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RESEARCH

Identifying Loneliness and Social Isolation in Care Home Residents with Sight Loss: Lessons from Using the De Jong Gierveld Scale

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Context: Experience of loneliness amongst care home residents with sight loss is associated with limitations in activities of daily living, poor self-reported health, and increased rates of depression. Care homes are encouraged to use screening tools to identify those at risk of loneliness.
Objectives: The study aimed to describe the findings and experience of applying a validated, multi-item scale to identify loneliness and isolation in care home residents with sight loss in England, UK.
Methods: The six-item De Jong Gierveld Loneliness Scale was administered to residents residing in long-term care homes with sight loss. Participants were aged 65+ years old with vision impairment that could not be corrected by glasses. Descriptive analysis of loneliness scale data was undertaken supplemented with observational field notes of implementation challenges.
Findings: Only 42 applications of the De Jong Gierveld Loneliness Scale were possible. The mean sub-scale scores for emotional loneliness, social loneliness and the mean overall loneliness score were 1.36 (sd = 1.16), 1.19 (sd = 1.04) and 2.55 (sd = 1.9) respectively. Challenges observed in scale administration and understanding of scale items by residents might preclude it as a loneliness case-identification tool in busy care home environments.
Limitations: The study reports on the challenges implementing a questionnaire which achieved a low rate of data collection.
Implications: For case-identification of loneliness, care homes may wish to consider use of a single-item loneliness question rather than multi-item scales due to variable length of administration and resident comprehension.

Keywords: loneliness; social isolation; sight loss; care homes; older people

Background

There is growing evidence around the challenge posed by loneliness, with over nine million people in the UK—almost a fifth of the population—reporting they are always or often lonely, although almost two thirds feel uncomfortable admitting to it (British Red Cross, 2016). Loneliness is a deeply personal experience, which makes the issue particularly complex. There is momentum in both policy and practice towards addressing what is widely regarded as a troubling phenomenon. The Campaign to End Loneliness (CEL, 2019a) UK has created a resource that provides adult social care, clinical commissioning groups and public health teams with guidance on planning how to address the loneliness experienced by older people in their local populations. The Care Act 2014 (HM Government, 2014) creates clear authority through the wellbeing principle for health and social care services to take action to address loneliness and isolation. This includes meeting the new prevention duties and addressing care and support needs identified during assessments. In addition, the Campaign to End Loneliness advises that local authorities ensure that their Better Care Fund plans include action to address social well-being (The Kings Fund, 2014).

Loneliness in care homes has been identified as a particularly acute problem; the prevalence of 'severe loneliness' reported by care home residents (22–42%) is more than twice that of residents in the wider community (10%) (Victor, 2016). The experience of loneliness in nursing home residents is associated with significantly higher limitations in activities of daily living, poor self-reported health, disability, mobility problems, reduced cognitive function, depression, poor psychological well-being and ultimately a significantly higher mortality risk (Jansson et al., 2017; Marx et al., 1992).

A related concern is the growing intersection between loneliness in care homes and visual impairment. The prevalence of sight loss increases with age, and current

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projections anticipate a 122 percent increase in the number of blind and partially sighted people in the UK by 2050 (Access Economics, 2009). While the exact number of people with sight loss living in care homes is not known, an RNIB estimate suggests that as many as half of older residents have some form of vision impairment (RNIB, 2010).

Sensory impairment has an impact on maintaining interaction with fellow care home residents (Cook et al., 2006) loneliness and isolation are not inevitable consequences of sight loss (Hodge & Eccles, 2014). Indeed, loneliness is linked more strongly to people's *experience* of sight loss than the extent of actual vision impairment (as clinically assessed). This suggests that there are multiple factors that mediate the link between sight loss and social health. One qualitative study found that residents with sight loss could not sustain friendships because they were unable to recognise people in a communal environment (Ward & Banks, 2017). Other challenges in addressing isolation included difficulties with getting around the care home and a lack of assistive technologies; for example computer tablets or E-readers to keep people occupied and an absence of befriending services from local sight loss charities (Ward & Banks, 2017). Similar research in the USA supports these findings (Meehan & Shura, 2016).

The challenge of measuring and identifying loneliness

The above studies relied on qualitative methods, and to the best of our knowledge no quantitative assessment of loneliness and social isolation has been undertaken amongst residents with sight loss living in care homes. The Campaign to End Loneliness UK (CEL, 2019b) recommends several validated measures, but it is not clear if they are appropriate for use in care home populations or with residents who have sight loss. The 6-item De Jong Gierveld Loneliness Scale (DJGLS) (De Jong Gierveld & Tilburg, 2006) is arguably the most robustly validated scale of all the measures recommended. This scale was designed to measure intensity of loneliness and can be self-administered alone or during a research interview (De Jong Gierveld & Tilburg, 2006).

The DJGLS has two sub-scales. Three statements represent 'emotional loneliness', which is said to occur when someone misses an intimate relationship, for example with a partner or best friend; and another three statements represent 'social loneliness', which is said to occur when someone misses connection to a wider social group. Each sub-scale can result in an emotional loneliness [EL] and social loneliness [SL] score of between zero (not emotionally and/or socially lonely) and three (intensely emotionally and/or socially lonely). The two sub-scales are also combined to produce an overall loneliness scale, which results in an overall loneliness score of 0 (not lonely) to 6 (intensely lonely).

The reliability and validity of the 6-item scale has been tested in community residences in Holland (De Jong Gierveld & Tilburg, 2006) and in other countries, populations and community settings (Dahlberg et al., 2017, De Jong Gierveld & Tilburg, 2010; Leung et al., 2008). However, the DJGLS was *not* designed for use in nursing home populations and, to the best of our knowledge, the psychometric properties of the scale are untested in the care home setting, so it is unclear how well the scale applies. Furthermore, it is unclear how suited the scale is to sub-populations who might experience nuanced features of loneliness, specifically residents with sight loss. The objective of this paper is to describe the administration, results and reflections associated with the use of a loneliness scale in a population of care home residents with sight loss.

Methods

This study administered the DJGLS to measure loneliness and social isolation in residents with sight loss living in care homes. This was part of a wider mixed-methods study examining different aspects of loneliness and vision impairment in residential settings. Participants were eligible for study inclusion if they had sight loss that could not be corrected by eyewear, including those born blind (those with congenital sight loss) as well as those with acquired sight loss through other causes; they were also required to have capacity to give consent in order to participate. To identify eligible participants, the research team first contacted care homes to seek their involvement in the study. Care homes were identified by virtue of being registered with the UK's Enabling Research in Care Homes (ENRiCH) Network (https://enrich.nihr.ac.uk/). Once care homes agreed to participate, through an informed consent process, all residents with sight loss and who might potentially have capacity to consent to an interview were approached and invited to a face-to-face interview to complete the DJGLS. The scale was verbally administered.

Use of questionnaires designed for sighted people that are administered to people with visual impairment are known to have limitations, including comprehension of the information being affected by the method by which information is accessed, memory burden and alteration of the construct that is being measured (British Psychological Society, 2016; Atkins, 2012). Accordingly, we recorded field notes to ascertain the time taken to complete the DJGLS, observations of participants' understanding and their verbal comments with regard to scale items, and any challenges for the researcher with the administration of the scale.

The descriptive characteristics of the participants and DJGLS data were entered into IBM SPSS Statistics Version 24 (IBM Corp, 2016). Descriptive analyses were undertaken for these data where appropriate. Fieldnotes were organised thematically in simple consultation between the researchers. Ethical approval for the study was granted by London – Camberwell St Giles Research Ethics Committee (Reference: 17/LO/2080).

Results

Participants were recruited to the study between May and August 2018. **Figure 1** displays the recruitment of participants. Twenty-six care homes consented to identify participants and of the 139 residents subsequently identified

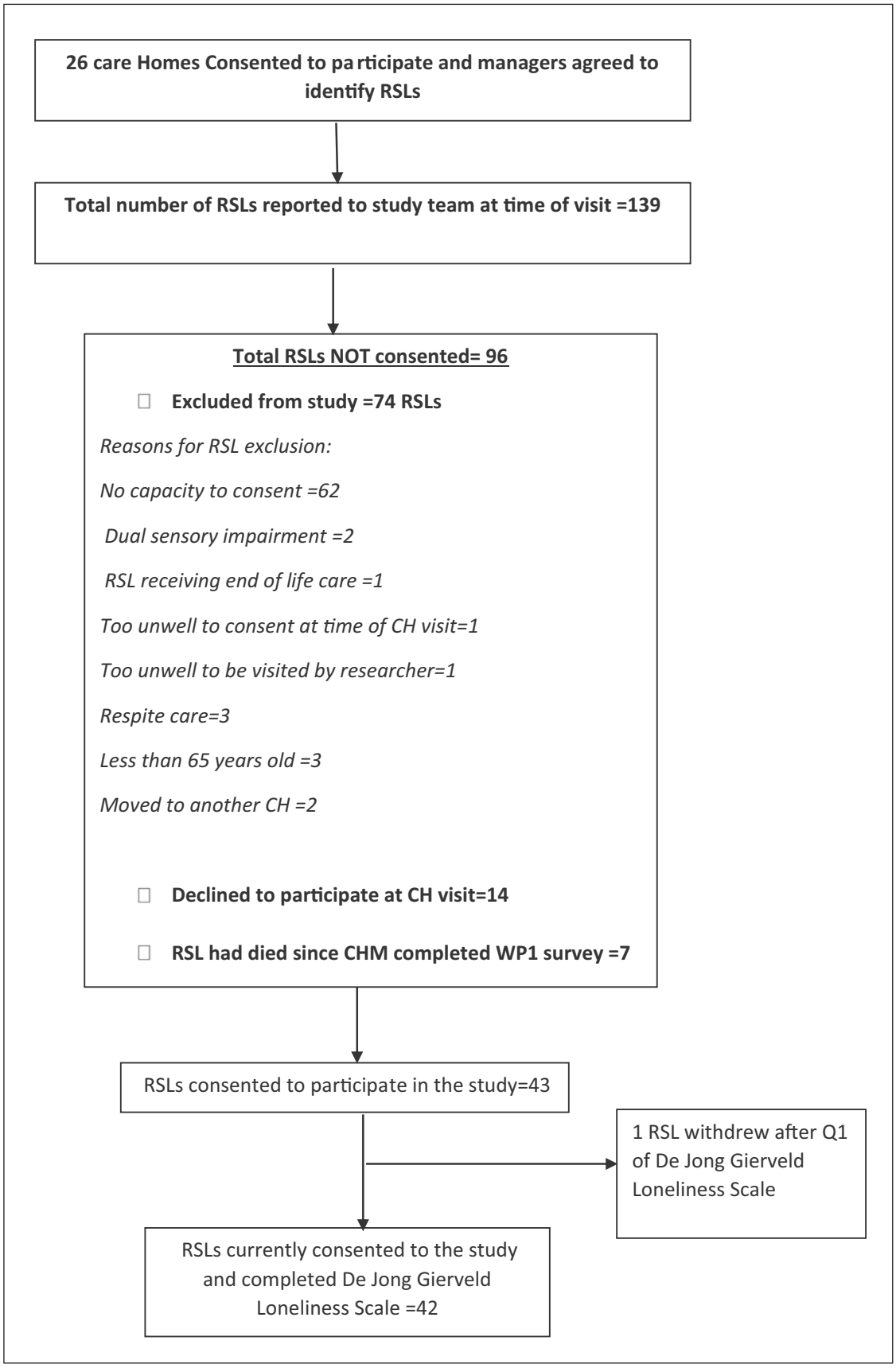

Figure 1: Recruitment of Residents with Sight Loss (RSLs).

with sight loss, 62 did not have capacity to consent. Of the remaining individuals, 43 consented to participate and 42 completed the 6-item DJGLS. The median age of the 42 participants in the study sample was 92 years of age (IQR 87–95); 83% (35) were female, and almost all identified their ethnicity as White British. Where known, the majority of the sample cited macular degeneration as the cause of their sight loss.

Table 1 displays the distribution of scores obtained for each subscale (emotional loneliness and social loneliness) in addition to the total score. Most of the sample scored 0–2 on the overall scale, but with nearly a quarter scoring five or six. The mean EL and mean SL scores were 1.36 (sd = 1.16) and 1.19 (sd = 1.04) respectively; the mean overall loneliness score was 2.55 (sd = 1.9).

Table 2 displays the frequencies for each item of the DJGLS scale. Although the response patterns to the DJGLS items was generally uniform, it was notable that two-thirds of participants responded affirmatively to the item, "I miss having people around me"; whilst a similar proportion of participants responded *negatively* to the item, "There are many people I can trust completely". This distinctive response profile for these two items suggests that participants may have been interpreting and answering these items in a significantly different way to the other four scale items.

As far as administration of the DJGLS was concerned, we observed the scale to be somewhat challenging for residents, with nearly 30% having one or more problems with the scale items according to fieldnotes. Before administering the scale, the verbal administration involved a relatively intensive introductory discussion to contextualise the items and to explain they were not worded as questions but as statements, which meant they were phrased in the first person. For example, one participant interpreted the first item ("I experience a general sense of emptiness") by responding "Do I?". An explanation of the three potential responses to each item was also required and this often had to be repeated, as some participants thought that different items had different response options.

Table 1: De Jong Gierveld Loneliness Scale score for RSLs (N = 42).

De Jong scale scores 0=not lonely 6= intensely lonely	**% (n)**
De Jong Emotional Loneliness sub scale score	
0	31% (13)
1	26.2% (11)
2	19.0% (8)
3	23.8% (10)
De Jong Social Loneliness sub scale score	
0	31% (13)
1	33.3% (14)
2	21.4% (9)
3	14.3% (6)
Total De Jong Score	
0	14.3% (6)
1	23.8% (10)
2	16.7% (7)
3	14.3% (6)
4	7.1% (3)
5	16.7% (7)
6	7.1% (3)

Table 2: Frequency table of DJGLS response by each item.

DJGLS EL item	**%**
I experience a general sense of emptiness	
0 *(no)*	54.8
1 *(yes)*	45.2
I miss having people around me	
0 *(no)*	35.7
1 *(yes)*	64.3
I often feel rejected	
0 *(no)*	73.8
1 *(yes)*	26.2
DJGLS SL item	
There are plenty of people I can rely on when I have problems	
0 *(yes)*	76.2
1 *(no)*	23.8
There are many people I can trust completely	
0 *(yes)*	39.0
1 *(no)*	61.0
There are enough people I feel close to	
0 *(yes)*	64.3
1 *(no)*	35.7

Our fieldnotes reflected that participants had no difficulty engaging with the concept of loneliness in general terms. Barriers to participation were not conceptual. When introducing loneliness as the subject of discussion, the majority of residents just simply stated "well of course I do", or "oh yes, I do feel lonely here"; or else "no I don't feel lonely, there is always something to do here or always someone to talk to/who pops into the room to see me", or similar sentiments. It was apparent that participants wanted to expand on this rather than engage with a quantitative measurement and they generally explored and reflected on their own experience in an unstructured narrative, which whilst useful in terms of setting the tone of the interview did not always necessarily reflect their ability to answer the DGJLS items. Administering the items also caused significant rumination about loneliness, often involving the extension of the narrative to a memory from their life before entering the care home. This meant that the length of time it took to administer the 6-item scale varied from anywhere between 5 to 10 minutes to over 25 minutes.

Item wording

The wording of the statements and the perceived complexity of the scale appeared to create issues with every scale item. **Table 3** displays responses based on themes identified within fieldnotes.

Table 3: Difficulties/issues with the De Jong Gierveld Loneliness Scale administration.

DJGLS Item	Thematic categorisation	n
I experience a general sense of emptiness	Some interpreted "emptiness" as a physical experience – "nothing in front of me or around me, it's just empty".	3
I miss having people around me	People around – "there are always people around me". There are people around here all the time [referring to life in the care home]	9
I often feel rejected	The specific word "rejected" was contentious. In a care home this may refer to care home staff, although not everyone interpreted this in this way.	2
There are plenty of people I can rely on when I have problems	RSLs tried to define what was meant by the word "Problems" – some RSLs spent time reflecting on number of family members or other people in the past they used to know, and The phrase "plenty of people" was questioned – what's defined as plenty?	12
There are many people I can trust completely	The issue of the word "Trust" and the context – did this mean trusting staff In CH RSLs often spoke about differentiation between whether it means, care home staff or who does it mean?	12
	RSLs queried 'many people' questioning what 'many ' was.	
	Also the word "completely" was an issue – some felt that it was difficult to quantify 'completely'	
There are enough people I feel close to	The words "Close to" were questioned – some RSLs stated that they were always close to someone in the CH [referring to physical presence of people in care home]; e.g one RSL stated "yes there are always people all around you; can't get away from them!"	12

These issues were mainly around the meaning of certain words and their application to residents with sight loss in a care home. For example, the concept of whether they "completely trust" those around them; participants queried to whom this referred, care home staff that participants interacted with on a daily basis, or did this mean other residents? Some participants were confused by the question "I miss having people around me" since life in a communal living environment such as a care home always involves fellow residents and care staff being in near proximity. Further, there was evidence that residents with sight loss may interpret some items as pertaining to objective, rather than subjective, aspects of the environment. For example, being "close to" people, "having people around me", and a "sense of emptiness" were all interpreted by some participants as physical characteristics of their immediate surroundings, rather than an evaluation of their emotional perceptions.

Discussion

Of the 139 participants available in the 26 participating care homes, 74 were excluded from the study. The study was therefore very limited in terms of the sample size and we were only able to collect a relatively small amount of loneliness scale data from 42 participants. This was because a large majority of eligible participants identified by care home managers were excluded from the study due to lack of capacity to undertake the schedule, or else acute ill health at the time of administration. The mean scores for EL and SL loneliness were both below their respective scale mid-points as was the overall mean loneliness scale score, indicating a low level of loneliness in our sample. This is in line with other samples where scores using the 6-item scale and the 11-item are below the mid-scale point (Dahlberg et al., 2017; De Jong Gierveld & van Tilburg, 2010). However, due to the limited sample size, loneliness in our sample of participants is not generalizable to the wider population of care home residents with sight loss in the UK.

Our main finding instead relates to the challenges and limitations of the administration of the scale and the extent to which participants had difficulty with contextual issues with the format of the DJGLS in the way in which was administered. We identified multiple issues with the verbal administration of the De Jong Gierveld scale by a third party in this population, including that the introductory explanations were not always understood, difficulty understanding the format of statements, and the meaning of item wording. Although the DJGLS was administered face-to-face, severity of participants' sight loss was such that they were unable to benefit from non-verbal interaction cues, and so they were solely reliant on auditory interpretation of scale items, which is known to elicit a level of cognitive burden in respondents and produce bias in scale data (Bowling, 2005).

This appeared to be demonstrated in the responses to the items "I miss having people around me" and "there are many people I can trust completely". Participants appeared to be answering differently to other items; this was also demonstrated by the number of comments about the meaning of 'complete' trust and of having people 'around me' in the context of a care home. The anchors in the response set were also queried. This potentially creates a bias in that items interpreted as "sometimes"

by participants (whether sighted or visually impaired) are not being answered as per the validated scale response (Bowling, 2005).

The administration of the scale was far from a simple, time-limited process with some participants needing over 25 minutes to complete the six items. Some of these difficulties were due to complexity, issues of processing and participants' articulating something sighted peers take for granted when reading text; for example, where questionnaires are verbally administered, memory becomes an important factor when responding (British Psychological Society, 2016). Atkins (2012) states that listening and reading are not homogenous processes that work in the same way, so people with sight loss need to use their short-term memory more than sighted people.

The original validation study of the 11-item scale, conducted in samples from three separate studies in Holland, included senior elders residing in private residences in the community (De Jong & van Tilburg, 20006); however senior elders residing in a long-term care setting were excluded. Similarly, UK studies examining the correlates of social and emotional loneliness using the DLGLS have been centred on community-based settings (Dahlberg et al., 2017). To the best of our knowledge, the psychometric properties of the scale have not been examined in a population with sight loss, either in the community or in care home settings. Useful work for future research might include examining the psychometric properties of the DJGLS in a UK population of people residing in long-term care settings, including those with sight loss.

Implications for practice

We identified several challenges in the administration of the DJGLS that, we believe at this time, might preclude it from use in measuring the intensity of loneliness in sight loss populations residing in long-term care facilities. Case-identification tools should ideally be quick to administer and relatively easy for the respondent to complete; however, we found these difficult in the research context. For busy, work-pressured practitioners, the DJGLS may not offer the expediency required for the practice setting. However, the properties of the scale have not been examined in sighted residents living in long-term care, so there may be potential for use as a case-identification tool in practice if a suitable validation study is undertaken in sighted residential populations. We also found that respondents, during orientation to the exercise, were capable of giving cogent responses to questions about the concept of loneliness. For this reason, the authors recommend the use of a clearer single-item question until formal validation of the DJGLS can be undertaken in care homes.

Limitations

The sample size that completed the DJGLS was relatively limited compared to the overall population with sight loss population living in the care homes; it is therefore difficult to generalise the findings with regard to the intensity of loneliness experienced to other residents with sight loss in other care homes. However, scores were comparable with other published norms (Dahlberg et al., 2017; De Jong Gierveld & van Tilburg, 2010). The scale is limited by the lack of use in the care home setting and the only comparable studies in terms of the EL and SL scores have been conducted in older community-dwelling samples, which have demonstrated equivalence in the scale identifying lower levels of loneliness.

Conclusion

Use of the DJGLS with residents in a long-term care home population is questionable until psychometric properties have been evaluated in this setting. In the practice context, practitioners may find the scale difficult to administer, particularly in those residents with some degree of sight loss or dual sensory impairment. Where practitioners wish to identify loneliness in residents, a single question about feeling lonely may suffice. Researchers may wish to include a single-item question in future studies as a comparison of loneliness measures to inform the research evidence.

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Competing Interests

The authors have no competing interests to declare.

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