

A Review of the literature on older people's experiences of living in a care home with sight loss

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February 2017

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Introduction

This volume outlines research which has been conducted in the area of sight loss in care homes. It highlights issues of relevance to this study as well as gaps in current evidence, knowledge and understanding.

Literature searches were carried out using the Web of Science, CINAHL, PsycINFO, Social Care Online (SCIE), Google Scholar and the University of Brighton online library database. The primary aim of these was to identify studies conducted in the area of visual impairment (VI) focussed on older people in care homes. Reference lists of identified articles were also perused in order to locate further relevant studies. The following search terms were used:

“sight loss” OR “visual impairment” AND

older OR elderly AND

“care home” OR “residential care”.

Sight loss detection and access to support

There has been relatively little research relating to vision screening in older people and its effectiveness (Jessa and Evans, 2008). Fewer studies still, have focussed on the need for improved visual screening among care home residents. However, clearly, undetected sight problems in care homes are common and have negative implications on access to appropriate treatment and rehabilitative or other support services which may be available. A study by Sturgess et al. (1994) (located in London) highlighted the high rate of undetected and untreated sight problems in the older care home population, and the low rate of sight loss registration. The literature also suggests this is not a problem limited to the UK. A Finnish study, for example, found similar rates of previously unrecognised ophthalmological errors and that treatment and rehabilitation was neglected in care homes (Rifaat and Kivelä, 1989). Sinoo et al. (2012) in a study in the Netherlands, found that there was a lack of assessment and recording of visual problems and functioning in nursing homes, whilst in the context of a developing

country (India) Marmamula (2013), found a much higher prevalence of uncorrected refractive errors among care home residents, i.e. more than three times greater than in the general elderly population (the percentage for the general population in India was also estimated to be more than double the rate in the UK).

Watson and Bamford (2012) note that current UK regulations and best practice guidelines draw some attention to care options for those whose sight problems had been detected prior to entering residential care, and to issues around severe injuries involving vision. However, they also highlight how “there is little that addresses the issue of undetected or worsening vision problems that are not an emergency for residents” (p.21) and how this is likely to be a neglected issue. Residents can be unaware of sight problems or may have communication difficulties. This can be a particular problem for those with dementia. Sight problems can therefore often go unnoticed (Watson and Bamford, 2012). Older people sometimes have a misguided belief that eyesight problems are inevitable and untreatable in old age, or they may worry about the cost of treatment (Cooper, 2013). Yet, clearly there is a link between early eyesight assessment and access to appropriate services, and quality of life/ well-being for older people with sight loss (NICE, 2013). Care home staff therefore, have an important role to play in recognising symptoms of sight loss, in promoting good eye and spectacle care and ensuring residents have regular and at least annual sight tests (Age UK and Thomas Pocklington Trust, 2014, Sturgess et al., 1994).

Once sight issues have been detected there remains an issue around inconsistency and lack of personalisation in terms of provision of support and signposting. In many cases, older people are not provided with access to the information, advice and support they require in terms of rehabilitative services, devices and other sources of social or practical support available (Cattan, 2011). If the older person does not receive this information and support from health and social services, research suggests that it is also unlikely to be identified and addressed by care staff (Cattan, 2011).

Falls and accident prevention

An increased risk of falls and accidents is generally associated with acquired sight loss (Cook et al., 2006, Turpin, 2011, Abdelhafiz and Austin, 2003) (although Kerse et al. (2004) found the opposite). The issue of injury prevention in old age has received a relatively significant degree of attention from government because of the cost to the NHS (Turpin, 2011). Falls directly relating to visual impairment in the UK are estimated to cost £128m a year in medical costs alone (Watson and Bamford, 2012). A number of papers relating to sight loss among older people in care settings focus therefore on prevention interventions.

Gleeson et al. have investigated the impact of various interventions on reducing the risk of falls for people with visual impairments including the Alexander technique (Gleeson et al., 2014a), and various types of exercise such as Tai Chi. Gleeson (2014b) found that exercise interventions in care homes improve performance on some tests of physical function for risk factors associated with falls. Chen et al. (2012a) found that poor vision decreased balance control, which could increase the risk of falls. Chen et al. (2012b) also investigated the use of Tai Chi with older visually impaired care home residents and found some improvements in balance control compared with the control group.

Another type of intervention studied by Anderson (2012) is based on a system improving staff interactions and channels of communications in order to reduce falls. Although not exclusively focussed on VI, systematic vision assessment was included as part of the strategy of risk reduction. This included attention to ensuring corrective devices and assistive technologies were provided where appropriate as well as attention to the suitability of the lighting and environment.

Staff awareness and training

As noted above, those working in care homes are not required to have specific training or knowledge of sight loss, nor an awareness of the needs of residents with poor sight (Cooper 2013). Yet, research has indicated there is a lack of awareness among care staff and managers of sight loss and associated health problems and symptoms. Therefore a lack of priority is given to eye health which tends to be regarded as an

'optional extra' rather than integral to health and wellbeing (RNIB, 2010 p.3, Watson and Bamford, 2012, RNIB, 2014 p.6). There is an identified need for better training of care staff in order to better understand, recognise and manage sensory impairments (NICE, 2013, Percival, 2012, APS Group Scotland, 2014).

Petrovich (2008) found that a sizeable minority of care home staff lacked confidence or felt unqualified to deal with the needs of residents with sight loss, and that the large majority of staff felt there was a need for greater training opportunities to develop expertise in this area. Cook et al. (2006 p.216) highlight a need for care staff to take a more "proactive role in screening for, and managing, visual and hearing impairments in residents". In particular, they note a need for staff to be aware of the impact of visual impairments on feelings of social isolation, loneliness and depression, and to find ways to facilitate positive social interactions between residents.

More broadly, Burtney et al. (2014) argue that the literature has neglected how to include sight loss as part of person-centred and relationship based care or how care models have incorporated the issue of visual impairment. From a review of the literature, the authors suggest that in order to deliver person-centred care delivery for residents with sight loss, staff need to be able to:

- recognise a deterioration in vision;
- assess the individuals' skills to navigate in a new or strange environment;
- sensitively offer help when it is needed;
- recognise emotional and mental health issues associated with visual impairment;
- deal with emotional aspects of visual impairment;
- be empathetic and have respect for individuality.

(Burtney et al., p.58)

To some extent the needs of people with sight loss may be met through an emphasis on a person-centred approach to care with a focus on meeting the individual needs of the resident. There are certain aspects

of care assessment which are important to older people with sight loss whether or not they have a visual impairment such as attention to independent living skills, emotional impact and risk (Burtney et al., 2014). However, research has also identified some specific and basic training needs which relate to simple steps care home staff can take to improve the eye health and/ or quality of life of residents with sight loss. These include, for example, introducing the resident in group situations, informing the resident when they are entering or leaving the room, avoiding moving furniture or personal items in the resident's room, etc. (Cattan, 2011, Hayes, 2013, Age UK and Thomas Pocklington Trust, 2014). Training for staff to be able to spot the signs of an emerging sight problem and to understand the potential ongoing capabilities of residents with sight loss is also vital (Horowitz, 1994). Such basic aspects of awareness can make a significant difference to the self-esteem of the resident in facilitating communication and enabling them to continue to perform basic tasks and activities. However, in the study by Cattan (2011), interviews with staff suggested that most had not been provided with such basic training and many did not see this as a priority.

Although many of the changes required to improve care practice appear relatively straightforward, within the mixed economy of care, there are nevertheless challenges to effectively expanding and sustaining the knowledge and skills base (Balloch et al., 2004). Interventions have been developed which appear to have been successful in helping staff to improve their skills and understanding around sight loss (e.g. see Cooper, 2013). However, as Watson and Bamford (2012 p.4) argue, the improvement of awareness and understanding of these issues in care homes is hampered due to funding issues, "restricted time, staff turnover and other practical barriers, such as shift working patterns". Since a major underlying barrier for care homes is the cost of training, a potentially effective approach would be investment by government in free awareness raising training sessions as have been provided in Scotland (AGCC, 2015) as part of the implementation of the 'See hear' strategic framework (APS Group Scotland, 2014). Further research is also required to evaluate such initiatives, to better understand barriers to accessing information and training and to develop appropriate interventions in the light of this understanding (Watson and Bamford, 2012).

Psycho-social support needs

The association between visual impairment and depressive symptoms and reduced well-being (Cabin and Fahs, 2011) and the need for emotional support has been well established in previous research (Gosney and Victor, 2009, Nyman et al., 2012). It is clear that acquired sight loss can pose significant challenges for older people in the community in terms of its impact on psycho-social adjustment, social inclusion/ isolation and well-being (Ward et al., 2012, Nyman et al., 2012, Zimdars et al., 2012, McManus and Lord, 2012), and support needs are often unmet (Hodge et al., 2015, Charles and Manthorpe, 2009).

Older people with sight loss are at a greater risk of experiencing mental health issues (Watkinson, 2011). Burmedi et al. (2002) found that depressive symptoms were about twice as common among older people with sight loss as among their sighted peers. This is related to functional loss, mobility loss, a related loss of self-esteem, and the social isolation often associated with sight loss in later life. Older people with vision loss may lose interest in activities which can require more effort and engender feelings of frustration (O'Donnell, 2005, Cattan, 2011).

A number of researchers have also highlighted how factors such as use of coping strategies, support through social networks and access to rehabilitation services can influence adaptation to age-related vision loss (Houde, 2007). Burmedi et al. (2002 p.47), for example, argue that "social support can provide a buffer against age-related vision loss". O'Donnell (2005) shows how rehabilitation support which is responsive to the complex needs of older people with sight problems is key to enabling the older person to find new strategies which can disrupt a potentially downward emotional spiral in which functionality is reduced. Horowitz (2004) also emphasises the importance of rehabilitative services to combat excess disability and subsequent reduced well-being. However, scarce vision rehabilitation services tend to be directed towards those in the community with a focus on enabling people to continue to live independently in their own homes. Those living in care homes are likely therefore, to be at a disadvantage in terms of benefitting from this support (Rabiee et al., 2015).

Studies focussing on the connections between acquired sight loss, well-being and support needs within residential care are less common than those based in the community. However, depression rates in general have also been found to be about three times higher among older people in care homes than in the older population as a whole (Moriarty, 2005). Therefore older people with sight loss in care homes are likely to be at particular risk of depression.

Quality of life (QoL) has also been found to be reduced for older care home residents with sight loss (Dev et al., 2014, Horowitz, 1994). In a study of residential care home residents in Australia (Lamoureux et al., 2009) QoL aspects most affected by sight loss related to: reading; general vision; hobbies; emotional wellbeing; and social interaction. A reduced QoL can also be particularly apparent where sight loss is unrecognised and untreated, owing to an excess decline in functional ability (Horowitz, 1994). It is argued that care home staff need to find ways to enable residents with sight loss to continue to be as independent as possible, since this improves self-esteem and can reduce depressive symptoms (Horowitz, 1994, Cattan, 2011).

Several studies have highlighted the particular impact of sight loss on communication and social activities. The importance of emotional, as well as practical, support within care settings in order to mitigate these effects has also been highlighted (Cattan & Giuntoli 2010; Cooper 2013; Hanson et al. 2002). However, as Cattan (2011) found, emotional support is rarely provided by care home staff, with family members tending to bear the responsibility for this. Clearly, this raises issues for those without family or friends who were also found to be less likely to engage in activities they enjoy. Provision of opportunities through volunteer schemes for older residents to have company, participate in activities and get out and about can reduce the risk of isolation and depression (Cattan, 2011). Most research has suggested that friendships between residents in care home settings are also important to well-being (McKee et al., 1999, Edwards et al., 2003). However, VI can also have a significant negative impact on social interaction between residents, potentially contributing to feelings of social isolation (Cook et al., 2006, Cattan, 2011).

A US study (Petrovich, 2008) of residents with sight loss, relatives and staff found that most residents coped well and did not display depressive symptoms. However, the presence of social support was a key factor associated with positive coping outcomes. Various means of help were considered critical to maintaining well-being including: help with paperwork; provision of visual aids; environmental adaptations; and assistance with getting around internally and externally. Ongoing care plan assessments were also considered particularly important in order to ensure appropriate support is identified and provided for residents with sight loss. However, despite care planning being a requirement in the UK, concerns have been raised around a lack of quality and consistency in care planning in practice (Worden and Challis, 2008). In particular, there is a lack of evidence around the extent to which issues around sight loss are incorporated into person-centred care planning (Burtney et al., 2014).

Assistive technologies

Literature on assistive technologies (AT) tends to be focussed on enabling those living in private homes to maintain their independence and helping people to age in place, including the use of home modifications and low vision devices (Levenson, 2011, Riazi et al., 2012, Simon, 2008), and with a view to reducing the costs of care (Mann et al., 1999, Miskelly, 2001). The literature has also shown, however, that AT is associated with other benefits for older people with sight loss which may be relevant to care home residents, such as: improving quality of life; reducing accidents; enhancing support; increasing independence (Percival, 2012) and reducing depressive symptoms (i.e. particularly through the use of optical devices) (Horowitz et al., 2006).

Older people with sight loss may be sceptical or fearful about the use of AT. However, there are also significant barriers around lack of information around availability and access; confusion regarding choices; cost; and lack of guidance on using aids (Hamblin et al., 2016). These barriers may be particularly acute for care home residents. Cattan (2011) found that care home residents often did not receive appropriate provision or information about devices which could be of help to them.

A study by Percival (2012), tests out 'demonstration programmes' for older people with sight loss, as a way to increase the awareness and understanding of devices. The author argues these could be transferred to a care home context. Such a project could also potentially allow residents the possibility of borrowing and 'trying out' items before deciding whether or not to purchase them (Percival, 2012). Another model which could benefit care home residents is the AT champions initiative, through which older people with sight loss and/ or staff can be trained to provide support in using devices and signposting (Levenson, 2011).

Clearly, as well as ensuring practical design and ease of use, staff involvement in maximising residents' access to, and appropriate use of, technologies is key (Percival, 2012). Deremeik et al. (2007), in their study of low vision rehabilitation in nursing homes, emphasise the need for staff training with a focus on changing attitudes towards facilitating residents' independence, whilst Levenson (2011) notes how staff need to be reassured that AT is compatible with person-centred care, and that rather than placing an additional burden on staff, in fact can free up time for caring activities.

Leat et al. (1994, 2016) highlight the benefits for older people to attend low vision clinics and use of low vision aids, particularly in terms of the impact on activities of daily living (ADL). However, there is an under-provision of such services in the UK which are mostly provided to those living in private homes (Gillespie-Gallery et al., 2012). Therefore, the extent to which care home residents are able to access these services - through which they might be provided with information and knowledge about appropriate aids - is unclear.

More research is required to identify the types of assistive technologies that may be of particular use to older people with sight loss in care homes; to better understand the barriers to access and use of aids and how these might be overcome; how care homes could better support residents with AT; and how AT for sight loss could be better incorporated into the care home environment.

Multiple health conditions

Multiple health problems are often faced by those with sight loss in older age (such as dementia, mobility problems, hearing loss etc.) and can further exacerbate the psycho-social challenges associated with sight loss, such as social isolation, reduced well-being and likelihood of depression (Cattan and Giuntoli, 2010, Murray et al., 2009, Pavey et al., 2009). Diabetes is also associated with sight loss (Athey, 2015) and this can therefore have a confounding impact on quality of life (Speight et al., 2013).

Estimates show that between 9-21% of people over 70 have some form of dual sensory impairment (DSI) (Saunders and Echt, 2007). It is an issue therefore which is likely to affect a significant proportion of the care home population. Most of the literature, however, is focussed on people living in the community. Some good practice information on DSI including some attention to care homes has, however, been published. The Department of Health (DH, 1997) issued guidelines for staff working with older people (including in residential care) with DSI, which included emphasis on orientation to the care home environment; staff communication skills; the care plan; the home environment; and social activities. More recently, Sense (2011) published guidelines which include involving the resident in accessible care planning; enabling residents with DSI to take part in social activities e.g. through use of tactile games; particular attention to needs at meal times; and use of AT. In Scotland, the government 'See Hear' strategy (APS Group Scotland, 2014) includes a focus on increasing staff awareness of DSI issues in care homes.

An estimated 63% of care home residents have some form of dementia (Luff et al., 2011) and dementia research has attracted a relatively significant degree of attention and funding investment (the government committed to £66 million in 2014/15) (Alzheimer's Society, 2014). Nevertheless, sight loss issues are generally overlooked in the dementia literature and dementia care models which are not always sensitive to the needs of people with sight loss. The general assumption in the literature is that dementia is a person's main or sole health concern (Bartlett and McKeefry, 2011). Few studies, in fact, address the issue of those experiencing the dual issues of dementia and sight loss despite

this being such a common phenomenon (Bartlett and McKeefry, 2009, Bartlett and McKeefry, 2011) and fewer still are also based in care homes.

Lawrence (2009) highlights how there is a lack of a joined up approach in practice as well as in the literature. VI services in the study appeared to be ill equipped to manage dementia-related needs, whilst at the same time sight issues were regarded as low priority by dementia services. This is despite the fact that sight loss and dementia are associated in complex ways. Not only can those with dementia experience age-related sight loss, dementia itself can be a cause of impairments in visual contrast sensitivity, perceptions of depth and motion and colour discrimination (Watson and Bamford, 2012), as well as causing hallucinations (RNIB, 2010, Murray et al., 2009). Yet, the sight related condition, Charles Bonnet disorder, can also cause hallucinations and can therefore be confused with dementia. There is a vital need for greater awareness of these issues and to ensure medical assessments are carried out (Terao and Collinson, 2000).

There are, however, interventions which could be of use to those with both sight loss and dementia, e.g. reminiscence activities which facilitate communication and positive social interaction between residents (Thorne, 2012). Guidance has also been published around eye care of those with dementia and sight loss (McKeefry and Bartlett, 2010) and in relation to design issues for care homes (and private homes) for people with sight loss and dementia (Greasley-Adams et al., 2012), an issue which is discussed further in the following section. Clearly, there remains a need, however, for further research and evaluation into the experiences and needs of VI older care home residents with dementia and other additional health conditions (Pavey et al., 2009, Lawrence et al., 2009, McKeefry and Bartlett, 2010).

Design and environmental issues

A number of studies have looked at issues around the design of the home environment but these have tended to focus on maintaining the independence of older people living in private homes (e.g. Levenson, 2011, Joule et al., 2009, Fisk and Rainham, 2010, Thomas Pocklington Trust, 2013). There has been less attention to the needs and

experiences of people with sight loss living in communal settings (Goodman and Watson, 2010). And yet, the care home environment in which residents spend the large majority of their time is clearly essential to quality of life (Parker et al., 2004).

Lewis et al. (2010), studied extra care housing design and included consideration of the suitability of buildings for those experiencing sight loss. They note, however, that the tool developed is not suitable for use in residential and nursing homes. They point to another tool which has been more specifically developed by Nordin et al. (2015) for the care home context. However, the said assessment tool tested by Nordin et al., and promoted as an instrument to support the care home design process, does not include any consideration of sensory impairments (Nordin et al., 2015).

Indeed, most literature around care home design tends to focus on other issues and conditions (particularly dementia) and neglect the problem of sight loss (Day et al., 2000, Fleming and Purandare, 2010, Parker et al., 2004, Torrington, 2007). Bowes et al. (2014), however, studied how private and care homes can be designed to reflect the needs of those living with both sight loss and dementia. Guidelines were produced for seven key topics: lighting; colour and contrast; gardens and outdoor areas; entrances and exits; kitchens and bathrooms; and fixtures and fittings (Greasley-Adams et al., 2012). Bartlett and McKeefry (2011) also make recommendations to help those with dementia to maintain or improve their visual performance, including attention to increasing contrast and colour and modifying lighting levels. Tensions can sometimes be apparent, however, where there are conflicting design needs relating to dementia and sight loss. These can pose particular problems for those with a dual diagnosis and for those with separate conditions sharing the same space (Greasley-Adams et al., 2012, Goodman and Watson, 2010).

Some good practice resources have included information to inform care home managers and staff about environmental issues relevant to those with sight loss, e.g. those around lighting, colour contrast and use of audio and tactile signage (Age UK and Thomas Pocklington Trust, 2014, RNIB, 2010, RNIB Scotland and Alzheimer Scotland, 2012, RNIB, 2015, Cooper, 2013). However, there has been a lack of evaluation as to the

extent to which such information has been accessed and acted upon, and around potential barriers to implementation of changes. There is also need for more research upon which to base such good practice information distributed to care homes. There is, therefore, a lack of knowledge currently available in order to identify what aspects of good practice identified in general care home studies or studies concerning older people with VI in other housing environments may be transferable. A clear need is apparent for future care home design research focussing on the specific needs of those with sight loss in care home environments.

Conclusion

There are a number of gaps in the literature with regard to sight loss research particularly regarding older people in care homes. Most studies have focussed on private households, whether in relation to social and medical needs or around adaptations and AT. In particular, there is a gap in the literature in relation to the needs and experiences of those living in care homes and the extent to which emotional and practical services are available within residential care.

As Cattan and Giuntoli (2010 p.2) state: “Very few studies have investigated what information older people with sight loss need. There is an assumption that their information needs are the same as for sighted people. The literature emphasises a lack of research on their specific information and care needs, whilst other studies have shown the importance of targeted interventions to improve their quality of life.”

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