



Advance Care Planning in Norwegian nursing homes—Who is it for?



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ABSTRACT

Advance care planning (ACP) is an international concept for improving patient autonomy and communication in the context of anticipated deterioration and end-of-life care. In a preparatory conversation, health care professionals facilitate one or more conversations where nursing home residents are invited to reflect on, and articulate wishes and preferences concerning future medical treatment and end-of-life care. Our aim with this study was to increase knowledge of existing ACP practices in Norwegian nursing homes. We wanted to know how nursing home residents, relatives and nursing home staff take part in the conversations, and to what extent these conversations can be regarded as promoting autonomy, legal rights and individual needs for the residents. We conducted participant observation of seven preparatory conversations, followed by interviews with health care staff (together) and resident and relative (together). In the result section, we present an informative case example of an ACP conversation where common and important characteristics running through our data are present. These are further elaborated under the following headings: Life critical questions, Residents' quiet participation in the conversations, the Dying phase – a clinical issue, Nurses and physicians; different domains and Timing. We find that nursing home staff in our study wants to contribute to open awareness, autonomy and a good death, but there are little reflections about the purpose and content of the conversations, how they should be carried out and when, and what frail nursing home residents are able to understand and express in ACP conversations.

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Introduction

The growing public interest, as well as research and health politics for end-of-life care and communication in contemporary Western countries provides the context for this paper. The claim for an open, person-centered and individual approach in end-of-life care and the call for improved rights, participation and autonomy for the dying have for the last decades been raised by a range of voices, such as health care professionals, researchers and from time to time, patients and their relatives

(Hviid Jacobsen, 2013). To ensure a good and dignified end-of-life period, it has in particular been argued that seriously ill patients should be given the chance to talk about important matters, wishes and preferences, and they should be given the opportunity to take part in decisions on medical treatment, care and where they want to die (Norwegian Directorate of Health, 2013). Communication has thus grown into one very important aspect of good end-of-life care.

As regards end-of-life care for older patients, studies indicate that autonomy, legal rights, individual needs, and wishes are often neglected or poorly taken care of (Dwyer, Nordenfelt, & Ternstedt, 2008; Evans et al., 2012). Nursing home residents are not well informed about diagnoses and prognoses, and are not taking part in decisions concerning treatment (Evans et al., 2012; Gjerberg, Førde, & Bjørndal,

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2011). Inadequate communication between nursing home residents and health care professionals may result in unaddressed needs and anxiety for the residents, difficult medical and ethical situations, unnecessary hospitalization, and conflicts with relatives (Dreyer, 2012; Gjerberg, Førde, Pedersen, & Bollig, 2010; Rodriquez, 2014; Sinuff et al., 2015).

Advance care planning

Since the 1990s, advance care planning (ACP) has appeared as a concept and been proposed as a promising tool for improving autonomy and communication in the context of progressive illness, anticipated deterioration, and end-of-life care (in der Schmitzen et al., 2014; Mullick, Martin, & Sallnow, 2013), also in nursing homes (Waldrop & Meeker, 2012; Wickson-Griffiths, Kaasalainen, Ploeg, & McAiney, 2014). Acceptance of ACP as a valued process of decision-making is particularly to be found for instance in the UK where ACP is recommended by the Department of Health's end-of-life care strategy (Mullick et al., 2013). A preparatory conversation is regarded as a voluntary communication process between health care professionals and patients to help the latter to reflect on their goals, values and beliefs, to appoint a surrogate (Detering, Hancock, Reade, & Silvester, 2010), and to articulate wishes and preferences for future end-of-life care and medical treatment (in der Schmitzen et al., 2014). Highly recommended, this process should take place in advance of a hypothetical future where the patient may lack competency or is no longer able to express his or her will. The health care staff is expected to facilitate this process, and furthermore to document the expressed views of the patients. The main purpose is articulated as “clearly formulated, valid advance care plans” (in der Schmitzen et al., 2014, p. 51). Known ACP outcomes are improved end-of-life care, improved patient and family satisfaction, and reduction of stress, anxiety and depression in relatives after the loss of a family member (Detering et al., 2010).

Even if communication has been a main issue in end-of-life care and has been studied for many years, there is an increased call for more extensive knowledge on exactly how conversations about end-of-life care and decision-making processes are carried out. As argued by severally, what is at stake in the conversations and what is the potential for improvement (Russell, 2014; Skår et al., 2014), and what is patients' and health care professionals' experiences of taking part in end-of-life conversations (Evans et al., 2012; Gjerberg, Lillemoen, Forde, & Pedersen, 2015) ought to be critically scrutinized. Parry, Seymour, Whittaker, Bird, and Cox (2013) suggest that direct observational studies should be included in research on decision-making and end-of-life communication.

In this article, we present findings from participant observations of conversations on future treatment intensity and treatment choices between nursing home staff, residents and relatives in seven Norwegian nursing homes. The observations were followed by interviews with resident/relatives together and with the staff who participated in the conversation. The present study is part of a larger research project at Centre for Medical Ethics at the University of Oslo: “End-of-life Communication in Nursing Homes. Patients' Preferences and Participation.” Before the development of guidelines for ACP in Norwegian nursing homes, our aim in this

paper is to increase knowledge of existing practices in nursing home. By presenting field notes from participant observations of the conversations, complemented with findings from the interviews, we hope to add important insights into how conversations are carried out and to illuminate the complexity and ethical challenges in the interactions that take place. Hence, our main research question in this paper is: how do residents, relatives and health care professionals take part in conversations about future treatment and end-of-life in these nursing homes? And to what extent can these conversations be said to promoting autonomy, legal rights and individual needs for older persons in nursing homes?

Relevant research and theoretical framework

Dying and death in nursing homes

When characterizing nursing home residents in Norway, aspects like high age (mean age is 84), frailty, vulnerability, disability and multiple diagnoses (Bollig, Gjengedal, & Rosland, 2014; Graverholt, 2014) are often mentioned. The high number of nursing home residents with mild to severe form of dementia (close to 80%) is part of this image (Selbæk, Kirkevold, & Engedal, 2007). The rate of hospital admissions from nursing homes is more than twice as high as others in the community (Graverholt, 2014).

Because of deteriorating health and high frequency of chronic multiple diseases, critical events are common in nursing homes. Nearly half of the Norwegian population end their life in a nursing home (Norwegian Institute of Public Health, 2015), where they spend about 2 years before they die (Statistics Norway, 2011). Thus, the *omnipresence of death and dying*, described by Whitaker (2010), as a major feature of a nursing home setting, is also a very notable part of daily life in Norwegian nursing homes. Based on a field work in a nursing home, Gubrium (1975, p. 197) describes how residents “live with the knowledge that dying and death are imminent events for them.” Yet, when describing the nursing home residents as simply frail and dependent, there is a risk of treating the elderly as one homogenous group (Österlind, Hansebo, Andersson, Ternstedt, & Hellström, 2011; Swane, 2011), or of cementing a stereotypical image of elderly people. According to Twigg (2006), such reductionist images are often created by professionals and policymakers as part of a literature written from an outsider perspective. The changing and aging body, and how older people experience themselves as dying are only partially described (Whitaker, 2010). This may be because dying in old age is often described as a natural part of life (Österlind et al., 2011).

Even if becoming old can make you more familiar with death, we know that dying in old age can also be a very disruptive experience (Whitaker, 2010) and not something ‘natural’ and easily accepted (Field, 2000). Old people's attitudes towards their own death may be diverse and complex and there exist different ideas on what it means to die well (Field, 2000; Swane, 2011; Williams, 1990). Getting old means to go through the loss of spouses and others close to you, and facing death without someone close may be a very lonely process. For instance few women will become very old alongside their husbands (Dwyer et al., 2008; Swane, 2011) and to old Europeans, the Second World War

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