Tidsskriftet Tidsskrift for Den norske legeforening

Advance care planning towards the end of life

SHORT REPORT

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Background

New national clinical guidelines are now available on advance care planning (ACP). Confidence in communication is important for implementation of the guidelines. This study aims to identify healthcare personnel's self-perceived confidence in communication about future medical care and patients' wishes at the end of life.

Material and method

Healthcare personnel in twelve geriatric units in South-Eastern Norway Regional Health Authority responded to an online questionnaire survey in autumn 2022. The four response alternatives for self-reported confidence – 'unconfident', 'fairly confident', 'very confident' and 'extremely confident'– are combined into two categories: 'limited confidence' ('unconfident' and 'fairly confident') and 'high confidence' ('very confident' and 'extremely confident').

Results

We received responses from 289 of the 470 (61.5 %) invited, with an average age of 37.8 ± 11.3 years, of whom 217 out of 289 (75 %) had more than five years of professional experience. Of the doctors, 15 out of 67 (22 %) reported limited confidence in communication about 'future deterioration of the patient's health condition', 20 out of 67 (30 %) about 'life-sustaining treatment'

and 13 out of 67 (19 %) about 'preferences towards the end of life'. For other healthcare personnel, the corresponding responses were 119 out of 222 (54 %), 140 out of 222 (63 %) and 109 out of 222 (49 %).

Interpretation

Self-assessed confidence in communication about future deterioration, future medical care and the patient's own wishes at the end of life varies, and such confidence is limited among many health personnel in geriatric units. Measures appear to be needed to increase confidence in the communication and implementation of ACP in the Norwegian health service.

Main findings

Twenty out of 67 doctors (30 %) reported limited confidence in communication about 'future medical care', while 140 out of 222 other healthcare personnel (63 %) reported the same. For communication about 'preferences towards the end of life', 13 (19 %) of the doctors and 109 (49 %) of the other healthcare personnel reported limited confidence.

The Norwegian Directorate of Health recently launched national clinical guidelines on advance care planning (ACP) for patients with a short life expectancy (1). ACP is a communication process about the patient's values and wishes for involvement and future treatment and care. Its goal is to ensure that future care aligns with these preferences, even as the patient's condition deteriorates. It is recommended that the patient's next-of-kin be involved and that ACP is documented.

ACP is particularly relevant for frail older patients with a significant disease burden. Systematic reviews indicate that ACP is perceived in a positive light by patients, their next of kin and clinicians, and that it improves communication and involvement (2). Nevertheless, ACP is an underutilised resource in hospitals. One possible explanation for this is lack of confidence in communication (3). Knowledge and experience in caring for patients towards the end of life likely enhance confidence in conducting ACP (3).

The aim of the study was to assess the confidence of healthcare personnel in geriatric units in relation to communication about future deterioration of a patient's health condition, as well as the patient's wishes for future treatment and care towards the end of life.

Material and method

Before initiating a cluster randomised controlled trial on the implementation of ACP in geriatric units in South-Eastern Norway Regional Health Authority, aimed at improving patient and next-of-kin involvement (4), we conducted an

online survey (see Appendix 1). Healthcare personnel from geriatric units in 12 out of 15 hospitals in Norway participated in the period 18 October 2022 to 14 November 2022, while three departments declined to take part. The purpose was to examine current practices for assessing preferences and compliance with these, decision-making processes in the absence of capacity to consent, and confidence in communication about the patient's future health condition. We present here Part 3 of the survey regarding self-assessed confidence in communication about future medical care, while the extent to which patients' preferences for information, involvement and treatment are complied with is covered in a previously published article (5). The hospitals in the study either had their own acute geriatric units or internal medicine units with dedicated beds for geriatric patients, staffed with specialised interdisciplinary healthcare personnel, including at least one geriatrician.

The four response alternatives for self-reported confidence – 'unconfident', 'fairly confident', 'very confident' and 'extremely confident' (see Appendix 2) – are combined in Table 1 into two categories: 'limited confidence' ('unconfident' and 'fairly confident') and 'high confidence' ('very confident' and 'extremely confident') in order to simplify the analysis and enable a clearer presentation of the results. Variables are presented separately for doctors and other healthcare personnel: continuous variables as mean ± standard deviation and categorical variables as absolute numbers/totals and percentages (Table 1). We also compared the responses of nurses with those of physiotherapists, occupational therapists and nursing associates to determine if nurses differed from healthcare personnel excluding doctors.

Table 1

Self-reported confidence in communication among healthcare personnel (n = 289) in 12 geriatric units in South-Eastern Norway Regional Health Authority, autumn 2022

Questions	Doctors (n = 67)	Other healthcare personnel (n = 222)
How confident are you that you can talk about …	*n* (%)	*n* (%)
… future deterioration of a patients' health condition?		
With the patient		
Limited confidence	15 (22)	119 (54)
High confidence	52 (78)	103 (46)
With the patient's next of kin		
Limited confidence	14 (21)	142 (64)
High confidence	53 (79)	80 (36)
With the patient and their next of kin		
Limited confidence	19 (28)	143 (64)
High confidence	48 (72)	79 (36)
With other healthcare personnel		

Questions	Doctors (n = 67)	Other healthcare personnel (n = 222)
Limited confidence	7 (10)	46 (21)
High confidence	60 (90)	176 (79)
... the patients' wishes for life-sustaining treatment following severe deterioration in their health condition?		
With the patient		
Limited confidence	20 (30)	140 (63)
High confidence	47 (70)	82 (37)
With the patient's next of kin		
Limited confidence	19 (28)	156 (70)
High confidence	48 (72	66 (30)
With the patient and their next of kin		
Limited confidence	23 (34)	156 (70)
High confidence	44 (66)	66 (30)
With other healthcare personnel		
Limited confidence	7 (10)	72 (32)
High confidence	60 (90)	150 (68)
... the patient's wishes for future care?		
With the patient		
Limited confidence	5 (7)	31 (14)
High confidence	62 (93)	191 (86)
With the patient's next of kin		
Limited confidence	6 (9)	42 (19)
High confidence	61 (91)	180 (81)
With the patient and their next of kin		
Limited confidence	7 (10)	41 (18)
High confidence	60 (90)	181 (82)
With other healthcare personnel		
Limited confidence	4 (6)	20 (9)
High confidence	63 (94)	202 (91)
... treatment and care towards the end of life?		
With the patient		
Limited confidence	13 (19)	109 (49)
High confidence	54 (81)	113 (51)

Questions	Doctors (n = 67)	Other healthcare personnel (n = 222)
With the patient's next of kin		
Limited confidence	13 (19)	121 (55)
High confidence	54 (81)	101 (45)
With the patient and their next of kin		
Limited confidence	17 (25)	123 (55)
High confidence	50 (75)	99 (45)
With other healthcare personnel		
Limited confidence	5 (7)	50 (23)
High confidence	62 (93)	172 (77)

The study was approved by Sikt – Norwegian Agency for Shared Services in Education and Research (805491) via digital consent. ClinicalTrials.gov identifier: NCT05681585.

Results

A total of 470 (61.5 %) healthcare personnel were invited to participate and 289 accepted (61.5 %). Among the 289 participants, 217 (75 %) had more than five years of professional experience. The average age of participants was 37.8 ± 11.3 years, 235 (81 %) were women, 67 (23 %) were doctors (41 of these 67 [61%] were geriatricians), 156 (54 %) were nurses, 31 (11 %) were physiotherapists and occupational therapists, and 35 (12 %) were nursing associates. Participation varied between the different units, from 6 out of 16 (38 %) to 24 out of 30 (80 %).

A total of 15 of the 67 (22 %) doctors and 119 of the 222 (54 %) other healthcare personnel reported limited confidence in discussing future deterioration with the patient (Table 1). Furthermore, 20 (30 %) of the doctors and 140 (63 %) of other healthcare personnel reported limited confidence in communicating with the patient about life-sustaining treatment, and 13 (19 %) and 109 (49 %), respectively, reported limited confidence in discussing preferences towards the end of life. Several respondents indicated limited confidence in communicating with the patient and their next-of-kin together, compared to communicating with the patient alone (Table 1). The nurses' responses did not differ from those of others in the group 'other healthcare personnel' (data not shown).

Discussion

In this online survey, varying degrees of confidence were reported in communication about future deterioration, life-sustaining treatment and medical care towards the end of life. Around a quarter of the doctors and half of the other healthcare personnel reported limited confidence. Some participants reported less confidence in communicating with the patient and their next of kin together, while a large proportion felt a high degree of confidence in communicating solely with healthcare personnel.

There are many possible explanations for the reported lack of confidence. These may include the increase in options for sustaining life, the focus on cure, uncertainty about prognosis and what constitutes an acceptable quality of life, a lack of openness and a reluctance to discuss death. Insufficient training or limited experience may also be factors. Other explanations could be unrealistic expectations and limited health literacy among patients and next of kin (6). A Norwegian qualitative study of young doctors describes a general uncertainty, with many refraining from providing specific prognostic information due to a poor knowledge base, lack of consensus among colleagues and personal insecurity (7).

Two-thirds of the doctors in this study were geriatricians. Doctors with this specialty have expertise and experience in discussing the end-of-life phase, which may explain why doctors reported a higher degree of confidence than other healthcare personnel. Furthermore, nurses work more closely with patients and are therefore in a better position to discuss end-of-life topics, while prognosis and treatment options are primarily the responsibility of doctors. It is reasonable to assume that uncertainty with this type of communication may be greater in other parts of the health service.

Confidence in communication is likely a necessary, but not sufficient, prerequisite for carrying out ACP. Training needs may vary depending on the profession. When carrying out ACP, an emphasis should be placed on interdisciplinary competence in communicating with both the patient and their next-of-kin. The role of doctors in ACP appears to be important, particularly in relation to the medical aspects of the conversations. Competence enhancement should be incorporated into all types of education programmes for healthcare professionals, including in continuing education (8).

The study has some limitations, including limited validation of the questionnaire, varying response rates since non-respondents may have provided different answers, and differences in the sizes of units. We do not know whether self-reported confidence, as measured in this study, improves the quality of ACP, communication or involvement. This should be further studied in future research.

Conclusion

Self-assessed confidence in communication about future medical care and the patient's preferences towards the end of life varied among healthcare personnel in geriatric units, and many of them had limited confidence. Knowledge and experience are probably conducive to boosting confidence.

The study was funded by the Research Council of Norway, project number 302880.

The article has been peer-reviewed

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Publisert: 1 November 2024. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.24.0105
Received 21.2.2024, first revision submitted 11.6.2024, accepted 23.9.2024.