MY HOME LIFE

RESEARCH BRIEFING 2: 2016

Our vision is a world where all care homes are great places to live, die, visit and work.

Sharing decision-making

This updated research briefing paper was written by David Innes and Tamsin MacBride and based on a review of the literature on quality of life in care homes, undertaken by the National Care Research and Development Forum in 2006[1], which was later updated by a review of reviews (2006-2016), undertaken by the My Home Life team. My Home Life is an international programme of work aimed at promoting the quality of life for those who are living, dying, visiting, or working in care homes for older people.

Overall, research on sharing decision making seems to reflect many of the findings of the original review (NCHRD, 2007). Post 2007, new evidence suggests:

- The types of decisions (resident dominant and resident subordinate) (Arendts et al., 2013)
- The use of decision aids in proxy decision-making (Lord et al., 2015)
- The type of information residents and families want in order to make decisions (Turnpenny and Beadle-Brown, 2015).
- Care conferencing rather than simply MDT involvement (Philips et al., 2013).

Introduction

The research literature indicates that shared decision-making benefits residents, families and staff within a care home environment. However, to date, although some the benefits and possibly barriers have been discussed within the literature, studies specific to care homes continue to be relatively sparse. Studies reviewed before 2006 (NCHRD, 2007) were found to have an overt focus on end-of-life care in regard to decision-making and latterly that of Advanced Care Planning (ACP). However, studies have demonstrated that micro decision-making by residents in their day-to-day life supports a sense of control and also enhances resident's quality of life (Kane et al., 1997; Bamford and Bruce, 2000, Tester et al., 2003; Boyle 2004). Relatives appreciate having their knowledge and experience recognised and to work in partnership with paid carers (Lundh et al., 2003; Davies and Nolan, 2006). Further, supporting staff to participate in decision-making has been shown to enhance job satisfaction and create a positive working and care environment (Banaszak-holl and Hines, 1996; Davies, 2003; Anderson et al., 2005; Hall et al., 2005). It is therefore important to understand what supports shared decision-making for all stakeholders within a care home.

Residents

Supporting residents to maximise their ability to make autonomous every-day decisions about their daily life is suggested as important for maintaining mental health and preventing depression (Boyle, 2005). A study comparing autonomy, quality of life and mental health in care homes in Northern Ireland and England found that

[1]NCHR&D Forum (2007) My Home Life: Quality of *life in care homes – Literature review, London: Help the Aged.*

restricted decision-making, regimented routines and a sense of diminished freedom could result in increased depression and hopelessness of residents, attributed to a reduced sense of control (Boyle, 2005).

Care staff reported that difficulty in communicating with residents who have a cognitive impairment can result in challenges to shared decision-making, with staff feeling they do not have the necessary skills to effectively communicate with all residents (Norwood-Chapman and Burchfield, 1999; Meehan et al., 2002). 'Elderly speak' such as using patronising tones and 'babying' language is suggested as further discouraging residents to express their views and partake in decisions pertaining to their care (Williams et al., 2003). However, communication has been shown to improve between staff and residents with structured interventions (Williams et al., 2003; Dijkstra et al., 2002; Proctor et al., 1998) and the use of technology, such as 'talking mats' to facilitate understanding what promotes and inhibits as residents' quality of life (Tester et al., 2003; Murphy et al., 2005).

Butterworth (2005) offered possible explanations for why residents may not be involved in decision-making. This included the difficulty in actually involving residents, in particular residents with a cognitive impairment and/or residents who may prefer to delegate responsibility for this to health professionals. Further, the necessity of a skilled and knowledgeable body of staff that can facilitate sensitive conversations, as well as the perceived or real lack of time available for staff to ascertain a resident's needs when it may appear more practical to assume these needs on the resident's behalf.

A joint report by the Royal College of Psychiatrists, the Royal College of Nursing and the British Gerontological Society (2000) argued that to prevent overlooking the health needs of residents in care homes there is a necessity for interdisciplinary collaboration. Philips et al's (2013) systematic review of case conferencing found that medication management was enhanced when discussed at a case conference rather than between one or two health professionals. However, with the exception of the review by Philips et al (2013), it is unclear from the review of the literature reviews (2007-2017) how well this has been implemented via the sharing and learning of skills and joint working practices between statutory service providers and commissioners of care homes.

Legislation in England (Mental Capacity Act, 2005), Scotland (Adults with Incapacity Act, 2000 and The Care and Treatment Act, 2003), Northern Ireland (Mental Capacity Act, 2016) and Wales (Mental Capacity Act, 2005) are in place to protect the rights of adults without capacity such as residents with a cognitive impairment within a care home, although there are limited studies discussing provisions made to promote shared decision-making to uphold these rights. Robinson et al (2012) suggests that in relation to Advanced Care Planning, the point of admission to a care home for a resident with dementia is too late to inquire about their wishes. Yet, proxy decision-making on behalf of a resident by their families was found to be distressing and challenging for families (Lord et al., 2015).

Families and staff

Supporting families to be involved in the care of a resident and having their knowledge and expertise valued is reported as of benefit for both staff and families (Davies and Nolan, 2006). Davies (2001b) described different types of relationships between staff members and families when a resident moved into a care home, including partnership care, substitute care, submission care and confrontational care. Partnership care being regarded as the ideal, involved families and staff working together in a reciprocal relationship where each party knew their responsibilities and that of the other, as well as, both recognising and valuing the contribution of the other.

Hertzberg and Ekman (2003) suggest it is necessary and beneficial for relationships between staff and families to build over time for both parties to feel comfortable. Encouraging relatives to be involved in wider decisions

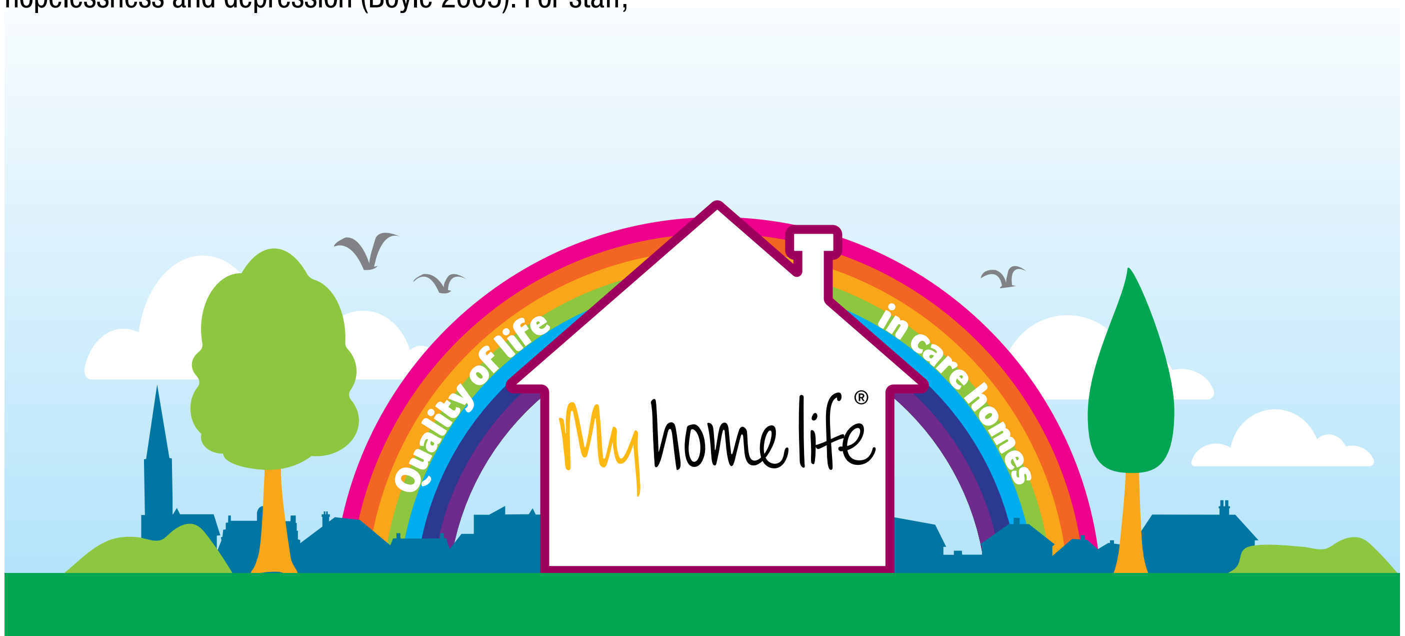
in the care home can contribute to partnership working and an appreciation of the contribution each other can make to enhance the quality of life for a resident and family member (Aveyard and Davies, 2000).

The research evidence from the original review (NCHRD, 2007) reported that families would appreciate more information about their relative's condition, illness, and any limitation they may have or develop (McDerment et al.,1997; Rantz et al., 1999; Davies, 2001). The review of literature reviews (2007-2017) found that families valued obtaining information from staff that they trusted, highlighting how this information was often subjective. Further, they regarded clinical information as difficult to interpret and to understand (Turnpenny and Beadle-Brown, 2015).

Gruss et al (2004) and Rowles and High (2003) argue that care staff working within a care home demonstrate the ability to make complex decisions, identifying and negotiating priorities to meet the needs of the residents and their families. Enabling staff to be empowered to contribute to decisions was found to improve the outcomes for residents (Flesner and Rantz, 2004; Rantz et al., 2003) and reduce staff turn-over (Yeatts and Seward 2000; Banaszak-Holl and Hines, 1996). Supporting staff in partnership working and decision-making was suggested as being of possible benefit for all stakeholders within the care home (Gruss et al., 2004; Rowles and High, 2003).

The addition of findings from the review of literature reviews does not appear to contribute significantly anything new to the understanding of what supports shared decision-making within a care home. The previous review (NCHRD 2007) found for residents, having the opportunity to make everyday decisions contributed to their quality of life (Rowles and High 2003; Kane et al 1997) and could prevent a sense of hopelessness and depression (Boyle 2005). For staff, working in partnership and contributing to relevant decision-making could improve resident outcomes (Flesner and Rantz 2004; Rantz et al., 2003), enhance reported job satisfaction and improve staff retention (Anderson et al., 2005; Davies, 2003; Yeatts and Seward,2000). Families reported appreciating having their knowledge and experience valued and accessed as well as working in partnership with staff to enhance residents' quality of life and care (Lundh et al., 2003; Davies and Nolan, 2006). Further, including the wider community and joint working with partners in health and social care to ensure residents are adequately supported in their health needs and additionally offering support for care home staff was seen as important for shared decision-making (RCPy, RCN and BGS, 2000).

In summary, evidence suggests that partnership working and effective and supportive relationships between all stakeholders is valued in enabling shared decision-making and also enhancing quality of life for staff, residents and their families within care homes.



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