Whose decision is it anyway?
Planning for future care at the end of life for Care Home residents.

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BACKGROUND
Advance Care Planning (ACP) facilitates discussion regarding planning for declining health and future care needs, between an individual and their care provider. This shared decision making has been highlighted as a key component in coordinating care at the end of life. It is important for older people in care homes to ensure choices for care at the end of life are respected.7 This has particular significance for people who may subsequently lose mental capacity.1

A current focus in the UK is to improve the use of ACP for patients with life limiting incurable disease.1 A recent editorial5 reflected findings in the literature demonstrating the importance of coordinating care at the end of life.1 ACP is important for older people in care homes with declining health and future care needs, between an individual and their care provider. Using the experiences of individual participants, regarding discussing plans for future care and death, the project will specifically focus on the experiences of:

- Residents
- Relatives/friends
- Healthcare professionals involved in the ACP process

AIM
The aim of this poster is to examine:

- the timing of discussions around residents choices at the end of life and planning for future care
- the process of shared decision making

METHODS

Figure 1: Longitudinal, Case Study Design

Interpretive phenomenology underpinned the research methods employed for this qualitative study. A longitudinal case study design was used, utilising in-depth semi-structured interviews with all stakeholders at the following time points (see figure 1):

- Initial interview after first discussion
- Follow up interview(s) at 3 monthly intervals throughout the study period
- Post bereavement interview if resident dies during data collection period

RESULTS

Of the nine cases recruited to date, none of the residents living in care homes have been directly involved in discussions about their future care at the end of life. The documented reason reported for this was that the resident did not have sufficient mental capacity to engage with the conversation and complex decision making process at the time of the discussion.

Discussions about plans for future care at the end of life take place between relatives, care home staff and health care professionals. When known they take into account the previously expressed wishes of residents. The documented plans for care are based on ‘best interest decisions’. While relatives report the discussions are of value to them and provide peace of mind about the future care of their relative, it is acknowledged that they fall short of the idea of shared decision making that includes residents.

DISCUSSION

Despite efforts to improve residents choice and encourage shared decision making through the process of ACP this study suggests that discussions about end of life for care home residents still occur too late in the disease trajectory for some residents to be involved in decisions about their own end of life care.

It is unclear why discussions are not taking place earlier although we know despite attempts to ‘normalise’ conversations around death and dying, it is still a taboo topic and often avoided, by health care professionals and wider society resulting in important conversations and decisions occurring at times of crisis.

Despite the benefits of ACP there is a recognition that it is complex, relying on multiple and varied interactions between the patient, relatives/friends and Healthcare professionals (HCP’s). Although studies of ACP report a relationship between documented medical ‘orders’ (‘Do not attempt cardio pulmonary resuscitation’ and ‘do not hospitalise’) and reduced hospital admissions and increased satisfaction with care,9 the nature of this relationship has not been well described, particularly in care homes.

Given projections that the number of people in the UK aged 65+ is likely to rise by nearly 50% in the next 20 years4 and many of these will require their care, planning for future care at the end of life because they reportedly lack mental capacity at the time of the discussions.

More understanding is required, regarding why ACP discussions with care home residents are not taking place earlier in the residents disease trajectory and whilst they have capacity.

CONCLUSION

Care Home residents in this study are not currently involved in discussions about their future care at the end of life because they reportedly lack mental capacity at the time of the discussions. This reflects national findings and perhaps denies care home residents the opportunity to discuss their personal choices at the end of life and be a part of the shared decision making process that is promoted through Advance Care Planning.

More understanding is required, regarding why ACP discussions with care home residents are not taking place earlier in the residents disease trajectory and whilst they have capacity.

REFERENCES

The Royal Liverpool and Broadgreen University Hospitals NHS Trust
The Marie Curie Palliative Care Institute Liverpool, University of Liverpool, United Kingdom

www.mcpcil.org.uk