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Isolation and loneliness in people with sight loss in care homes (the INSIGHT project)

RESEARCH FINDINGS

Most residents with sight loss appeared to be broadly satisfied with their wellbeing. However, measuring loneliness was difficult, even using established scales.

Residents often experienced: a lack of social connectedness; a sense of detachment from other residents in the care home; and a tendency to 'keep themselves to themselves'.

Loneliness was not equivalent to the mere absence of social contact: some residents felt lonely, others were quite satisfied with relative solitude, while others preferred more contact but did not consider it a 'problem'.

There were four common features of loneliness:

Intellectual – feeling that care home life lacked stimulation;

Physical – feeling that access to social activity was impeded;

Emotional – feeling absence of a close personal connection to others;

Institutional – feeling cut-off from the outside world.

Sometimes, efforts to include people in social activities went too far, with staff effectively taking over the task. If an activity cannot be adapted for someone with sight loss, the study suggests it is better to find an alternative than to superficially include those to whom it is not suited.

Social Policy Research Unit
University of York

BACKGROUND

Admission to residential care is connected with both isolation and loneliness in older people and there is evidence suggesting that rates of 'severe loneliness' reported by people living in care homes (22–42%) are more than twice that of those in the wider community (10%). It is also known that sensory impairment has an impact on maintaining interaction with fellow care home residents.

However, while care home residents are more likely to experience sight loss than someone cared for at home, loneliness and isolation of older people with sight loss who live in residential care remains an under-researched area.

The aim of this study was to increase knowledge and understanding about relationships between sight loss and social isolation/loneliness in care homes.

Methods

The objectives were to:

- to map out the basic characteristics of care homes' sight loss populations and efforts to address social isolation and loneliness; and
- explore perspectives of residents with sight loss, family members and care home staff.

This was achieved through a short survey of care home managers, the administration of a measure of loneliness amongst residents with sight loss, and semi-structured interviews with a subsample of residents, care home managers and family members.

FINDINGS

SIGHT LOSS IN CARE HOMES AND EFFORTS TO ADDRESS SOCIAL ISOLATION

Of 134 invitations to participate in the survey, just under two thirds of care home managers (n=85) returned a completed questionnaire to the research team. A majority of care homes provided residential care, were managed by a private provider, were of medium size, and with the majority of residents self-funding their care.

The research team defined sight loss as a vision impairment that could not be corrected using eyewear. Under this definition, most care homes had between one and three residents with sight loss. Most reported that they assessed new residents' vision using a specialist service, and referred current residents every 12 months for a vision assessment.

The most frequent resource to assist residents with sight loss in accessing reading materials was a magnifying device. However, 1 in 6 care home managers reported they did not have any specific resources to assist residents.

Most care home managers (60%) reported that they did not give specific vision impairment training to staff. Care homes that did provide specific training stated they received this from a specialist vision assessment service contracted to their care home.

A majority of managers reported that they either did not specifically use, or did not distinguish between, strategies they used to prevent or address isolation and loneliness in the wider population of residents and those with sight loss. Just three care homes in the sample said they utilised external volunteer services or a local sight loss charity to assist residents with sight loss to promote recreational/social activities.

MEASURING LONELINESS AMONGST RESIDENTS WITH SIGHT LOSS

Forty-two residents were asked questions about loneliness using the well-established De Jong Gierveld scale. Their median age was 92, 83% (n=35) were female; and almost all described their ethnicity as White British. The most common reason for sight loss, amongst those where this was recorded, was macular degeneration.

The measured levels of loneliness amongst residents with sight loss was generally low. About a quarter (24%) of participants scored just one out of six on the De Jong Gierveld scale.However, 10 residents scored either five or six, indicating significant loneliness for this minority of respondents.

EXPERIENCES OF ISOLATION AND SUPPORTING RESIDENTS WITH SIGHT LOSS

Eleven care homes participated in the qualitative element of data collection including one defined as a specialist home for those with sight loss. Of 42 residents signalling their interest in the qualitative elements, 18 were interviewed (others either declined at a later point, or were not able to participate for other reasons). Interviewees were aged between 66 and 98 years; 16 were aged 86 and over. Fourteen interviewees were female. All interviewees were white British; three were blind and the rest had some residual sight. Six interviewees were resident in a specialist care home for people with sight loss.

FINDINGS

Some residents with sight loss experienced a lack of social connectedness, a sense of detachment from other residents in the care home, and a tendency to 'keep themselves to themselves'. Although not everyone saw this as a 'problem', there were a number of barriers identified in addressing isolation. These included:

- **Difficulties using communal areas**, such as by not being able to recognise people, a lack of topics for stimulating conversation (as their life revolved around the care home routine), and difficulties in moving around so they could sit next to particular people.
- **Noise and background activity** was particularly disruptive for residents with sight loss, who depended a great deal on their auditory senses. For example, mealtimes proved particularly difficult because of the range of sounds during such a busy time in the care home.
- **Inaccessible activities** could be frustrating. Some activities were difficult to adapt to those with sight loss, whilst others were thought of as being boring. Staff generally did their upmost to include residents with sight loss, but some activities were simply too challenging to adapt. In some instances, people were unaware of what activities were available, since the programme was written and not read to them.

Most people maintained close relationships with their family and friends outside the care home and these were regarded as most important to maintaining social connection. However, others did not have family and friend to visit them. Those with access to adapted computers or phones used these to maintain those contacts.

The research prompted some evaluation of what it means for people with sight loss to 'be lonely'. As found in other research with older people in general, loneliness for this group cannot be simply equated to the mere absence of social contact. Some were satisfied with being relatively isolated compared to others, preferring individual activities or solitude. Others did express preference for more social contact, but nevertheless did not consider it a 'problem' that needed to be rectified.

For those that did report feeling lonely, there were several elements to this:

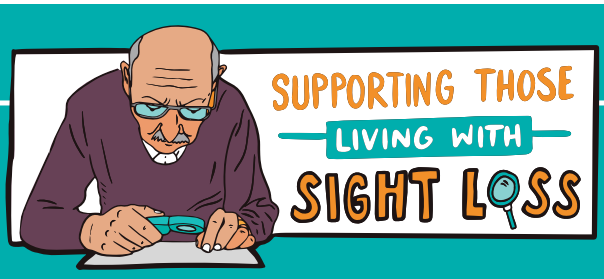
- **An intellectual isolation:** some felt that there were lots of people with whom they could interact and converse, yet this did not make them feel less isolated because it lacked stimulation and purpose. Scheduled activities were similarly lacking stimulation, and family members suggested they should be undertaken in smaller groups to help residents with sight loss to engage fully.
- **Physical isolation**: some felt that they could not access the areas, activities or rooms with confidence, or could not communicate with those they wanted to. This physical sense of separation from their preferred place was a significant loss for some, and those with more independent mobility (typically younger residents with some residual sight) appeared better able to make the most of communal environments.
- **Emotional isolation:** others felt a longing for re-connecting important relationships they felt they had either lost or which had dwindled, particularly with long-term friends and family. It appeared that those with sight loss perceived that they were at particular risk of losing these connections.
- **Institutional isolation:** Even where care homes provided relevant activities, some felt cut-off from the outside world. Family members noticed that care home residents seem to live 'in a bubble'. Tentatively, there may be some suggestion that this form of isolation coincided with a sense of identity loss; that maintaining routines, activities and connections that existed before entering the care home were important components of 'who they were'.

Emotional isolation as identified in this study appeared to echo other research with sighted residents, so this may not be distinct to residents with sight loss. However, other forms of isolation had particular features directly arising from vision difficulties.

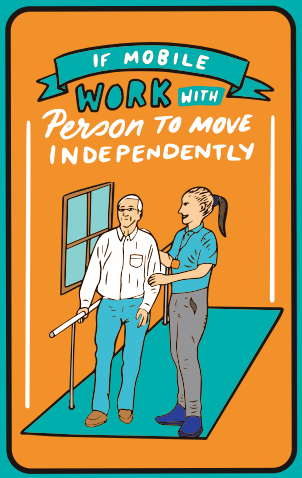
Interviews with care home managers indicated that they were aware of the many challenges in maintaining the engagement of residents with sight loss within the care home. Nevertheless, it was acknowledged that the busy care home environment meant that it was easy for simple steps to be missed. The research has identified several 'top tips' for practice, to help care home staff to keep simple things in mind which can make an important difference for those with sight loss.

Care home managers appeared more focused on internal solutions (within the care home) in promoting social engagement amongst residents with sight loss. Much emphasis was devoted to the activities coordinator and other members of staff in ensuring those with sight loss were 'integrated'. However, there were indications that those homes able to make use of external resources, such as local volunteers, involvement from faith-based organisations or other community groups, could enable more meaningful participation. Such an assets-based approach could potentially offer opportunity for care homes to enable greater engagement, but without the expectation that busy staff must simply 'do more'.

FINDINGS



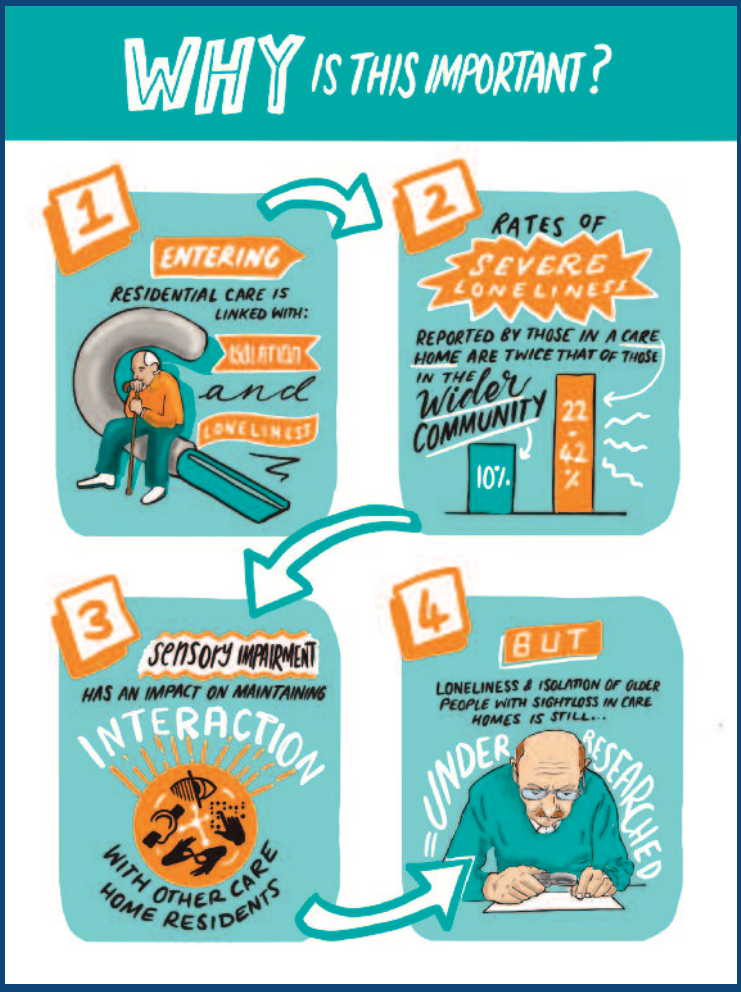
QUICK TIPS THAT HELP



FIND OUT MORE: bit.ly/sight-loss-uni-of-york

CONCLUSIONS & IMPLICATIONS

- When using a well-established measure of loneliness, most participants in this study reported that they were not lonely or isolated.
- In interviews, the research team found that loneliness was a problem for some residents with sight loss, and it is possible that their sight loss made it more difficult for this to be addressed. Some of this can be countered with closer attention being paid to simple tips to maintain engagement (which are easy to forget in the context of a busy care home) – and a final research output includes a large visual poster to assist staff to put these into practice.
- Activities within the care home did not offer sufficient stimulation for some residents. In some instances, attempts to 'integrate' residents with sight loss meant that they were engaging in activities that had little meaning or value. Where activities are not adaptable for people with sight loss, this research suggests it is better to find alternatives than to encourage superficial engagement.
- The study also found the most valued contacts and networks appeared to be outside the care home, and we recommend research to explore the value of local volunteers and other community assets to support more purposeful engagement in care homes.



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NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
WC2A 2AE

Tel: 020 7955 6238

Email: sscr@lse.ac.uk

sscr.nihr.ac.uk

THE UNIVERSITY of York

The research was carried out by Dr Parvaneh Rabiee (Principal Investigator), Dr Rachel Mann, Dr Mark Wilberforce, Professor Yvonne Birks at the University of York.

Further details are available from Professor Yvonne Birks at:
Social Policy Research Unit
Department of Social Policy & Social Work
University of York
Heslington
York
YO10 5DD

yvonne.birks@york.ac.uk

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