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The establishment of a shared care plan as it is experienced by elderly people and their next of kin: A qualitative study

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ABSTRACT

One strategy to achieve coordination of care for older people with complex care needs is the establishment of shared care plans. The aim of this study was to explore the process of establishing a shared care plan from the perspective of elderly people and their next of kin. Data were collected via 12 semi-structured interviews with 12 older persons targeted in joint care planning and 11 next of kin, either alone or together. The analysis was conducted using content analysis. The results reflect the process of establishing a shared care plan in the three categories; *Preparation, Content* and *Results* with belonging sub-categories. *Preparation* showed that the possibility to influence the preparation of the joint care plan meeting was sometimes limited and the purpose was not always clear. The *Content* category showed that the meeting was sometimes experienced as an unstructured, general conversation or focused on practical matters. And *Results* of the process were shown to be successful in terms of having positive effects or fulfilling needs, but also sometimes as being pointless. Thus, the results show that the process of establishing a shared care plan is somewhat unclear to the older person and their next of kin and that they are rarely involved in the decisions regarding when and if a shared care plan is needed. If joint care planning is expected to serve as a tool to accomplish a more person-centred care, then the person must be regarded as an equal partner all throughout the decision-making and planning process.

1. Introduction

Older people often suffer from chronic and comorbid conditions (Abad-Diez et al., 2014; Marengoni, Winblad, Karp, & Fratiglioni, 2008; Wang et al., 2015) which are difficult to handle within health systems that are characterised by organisational, clinical and cultural fragmentation (Åhgren, 2007). The greater system fragmentation, the greater the need becomes for coordination of care (McDonald et al., 2014). Numerous forms of integrated care models for older people have been introduced and evaluated during the latest decades with the aim to overcome fragmentation and improve continuity of care (Tsakitzidis et al., 2016; Wodchis, Dixon, Anderson, & Goodwin, 2015). To better meet the care needs of older people it has been suggested that care should be organised around the needs and preferences of the person instead of focusing on specific diseases (WHO, 2015). It has also been suggested that care should be provided by flexible teams where the professionals vary depending on the specific needs of the person (Patterson, 2014). One strategy, which is more often advocated in guidelines and health policies to achieve this, is the establishment of shared care plans. However, few studies have focused on evaluating shared care plans and its outcomes for those who are targeted (Newbould et al., 2012; Tsakitzidis et al., 2016). To investigate the establishment of shared care plans, from the perspective of older people and their next of kin, may provide valuable insights into this process and its significance for this group.

A shared care plan is a document that is established through inter-professional collaboration and is shared between professionals and organisations (van Dongen, van Bokhov et al., 2016). A shared care plan is to be distinguished from a plan of care, which is established by a specific profession in a specific setting and for one specific condition (Dykes et al., 2014). An older person with multi-morbidity will often have several plans of care, set up by several professionals in various organisations simultaneously, without connection or dialogue between professionals. A shared care plan is a way to gather these plans of care and formulate them into one document through dialogue and collaboration between professionals and the individual. It is important to acknowledge that the shared care plan cannot be established without a care planning process and that a written document can never compensate for a dysfunctional care planning process (Dellefield, 2006; Parry, Kent, Forsythe, Alfano, & Rowland, 2013).

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The process of implementing shared care plans has been shown to be slow with great disparities in their spread and use in various settings (Condelius, Jakobsson, & Karlsson, 2016; Dykes et al., 2014). This may partly be explained by the difficulties connected to inter-professional collaboration that may obstruct the process (van Dongen, van Bokhov et al., 2016). Professional roles, boundaries and authorities have been shown to cause uncertainty, frustration and even conflicts between professional groups when trying to work together (Harris et al., 2016). The use of discipline specific language, diversity of culture, perspectives and values and hierarchical structures among professionals constituted barriers to inter-professional collaboration and also to a patient-centred care planning process (Ramgard, Blomqvist, & Petersson, 2015; van Dongen, Lenzen et al., 2016).

Older people can experience themselves as powerless in relation to the health care system and as in need of guidance and support in their coordination of care (Hjelm, Holst, Willman, Bohman, & Kristensson, 2015; Kristensson, Hallberg, & Ekwall, 2010). The increasing number of older people with disabilities, who are cared for at home, puts demand on informal caregivers to provide care and support (Sjolund, Wimo, Engstrom, & von Strauss, 2015). Informal caregivers, who are usually family members, often struggle to fulfil the needs of their older relative, acting as their spokesperson, guardian and as coordinators of care (Andersson, Ekwall, Hallberg, & Edberg, 2010; Condelius & Andersson, 2015; Lethin, Hallberg, Karlsson, & Janlov, 2016). The establishment of shared care plans through joint care planning may be of great significance to older people and their next of kin, and has the potential to improve their involvement in decisions regarding care and treatment, and to decrease the burden on informal caregivers.

A person-centred care planning process should be characterised by shared decision making where the older person is regarded as an equal partner and that decisions are based on his/her true preferences, knowing the alternatives and the consequences of these alternatives in care (Elwyn et al., 2012). Shared decision making puts a demand on relational and risk communication competence among professionals and is not easily achieved even with targeted interventions (Legare et al., 2013). Previous research has shown that the involvement of the person and his/her family in the care planning process is often peripheral and that the care plan tends to be agreed on by the professionals already before the meeting (Dykes et al., 2014). Newbould et al. (2012) showed that the care planning process was considered to be vague to the older participants, without clearly defined goals and that the written care plan was rarely shared with the patients and their next of kin. Berglund, Duner, Blomberg, and Kjellgren (2012) conducted observations at care planning meetings involving older persons. They found that professionals tended to steer the meeting towards predefined goals and that issues that were brought up by the older person were neglected if they did not fit into their predefined goals. Professionals, and even family members, were shown to use persuasive strategies to make the older person agree to the care they thought would be the best for them. Having the care planning meeting in the home of the elderly person gave the older person more of an opportunity to speak than if the meeting were held at a hospital, which may indicate that it is beneficial for the older person to have the meeting at home (Berglund et al., 2012). Previous research has indicated that inter-professional collaboration may be complicated and that shared decision making is not always applied in joint care planning for older people. However, these studies did not focus on the process of establishing shared care plans from the perspective of older people and their next of kin and their views thus need to be explored.

The aim of this study was to explore the process of establishing a shared care plan from the perspective of elderly people and their next of kin.

2. Material and methods

2.1. Sample and data collection

The sample was comprised of 12 elderly people who had a shared care plan established during the period November-2013 to December-2014 and 11 next of kin to these older persons. The mean age of the older persons was 78.3 years and four were women. Next of kin were represented by seven husbands/wives, three daughters/sons and one nephew. Data were collected through 12 interviews of which three were conducted with the older person alone, two with next of kin without the older person and seven with the older person and next of kin together.

The sample was identified through a contact person in five municipalities in southern Sweden. When a shared care plan was established for an older person, in collaboration between the municipality and the county council, the contact person asked the older person for permission to hand over their contact information to the research group. In total, 14 persons agreed to this and gave their written, informed consent to participate in the study. If the older person wished for the next of kin to participate, the next of kin was also addressed and included after giving their written, informed consent. All of the next of kin had participated in the care-planning meeting that resulted in a shared care plan. Two of the interviews that were conducted with an older person alone were disrupted due to incomprehensive dialogue and could thus not be included in the study.

Qualitative interviews were conducted in the older person's home following a semi-structured interview guide. A PhD student, who was also a district nurse, conducted all the interviews, and due to the nursing background was experienced in communicating with older people regarding their health situation. The interviews started with the open-ended question, "Can you please tell me about the care planning meeting you had with professionals from the municipality and the county council?". To capture the process of establishing a shared care plan through joint care planning, questions were asked regarding their experience of the time before, during and after the care planning meeting. All interviews were recorded and transcribed verbatim for analysis.

The Regional Ethical Review Board in Lund approved the study (Dnr 2013/549).

2.2. Data analyses

The interviews were analysed using content analysis inspired by Graneheim and Lundman (2004). At first, two of the authors (JK, AC) read all the interviews to get an overall sense of the content. They then collaborated to discuss their first impressions of the content as a whole. The interviews were then divided so the two authors analysed six interviews each. The analysis was performed by dividing the text into meaning units (i.e. parts of the text that were related to the study aim). They were then coded which means that the meaning units were condensed and labelled with words or short phrases capturing the core of the meaning unit. The codes were then grouped together into categories according to the mutual or variant content. Categories reflecting the same and mutual content were merged together into categories and subcategories based on the codes from all of the interviews (Table 1). Then the authors collaborated to discuss and agree on these categories. At this stage the third author (MA) read the interviews, categories and the belonging codes to confirm the results and that all aspects and variation in the codes were captured. All the authors then discussed the categories and came to an agreement of final categories and subcategories.

3. Results

The results showed that the process of establishing a shared care plan from the perspective of the older person and next of kin were