally confirm their understanding of the research project and provide written consent. Three were unable to do this satisfactorily, despite showing an interest and willingness to take part. In all cases, verbal and written consent was also obtained from a family carer/guardian for their participation. This project was granted ethics approval from the University of Wollongong (HE16/236) and was conducted from June 2017 to Feb 2018.

Consent for publication

This manuscript does not contain any individual person's data requiring consent for publication

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due the conditions of the ethics approval.

Competing interests

The authors declare that they have no competing interests.

Funding

This work was supported by a National Health and Medical Research Council-Australian Research Council Dementia Development Fellowship (APP1107401) and by an IRT Community Foundation Grant.

Authors' contributions

LP was the chief investigator on the study and was responsible for the overall study design, conduct, data collection, data analysis and led the writing of the manuscript. JC and AT contributed to the study design, provided advice on data analysis and contributed to drafts of the manuscript. LS was involved in supporting data analysis and was a major contributor in writing the manuscript. All authors read and approved the final manuscript.

Acknowledgements

We would like to acknowledge Susan Jenkins who provided worked as a Research Assistant on this project and assisted with some of the participant interviews and assessments. We thank the service provider who supported recruitment of participants for this study. We would also like to acknowledge the participants and their care partners for the time and effort involved to reflect on the value of your care services.

Authors information

Lyn Phillipson is a public health academic who engages in research and action to promote aged and dementia friendly communities. She is known for her community engaged approach to undertaking research with impact. She uses qualitative and participatory methods to work with older people to promote understanding and change in the social, physical and service environments that contribute to their wellbeing. She has particular expertise in working with people with dementia and their care partners.

Ann-Marie Towers is a social care researcher and leads a programme of work to support the development and application of the Adult Social Care Outcomes Toolkit (ASCOT) by researchers, policy makers and care providers. Her research centres on the care of older people, with a particular focus on care homes residents and those living with dementia.

James Caiels has been involved in health and social care research for over 15 years. Much of his research has centred on developing methods to improve the participation of hard-to-engage people in research. He has led numerous projects with the aim of improving engagement with older adults with

Dementia, people with intellectual and developmental disabilities, and people with Autism. Other recent work includes evaluation of the Better Care Fund funded by the Department of Health and Social Care (a policy intended to promote and facilitate better integrated and joint working between the health and social care sectors).

Louisa Smith's research interests centre on the relationship between experiences of disability across the life course, complexity, social policy and social change. Her research works across the disciplines of sociology, disability studies and policy studies. She approaches all research and teaching as means of fostering social inclusion and belonging, through co-production, arts based methods and knowledge translation at all stages of the process.

References

1. World Health Organization. World Health Organization. Global action plan on the public health response to dementia 2017–2025 WHO; 2017 [Available from: <http://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=CEEE5541A5C790F766151B3F5CEAE59?sequence=1>]
2. United Nations. Living arrangements of older persons around the world. New York, US: The Department of Economic and Social Affairs. ; 2005. Report No.: E.05.XIII.9.
3. Department of Health. Aged Care Programs: Commonwealth Government of Australia; 2016 [Available from: <https://agedcare.health.gov.au/programs>].
4. Kodner DL. Consumer-directed services: lessons and implications for integrated systems of care. *International Journal of Integrated Care*. 2003;3:e12.
5. Low LF, Yap M, Brodaty H. A systematic review of different models of home and community care services for older persons. *BMC Health Services Research*. 2011;11:93.
6. Slasberg C, Beresford P, Schofield P. Can personal budgets really deliver better outcome for all at no cost? Reviewing the evidence, costs and quality. *Disability & Society*. 2012;27(7):1029-34.
7. Lundsgaard J. Choice and Long-Term Care in OECD Countries: Care Outcomes, Employment and Fiscal Sustainability. *European Societies*. 2006;8(3):361-83.
8. Meng H, Friedman B, Wamsley BR, Van Nostrand JF, Eggert GM. Choice of personal assistance services providers by Medicare beneficiaries using a consumer-directed benefit: Rural-urban differences. *The Journal of Rural Health*. 2010;26(4):392-401.
9. Netten A, Jones K, Knapp M, Fernandez JL, Challis D, Glendinning C, et al. Personalisation through individual budgets: Does it work and for whom? *British Journal of Social Work*. 2012;42(8):1556-73.
10. Cornell V, Faulker D, Beer A, Karnon J, Beilby J. The rise of the consumer: Engagement of older people with consumer directed care. Centre for Housing, Urban and Regional Planning; 2015.
11. Glendinning C, Challis D, Fernandez JL, Jacobs S, Jones K, Knapp M, et al. Evaluation of the Individual Budgets Pilot Programme. Final Report. Network IBE; 2008.

12. Low LF, Yap M, Brodaty H. A systematic review of different models of home and community care services for older persons. *BMC Health Services Research*. 2011;11:93.
13. Simons B, Kimberley H, McColl Jones N. Adjusting to Consumer Directed Care. The experience of Botherhood of St Laurence community aged care service users. Victoria, Australia; 2016.
14. Gill L, Bradley SL, Cameron ID, Ratcliffe J. How do clients in Australia experience Consumer Directed Care? *BMC Geriatrics*. 2018;18(1):148.
15. Beattie E, O'Reilly M, Brooks D, MacAndrew M, McCrow J. Recruitment of people with dementia and their carers for social research: Lessons learned from nine studies. *Journal of Gerontological Nursing*. 2018;11(3):119-28.
16. Dewing J. Participatory research: a method for process consent with persons who have dementia. *Dementia*. 2009;6.
17. Abbato S. The case for evaluating process and worth: Evaluation of a programme for carers and people with dementia. *Case Study Evaluation: Past, Present and Future Challenges*: Emerald Group Publishing Limited; 2015. p. 107-31.
18. Hubbard G, Downs M, Tester S. Including older people with dementia in research: Challenges and strategies. *Aging and Mental Health*. 2003;7(5):351-62.
19. Crisp J. Making sense of the stories that people with Alzheimer's tell: A journey with my mother. *Nursing Inquiry*. 1995;2:133-40.
20. Hellstrom I, Nolan M, Nordenfelt L, Lundh U. Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*. 2007;14(5):608-19.
21. Smebye KL, Kirkevold M, Engedal K. How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Serv Res*. 2012;12.
22. Dewing J. From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*. 2002;1(2):157-71.
23. De Boer ME, Hertogh CM, Dröes R-M, Riphagen II, Jonker C, Eefsting JA. Suffering from dementia—the patient's perspective: a review of the literature. *International Psychogeriatrics*. 2007;19(6):1021-39.
24. Bowling A, Rowe G, Adams S, Sands P, Samsi K, Crane M, et al. Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging & Mental Health*. 2015;19(1):13-31.
25. Phillipson L, Smith L, Caiels J, Towers A, Jenkins S. A cohesive research approach to assess care related quality of life in older people with cognitive impairment: Lessons learned from adapting an Easy Read survey. *International Journal of Qualitative Research Methods*. 2019;18:1-13.
26. Netten A, Burge P, Malley J, Potoglou D, Towers A-M, Brazier J, et al. Outcomes of social care for adults: developing a preference-weighted measure. *Health Technology Assessment*. 2012;16(16):16.
27. Bauer A, Knapp M, Wistow G, Perkins M, King D, Lemmi V. Costs and economic consequences of a help-at-home scheme for older people in England. *Health & Social Care in the Community*.

- 2017;25(2):780-9.
28. Callaghan L, Brookes N, Palmer S. Older people receiving family-based support in the community: a survey of quality of life among users of 'Shared Lives' in England. *Health & Social Care in the Community*. 2017;25(5):1655-66.
 29. Netten A, Burge P, Malley J, Potoglou D, Towers A-M, Brazier J. Outcomes of social care for adults: developing a preference-weighted measure. *Health Technol Assess*. 2012;16.
 30. Steffansson M, Pulliainen M, Kettunen A, Linnosmaa I, Halonen M. The Association between Freedom of Choice and Effectiveness of Home Care Services. *International Journal of Integrated Care* 2016;16(1).
 31. van Leeuwen KM, Bosmans JE, Jansen AP, Rand SE, Towers A-M, Smith N, et al. Dutch translation and cross-cultural validation of the Adult Social Care Outcomes Toolkit (ASCOT). *Health and Quality of Life Outcomes*. 2015;13(1):56.
 32. Hajji A, Trukeschitz B, Malley J, Batchelder L, Saloniki E, Linnosmaa I, et al. Population-based preference weights for the Adult Social Care Outcomes Toolkit (ASCOT) for service users for Austria: Findings from a best-worst experiment. *Social Science & Medicine*. 2020;250:112792.
 33. Agree Collaboration. Development and validation of an international appraisal instrument for assessing the quality of clinical practice guidelines: the AGREE project. *Qual Saf Health Care*. 2003;12.
 34. Cardona B, Fine M, Stebbing A, Duncan C, Samsa P, Eagar K. Measuring consumer outcomes: Development and testing of the Australian Community Care Outcomes Measure. *Australasian Journal on Ageing*. 2017;36(1):69-71.
 35. Kaambwa B, Lancsar E, McCaffrey N, Chen G, Gill L, Cameron ID, et al. Investigating consumers' and informal carers' views and preferences for consumer directed care: A discrete choice experiment. *Social Science and Medicine*. 2015;140:81-94.
 36. Tang J, Ryburn B, Doyle C, Wells Y. The Psychology of Respite Care for People with Dementia in Australia. *Australian Psychologist*. 2011;46(3):183-9.
 37. Rand S, Caiels J, Collins G, Forder J. Developing a proxy version of the Adult social care outcome toolkit (ASCOT). *Health and Quality of Life Outcomes*. 2017;15(1):108.
 38. Turnpenny A, Caiels J, Whelton B, Richardson L, Beadle-Brown J, Crowther T, . . . Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT). *Journal of Applied Research in Intellectual Disabilities*. 2016;31(1):e36-e48.
 39. Turnpenny A, Caiels J, Whelton B, Richardson L, Beadle-Brown J, Crowther T, et al. Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT). *Journal of Applied Research in Intellectual Disabilities*. 2018;31(1):e36-e48.
 40. Department of Health. Consumer Directed Care - Online Video: Australian Government 2017 [Available from: <https://agedcare.health.gov.au/programs/home-care/information-resources-home-care-package-delivery>].

41. Borson S. MiniCog Screening for Cognitive Impairment in Older Adults 2017 [Available from: <https://mini-cog.com/about/strengths-and-limitations/>].
42. Lorentz W, Scanlan J, Borson S. Brief screening tests for dementia. Review. Canadian Journal of Psychiatry. 2002;47(8):723-33.
43. Eagar K, Owen A, Marosszeky N, Poulos R. Towards a measure of function for home and community care services in Australia: Part 1 Development of a standard national approach Australian Journal of Primary Health. 2006;12(1):73-81.
44. Green JC, Eagar K, Owen A, Gordon R, Quinsey K. Towards a measure of function for Home and Community Care Services in Australia: Part 2 – Evaluation of the screening tool and assessment instruments. Australian Journal of Primary Health. 2006;12(1):82-91.
45. Netten A, Jones K, Knapp M, Fernandez JL, Challis D, Glendinning C, et al. Personalisation through Individual Budgets: Does It Work and for Whom? The British Journal of Social Work. 2012;42(8):1556-73.
46. Phillipson L, Hammond A. More Than Talking: A Scoping Review of Innovative Approaches to Qualitative Research Involving People With Dementia. International Journal of Qualitative Methods. 2018;17(1):1609406918782784.
47. Health Do. Basic guidelines for people who commission Easy Read information. 2010.
48. Cridland EK, Phillipson L, Brennan-Horley C, Swaffer K. Reflections and Recommendations for Conducting In-Depth Interviews With People With Dementia. Qualitative Health Research. 2016.
49. Wilkinson H. The Perspectives of People with Dementia: Research Methods and Motivations. Philadelphia, US: Jessica Kingsley Publisher Ltd; 2002.
50. Cardona B. Measuring outcomes of community aged care programs: challenges, opportunities and the Australian Community Outcomes Measurement ACCOM tool. Health and Quality of Life Outcomes. 2018;16(1):104.
51. Towers A-M, Holder J, Smith N, Crowther T, Netten A, Welch E, et al. Adapting the adult social care outcomes toolkit (ASCOT) for use in care home quality monitoring: conceptual development and testing. BMC health services research. 2015;15:304-.

Figures

This question is about what you eat and drink. Think about if:

- You can have the food and drinks you like.
- You have enough food and drinks to keep you healthy.
- You can eat and drink as often as you need to.

What do you think about what you eat and drink?

Please tick (✓) 1 box

I get all the food and drink I like when I want.	☐	
I get enough of the food and drink I like when I want.	☐	
I get some of the food and drink I like when I want, but not enough.	☐	
I do not get any of the food and drink I like so I might get ill.	☐	

3. Thinking about the food and drink you get, which of the following statements best describes your situation?

Please tick (✓) one box

I get all the food and drink I like when I want	☐
I get adequate food and drink at OK times	☐
I don't always get adequate or timely food and drink	☐
I don't always get adequate or timely food and drink, and I think there is a risk to my health	☐

Figure 1

ASCOT 'Food and Drink' domain, ASCOT-ER Pictures, Stem and Response options (top), SCT4 version (below)

This question is about what you eat and drink. Think about if:

- You can have the food and drinks you like.
- You have enough food and drinks to keep you healthy.
- You can eat and drink as often as you need to.

What do you think about what you eat and drink?

Please tick (✓) 1 box

I get all the food and drink I like when I want.	☐	
I get enough of the food and drink I like when I want.	☐	
I get some of the food and drink I like when I want, but not enough.	☐	
I do not get any of the food and drink I like so I might get ill.	☐	

3. Thinking about the food and drink you get, which of the following statements best describes your situation?

Please tick (✓) one box

I get all the food and drink I like when I want	☐
I get adequate food and drink at OK times	☐
I don't always get adequate or timely food and drink	☐
I don't always get adequate or timely food and drink, and I think there is a risk to my health	☐

Figure 1

ASCOT 'Food and Drink' domain, ASCOT-ER Pictures, Stem and Response options (top), SCT4 version (below)

Figure 2

Study flowchart

Figure 2

Study flowchart

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [GRIPPShortForm.docx](#)
- [GRIPPShortForm.docx](#)