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Towers, A., Nelson, K., Smith, N. & Razik, K., (December 2018/January 2019). Using ASCOT in care planning conversations. Australian Journal of Dementia Care, 7(6), p31-35.

Report on a joint UK-Australian project which trialled a new and innovative use of the ASCOT tool in residential aged care planning to help staff initiate and hold conversations with residents, including those with dementia, about their emotional and social wellbeing

Australia's population is ageing and with 54% of aged care residents estimated to have dementia (AIHW 2012), finding ways to measure and improve the quality of the care and support they receive is becoming increasingly important. As providers face increasing pressure to be accountable for the quality of their services, being able to measure outcomes will also become even more imperative.

However, measuring the quality of care and the impact of aged care services on quality of life and wellbeing, consistently and systematically, is a challenge for many aged care providers. The clinical bias in care planning and reporting in Australian residential aged care is exacerbated by the (mainly) clinical base of the current Aged Care Funding Instrument (ACFI). This has resulted in a lack of focus on evaluating the impact of services on wellbeing.

The Adult Social Care Outcomes Toolkit (ASCOT), developed by the Personal Social Services Research Unit (PSSRU) at the University of Kent in the UK, is one of the few tools able to measure the impact of care services on user wellbeing or Social Care Related Quality of Life (SCRQoL). It is internationally recognised as robust and can be used in a variety of settings and with people with any disability, including dementia.

ASCOT measures Social Care-Related Quality of Life (SCRQoL) across eight domains (see Box 1 and Table 1) and can also be used to estimate the impact a service is having on those outcomes. The eight domains of wellbeing cover four lower-order-needs (accommodation, food, safety, personal care) and four higher-order-needs (social interaction, occupation, control over daily life, dignity). The four lower domains are traditionally much easier to support, whereas the four higher domains are more challenging for providers to support well.

Reliability of the ASCOT tool is well evidenced internationally. The measure has been used in research in the UK, Australia, Japan and Europe and its domains have been found to be relevant to providers, service users and their families and sensitive to the impact of services on users' quality of life (Malley, Towers et al 2012; Netten, Burge et al 2012)

While widely used to assess and review care programs and services in the UK and other countries, the ASCOT's use in Australia is less common.

In 2016, the ASCOT team at PSSRU and Australian aged care provider the Whiddon Group embarked on a project to explore how they might use the ASCOT to inform care planning conversations with residents, including those living with dementia, in their aged care services. Whiddon's review of its care planning practices had

identified a gap around consistent evaluation, goal setting and structures in the wellbeing area. Importantly, some RNs said they were not confident initiating and conducting conversations with residents around their emotional and social needs

During 2016-2017 the PSSRU team and the Whiddon Group conducted a 15-month trial at four Whiddon aged care homes in NSW to test the feasibility and benefits of using the ASCOT in care planning in residential aged care, as well as the sustainability and effectiveness of the 'circle of care' interview methodology designed for the trial.

Although ASCOT has previously been used in 'assessment and review' in the UK (Johnstone & Page 2014) the integration of ASCOT into care planning, and the 'circle of care' approach that enabled people with dementia to participate, represented a new use of the ASCOT both in Australia and internationally, particularly in residential aged care.

This article provides an overview of the ASCOT pilot study in Australia, along with Whiddon's perspective on what was learnt through the trial in terms of value added to care planning and quality of care, relationship-based care and client and family empowerment, as well as the sustainability of the methodologies used.

Box one: the ASCOT domains

The Whiddon trial

The University of Kent's ASCOT team helped design the trial and methodology, and provided webinar and online training tools for Whiddon's RNs, as well as ongoing support to the trial managers. Whiddon ran the trial, conducted mentoring and support sessions before and semi-structured interviews with RNs after each wave of

the trial. The RNs conducted ASCOT conversations and collected data, which was submitted to, analysed and reported by the ASCOT team.

The main goals were to test the integration of the ASCOT in care planning. This included:

- Its value to residents and improved quality of their care (including its alignment with Whiddon's MyLife model and relationship-based care approach).
- User-friendliness and effectiveness of the tool and 'circle of care' methodology for residents, families and RNs.
- Sustainability of conducting ASCOT conversations as part of care planning in terms of additional RN time and burden to residents and families.
- The value to quality improvement of services at individual, service and system level.

Adapting ASCOT for care planning purposes
The ASCOT consists of a suite of measures for service users ((https://www.pssru.ac.uk/ascot/), including; self-completion questionnaires (SCT4 & SCT4-ER), face-to-face interviews (INT4) and a mixed-methods approach for measuring the outcomes of care home residents (CH3). Different tools are recommended for different settings and user groups.

We used the ASCOT face-to-face interview tool (INT4) in care planning conversations in the four sites. As the ASCOT INT4 measure was not designed for people with cognitive impairment and/or difficulty communicating, we expected most aged care residents to struggle to complete it without help. To overcome this but still include clients in their care planning conversations, we needed a methodology where a rounded perspective was gathered for residents living with dementia and then used to complete the ASCOT interview tool (INT4). The ASCOT team proposed an innovative approach to completing the INT4 whereby trained RNs led care-planning conversations involving the resident, their family members and their dedicated care worker. We called this a 'circle of care'.

Together, the circle of care worked through the eight ASCOT domains, discussing the residents' quality of life in each. Ultimately, the aim was to indicate, by ticking one of four possible response options, whether the residents' needs were being met by the service in this area of their life and, where necessary, discuss how their experience might be improved. An example taken from the control over daily life domain can be found in Box 2.

For each ASCOT domain, there is one question regarding the person's current quality of life and four possible response options. Conceptually, these response options correspond to the following outcomes states:

1. Ideal state (person's needs and preferences are met in this area of life).
2. No needs (person has no or only temporary/trivial unmet needs).

3. Some needs (sufficiently important or frequent to affect the person's quality of life).
4. High needs (physical or mental health implications if they are not met over a period of time).

Box 2: question and response options from the ASCOT 'control over daily life' domain

Which of the following statements best describes how much control you have over your daily life?

Interviewer prompt: By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want. If needed, please prompt: When answering the question, think about your situation at the moment.

Please tick one box.

I have as much control over my daily life as I want	[ ]
I have adequate control over my daily life	[ ]
I have some control over my daily life, but not enough	[ ]
I have no control over my daily life	[ ]

For each ASCOT domain there is also a second question which asks the person (or their carer) to say what their expected quality of life would be if they were not in a care home and were living in the community with no additional support services. The responses help identify the gap between the person's expected and current quality of life and the impact of care services.

Balancing the perspectives of clients, their family member(s) and the dedicated care worker and then using this information to choose a rating that accurately represents the resident's quality of life in each domain requires a skilled and considered approach. The reliability of the ratings, and the sustainability of the approach, measured in terms of additional RN time, were set as critical success factors for the trial.

The pilot study

All participating RNs at the four sites received online, webinar materials before baseline and had ongoing support from the ASCOT team throughout the study.

ASCOT data were collected at baseline (T1), six months (T2) and 12 months (T3), along with data on participating residents' needs and characteristics and feedback from RNs, collected by Whiddon, about the 'circle of care' conversations.

This article focuses on the 12-month follow-up data and the feedback from qualitative interviews with RNs regarding their experience of using ASCOT in care planning.

Results

Residents*' needs* and characteristics

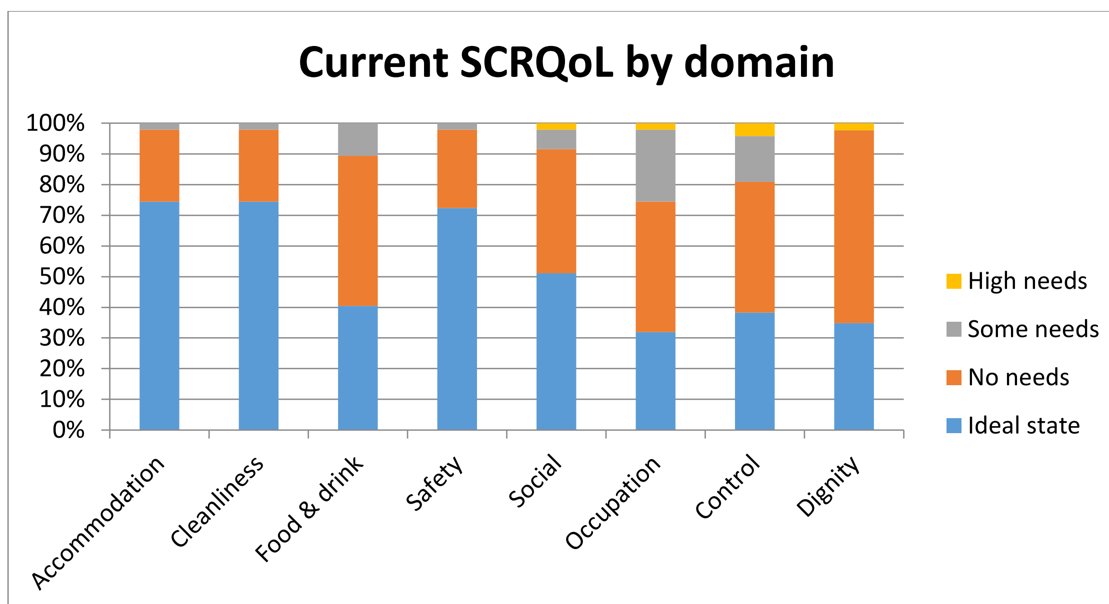
A total of 61 residents took part in the trial across the three waves. This summary focuses on the findings at wave three (12 month follow up), which had a sample size of 47 residents (ranging from 11 to 13 per service) with an average age of 86 years. The majority (62%) were women. Nineteen participants were diagnosed with dementia, but more (n=31) had short-term memory problems. On average, most residents had lived in the service for about 16 months and could manage about six activities of daily living (ADLs) on their own without help.

Residents' SCRQoL

As the ASCOT is preference-weighted for use in economic evaluations (Netten, Burge et al 2012), scores for SCRQoL range between 1 and -0.17. A score of 1.00 is achieved when each domains is rated as ideal state. A score of -0.17 is achieved when each domain is rated as high needs. A score of below 0 is equal to what the general population sees as a state worse than death.

The average SCRQoL score at the 12-month follow-up (T3) was 0.83 across all four settings (ranging from 0.76-0.87 per setting). Although this is high compared to other studies of ASCOT use in the UK, in which the mean current SCRQoL score for care home residents was around 0.71 (Netten, Trukeschitz et al 2012; Towers, Smith et al 2016), it is comparable with other work using the ASCOT in Australia (Kaambwa, Gill et al 2015; Cardona, Fine et al 2017).

The bar chart below summarises the distribution of responses in each domain. Services were very good at meeting residents' needs in the four basic domains (accommodation cleanliness and comfort, personal cleanliness and comfort, food and drink and personal safety) and dignity. In these domains, no residents were recorded as having high (unmet) needs, although a small proportion did have some unmet needs, meaning their quality of life was being affected. Following the pattern found in English care homes (Towers, Smith et al 2016), there is more evidence of unmet needs in the higher order domains of social participation, occupation and control over daily life and also less evidence that people are in the 'ideal' state compared with personal safety, accommodation cleanliness and comfort and personal cleanliness and comfort.



Time taken to complete the interviews
Based on the RNs' estimations, the mean time to complete the ASCOT care planning conversations ranged from 19-28 minutes, with a mean of 25 minutes across all four services. On average, RNs estimated that these interviews took only an additional two minutes, compared with usual care planning conversations, by wave three.

RNs' perspectives
Whiddon conducted semi-structured interviews with the RNs at six-monthly intervals. The majority of RNs reported that residents were feeling empowered, "at the centre of their world" as a result of having structured conversations around their wellbeing. "They feel that it gives them a safe place to talk about feelings, and that we want to hear them. It doesn't feel like a whinge."

RNs reported learning things about new residents that would normally take much longer to 'come out' and that the structured conversations helped to facilitate good outcomes and solutions. For example, one lady with dementia, who came into care with her husband, who had been her primary carer, immediately confided in the RN that she was distressed that her husband had requested that she be excluded from the social and creative programs. The RN was able to discuss this openly, as part of an ASCOT conversation, with her husband and a joint decision was made that his wife should participate in the painting program, which she did with enthusiasm. For his part, through these conversations, her husband was able to come to terms with being in residential aged care, and the benefits to his wife.

Residents' and family members' feedback
Residents reported that having the structured conversations, and seeing issues followed up, made them feel that "the staff really care about me". Family members reported that they were learning things about their family member that they had not heard before, and they now felt more involved in their care, and able to follow up on things with the RN.

Feasibility of using ASCOT in care planning conversations
RNs reported that the tool was easy to use and a good base for conversations. Some of the wording required explanation, reflecting cultural differences. This, coupled with the high average SCRQoL scores, which have also been reported in other Australian research using ASCOT, might indicate the need for future research to test and culturally adapt the wording for an Australian population.

There is also likely to be value in conducting a preference study to develop scoring weights specific to the Australian population.

The question about 'expected quality of life' if the person was not in a care home attracted criticism. It was deemed relevant to ask new residents, but not beyond three months when it had the effect of 'closing down' conversations with traumatic thoughts. Instead, it might be better for these estimations to be made by trained RNs instead of asking residents directly, which is more in line with the mixed-methods ASCOT toolkit used by researchers in care homes (Towers et al 2016).

The circle of care methodology, while effective for residents with dementia, required some amendment as the administrative burden of trying to hold one conversation with all participants present proved too onerous.

Notwithstanding these areas for review, the value to care planning and the sustainability of integrating the ASCOT conversations in Whiddon's normal case conferencing and annual care planning cycle was clear for most of the RNs.

The consistent and structured conversations and the insights gained around residents' social and emotional needs is a good support to the relationship-based care which underpins Whiddon's model of care. This is illustrated by the following quote from a RN: "This gives us the time to stop and recognise that they are people too, like us, and the challenges they experience around accepting help".

Discussion: what we learnt

The data showed us that the homes in this pilot study were good at supporting residents across most of the lower order domains and that staff deliver care in a way that makes residents either feel good about themselves or does not affect their self-image.

Food and drink was more challenging. Our relationship to food is complex and touches many emotional and social needs. Some residents were not happy with the modifications to their food following a dietician's prescription. One or two residents were not happy with the quantity they were receiving, and this trial was the first time that they had given this feedback. This information gave Whiddon staff the opportunity to make improvements and during the study they were able to work on all of these needs and saw improvement from waves 1 to 3.

The higher order domains are relatively more difficult to support. The services were particularly good at supporting social participation but scores were relatively lower for control over daily life, suggesting further areas for focus.

Whiddon learnt that average SCRQoL scores on their own are not a good indicator of service performance. They have to be seen in the context of the individual's care and functional needs and the care profile of the different services. As this was a pilot, there were not enough data to really understand this; with more time and data we should be able to better interpret trends.

Conclusion

Residents and their families responded well to the ASCOT domains and the questions opened up conversations about aspects of their lives that staff felt would otherwise have been missed. Indeed, in one site, a whole service issue around meals was identified because of the focus of the ASCOT questions. The care planning meetings lasted no longer than usual but successfully refocused the attention on well-being. Staff reported having a better understanding of how they could better support residents' social and emotional needs with more tailored and personalised care.

Structured interviews around residents' emotional and social needs don't usually happen in residential aged care. The use of the ASCOT tool facilitates this process, providing a basis for these conversation. It also has the benefit of being able to rate quality of life and measure outcomes over time.

The increased empowerment of residents and families and the underpinning of Whiddon's relationship-based care approach were two of the strongest factors in the organisation's decision to pursue full integration of ASCOT in its care planning processes and systems following the trial. Whiddon is currently working with the ASCOT team and its care planning systems provider to integrate the ASCOT tool. In the meantime the ASCOT is an integral part of evaluating and providing wellbeing goals for our relationship-based care program.

Accessing the ASCOT tool and training

Service providers or individuals in Australia and overseas can access the ASCOT by registering with the University of Kent PSSRU and obtaining a licence. The registration form can be downloaded from the ASCOT website at www.pssru.ac.uk/ascot/licensing/. The licence is free for not-for-profit use. For-profit use incurs a fee based on type of use, number of participants, size of the study etc. For more information, visit the website and watch the tutorial videos: https://www.pssru.ac.uk/ascot/tools/

- **In June 2018, the Whiddon Group won the 2018 NSW/ACT Organisation Award in the inaugural Leading Age Services Australia (LASA) Excellence in Age Care Service Awards for the ASCOT work and was listed in the 2017 Australian Financial Review's Top 50 most innovative Australian and New Zealand companies, primarily for its integration of the ASCOT tool.**

- **Authors Karn Nelson, Ann-Marie Towers and Nick Smith, also spoke at the British Society of Gerontology conference in Manchester in July on different projects where the ASCOT tool was used to measure outcomes (www.britishgerontology.org/events-and-courses/past-conferences/2018-manchester).**

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Table 1: ASCOT domains of social care-related quality of life

Domain	Definition
Control over daily life (choice)	The person can choose what to do and when to do it in his/her daily life
Personal comfort and cleanliness	The person is personally clean, comfortable and is dressed and groomed in a way that reflects his/her personal preferences
Food and drink	The person feels that s/he has a nutritious, varied and culturally-appropriate diet with enough food and drink that he/she enjoys when s/he wants it
Accommodation comfort and cleanliness	The person feels their home environment, including all the rooms, is clean and comfortable
Personal safety	The person feels safe and secure; not feeling worried about bullying or abuse, falling or other physical harm, or being attacked or robbed.
Social participation and involvement	The person is content with their social life; spending time with the people they like, including friends, family and people in the community.
Occupation (how you spend your time)	The person feels that they are able to spend their time during the day doing enjoyable and meaningful activities, which could include free time or leisure activities, housework, going to work, college, or volunteering.
Dignity	The psychological impact of support and care on the person's personal sense of significance; the person feels that s/he is treated nicely and kindly by paid support staff

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