



ORIGINAL ARTICLE

Patients' attitude and knowledge towards resuscitation and advance care planning at the palliative care unit

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Abstract

Objective: There is a lack of information about patients' attitudes towards and knowledge of resuscitation and advance care planning (ACP) in the palliative care unit (PCU). The aims of this study were to examine (a) patients' attitudes towards and knowledge of the topic of resuscitation, (b) patients' level of education about their illness and (c) their concept of ACP.

Methods: This study used a qualitative methodology that involved semi-structured interviews with advanced cancer patients admitted to the PCU. Interviews were conducted during the first week after admission, recorded digitally and transcribed verbatim. Data were analysed through content analysis using NVivo 12.

Results: Eighteen interviews revealed the following themes: (a) ambivalence regarding preference for or refusal of resuscitation, (b) patient confidence concerning their level of education, (c) lack of information about ACP and (d) positive perception of the stay in the PCU. The data showed that a high percentage of PCU patients desired resuscitation even though education about their illness was mostly perceived as good. Many patients did not receive information about ACP. Patients perceived the stay in the PCU positively.

Conclusion: The study results reveal that there is lack of knowledge about ACP and resuscitation in patients in the PCU.

KEYWORDS

advance care planning, neoplasms, palliative care, qualitative research, resuscitation, terminal care

1 | INTRODUCTION

Palliative care is a multidisciplinary subject, and it is particularly associated with providing medical care for patients with life-limiting diseases. It emphasises well-being at all points of the disease trajectory on the basis of need and regardless of prognosis (LeBlanc & El-Jawahri, 2015).

Until now, only a few studies have dealt with topics such as resuscitation and life-prolonging measures or advance care planning (ACP) from the patients' perspective. A previous study examined the expectations and hopes that caregivers expressed towards the palliative care team (Bleidorn, Pahlow, Klindtworth, & Schneider, 2012). Furthermore, there are studies that have described the preferred care and death location of patients (Robinson, Gott, Gardiner,

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& Ingleton, 2015), preferences for communication with physicians in the last phase of life (Back, Trinidad, Hopley, & Edwards, 2014; Brom et al., 2014) and the ideas that patients have about what makes a good palliative care physician (Masel et al., 2016).

The efficacy and proportionality of a treatment should be assessed with regard to a defined therapeutic goal to determine whether such a treatment is indicated. If the death of a patient is foreseeable, patient-centred comfort terminal care that is adapted to the situation should be the aim. A "do not resuscitate" (DNR) order means that in the case of a functional cardiovascular standstill, no mechanical, medical or electrical measures should be performed to revive the patient. Furthermore, in the case of rejection of resuscitation by a patient, this decision must be respected and documented. However, many patients lack knowledge of resuscitation (Wee, Chang, Lau, Wong, & Ong, 2017). The handling of resuscitation policies also varies within different countries and institutions.

Advance care planning is defined as the process of enabling individuals to define goals and preferences for future medical treatment, to discuss these goals and preferences with family and healthcare providers, and to record and review them if appropriate (Rietjens et al., 2017). ACP is a processual event centred on one or more conversations. These discussions may result in different scenarios, including concrete orders and declarations, often legally binding, such as an advance directive; the naming of a person who decides for the patient if the patient cannot make decisions (preventive power of attorney, proxy), and statements or opinions on general preferences and values. ACP should focus on patients' perspectives and preferences; given these considerations, Wichmann et al. consider ACP and resuscitation as hot topics (Fahner et al., 2018; Pifer, Farrugia, & Mattes, 2018; Wichmann et al., 2018). In Anglo-American countries, ACP programmes are widespread. In comparison, the integration of ACP and professional ACP consultants into the Austrian healthcare system is still under development.

Palliative care addresses end-of-life (EOL) issues, which includes the topics of resuscitation and ACP, but there is still a lack of information among the public on the purpose of this discipline (McIlpatrick et al., 2014).

Therefore, the purpose of this study was to examine (a) patients' attitude towards and knowledge of resuscitation, (b) patients' level of education about their illness and (c) their concept of ACP in relation to their personal situation.

2 | METHODS

This study used the qualitative methodology of content analysis (Elo & Kyngäs, 2008). The authors adhered to the 32-item checklist included in the consolidated criteria for reporting qualitative research (CoreQ) (Tong, Sainsbury, & Craig, 2007). This study was approved by the Ethics Committee of Vienna (Approval no. 1945/2017).

2.1 | Participants and data collection

The investigation was performed in the clinical division of palliative care of the Medical University of Vienna, a hospital-based facility consisting of 12 beds, mainly attending to cancer patients and regularly providing ACP. The multidisciplinary palliative care team includes nursing staff, physicians, a psychologist and psychotherapist, a social worker, a chaplain, a dietician and volunteers.

The inclusion criteria were as follows: over 18 years of age, has no reasons for non-participation (e.g., cognitive deficit, delirium, mental illness, excessively poor performance status, severe septicæmia with impaired consciousness), has no language problems and has the ability to give written informed consent.

The Karnofsky Performance Status Scale (KPS) was used to rate each patient's functional status. The KPS ranges from 0 to 100, with 0 signifying death and 100 indicating perfect health (Mor, Laliberte, Morris, & Wiemann, 1984).

The participants gave written consent to participate in the study and to be digitally recorded during the interviews. Caregivers were allowed to be present during the interviews.

The interviews were conducted using predetermined open-ended questions (Table 1) (Gysels, Shipman, & Higginson, 2008). The interviews were conducted in German. All patients were interviewed by a female medical student (GM.G.), who was not a team member. Interviews were conducted during the first week after the patients' admission to the palliative care unit (PCU).

When theoretical saturation was achieved, no further participants were enrolled. Theoretical saturation was reached when no new codes arose and all major themes were well developed and supported by data.

2.2 | Data analysis

The interviews were recorded digitally and transcribed verbatim. German statements were transcribed by a professional transcriptionist and translated into English by a professional translator. The

TABLE 1 Interview guide

1. You are now admitted to a palliative care unit. What information did you receive about this unit?
2. How did you find the previous information you have regarding your illness and its course?
3. What is your current state of knowledge about the topic of resuscitation?
4. How do you feel about the topic of resuscitation?
5. What is the significance of resuscitation for you in relation to your present situation?
6. What information do you know about the topic of advance care planning, such as advance directives and the preventive power of attorney?
7. What needs and wishes do you want to address to your treating team in view of your current situation?
8. Is there anything else you would like to communicate about this subject?

transcripts of the interviews were not returned to the participants for comments or corrections.

Content analysis was applied using a step-by-step procedure (Ramani & Mann, 2016). By using content analysis, we systematically transformed the text of the interviews into an organised and concise summary of key results. Coding categories were derived directly from the text data. The analysis started with the relevant research findings, which served as a guide for the initial codes. Summative content analysis involved counting and comparing keywords, followed by the interpretation of the underlying context.

Two researchers with experience in qualitative research (M.U. and E.K.M.) analysed the interview transcripts by using open coding. Neither of them had established a relationship with the study participants prior to the study. To ensure the reliability of the coding process, three researchers (G.M.G., M.U. and E.K.M.) independently generated a list of codes.

The results were then compared, and differences were resolved by verbal discussion with three other researchers (F.A., A.K. and S.R.S.). The themes were identified by group discussion until consensus was achieved.

The software program NVivo 12 was used to analyse the data.

3 | RESULTS

Interviews were conducted between October 2018 and February 2019. The duration of each interview ranged from 7 to 48 min (mean: 20 min). The analysis of the interview transcripts revealed the following four themes, which are presented in a narrative manner using

patient quotations to explore each theme further: (a) ambivalence regarding preference for or refusal of resuscitation, (b) patient confidence concerning their level of education about their illness, (c) lack of information about ACP and (d) positive perception of the stay in the PCU. The interviews are marked with Px (patient number x).

3.1 | Patient characteristics

Eighteen consecutive interviews were conducted. The interviewees were selected from a larger cohort of 43 patients. All patients were being admitted to the PCU for the first time. Twenty-five patients had to be excluded for the following reasons: (a) 20 patients did not meet the inclusion criteria (11 had an excessively poor performance status, five were suffering from a cognitive deficit caused by delirium, three had severe septicaemia and one had language problems) and (b) five did not consent to participate in the study. The patients' characteristics are shown in Table 2. The reasons for hospitalisation were uncontrolled cancer-related pain (40%), dyspnoea (30%), cachexia and lack of appetite (15%) and psychosocial factors (15%). A caregiver stayed with a patient during one interview (P8). The themes, categories and examples of the codes are shown in Figure 1.

3.2 | Theme 1: Ambivalence regarding preference for or refusal of resuscitation

An observation was that seven of the 18 patients misunderstood the question about their current knowledge on the topic of resuscitation and had the impression that they were being asked about their capacity to resuscitate a person. However, after the misunderstanding was

TABLE 2 Profile of the study participants

Participants	Age (years)	Sex	Cancer disease	Karnofsky performance status scale (%)
P1	77	F	Pancreatic	60
P2	46	F	Ovarian	60
P3	79	M	Pancreatic	50
P4	66	F	Lung	50
P5	90	F	Ovarian	50
P6	54	F	Breast	70
P7	78	M	Lung	50
P8	57	F	Pancreatic	50
P9	64	M	Lung	50
P10	43	F	Breast	60
P11	70	F	Gastric	70
P12	88	F	Breast	60
P13	46	M	Pancreatic	70
P14	55	M	Head and neck	50
P15	61	F	Pancreatic	60
P16	50	M	Head and neck	60
P17	55	M	Lung	60
P18	81	M	Colorectal	60

Topic	Themes	Categories	Examples for codes
Patients' attitude and knowledge towards resuscitation and advance care planning	Perception of resuscitation	Desire or decline of resuscitation	Unclarity about resuscitation Lack of information Desire of resuscitation Decline of resuscitation Ambivalence
	Education about illness	Information	Dissatisfaction Lack of resources Positive perception
		Communication	Humanity Honesty Lack of time
	Information about advance care planning	Arrangement of advance care planning	Own initiative Caregivers Physicians
Information		Lack of information Misconception	
Stay in the palliative care unit	Patients' experiences	Personal situation	Ambivalence Lack of interest Accurate timepoint
			Being in good hands Holistic view Symptom control

FIGURE 1 Themes, categories and codes generated from the patient interviews

clarified and the question was rephrased, the different views and attitudes of the patients were determined. Eight patients, by contrast, related the question directly to their situation and responded accordingly.

With regard to resuscitation, the patients reported different views. Eight of the 18 patients were clearly opposed to resuscitation. By contrast, seven out of the 18 patients wanted resuscitation.

A patient reported, "Well, I do not want to be resuscitated [...]. So if I'm practically out of consciousness or something, then I do not want life-prolonging measures; that's actually a resuscitation [...]." Furthermore, she said, "I think if your body says it's enough, it's not working anymore, then I have to accept it and I do not want it (...). I am glad that it actually can decide a bit, how far it can be delayed and how far not" (P2).

One patient stated, “[...] I like to live, and our mission is to live. And if you get help there, then you should accept it for the sake of God” (P1).

3.3 | Theme 2: Patients were confident in their level of education about their illness

In summary, upon arrival in the PCU, 14 out of the 18 patients regarded the information provided to them about their disease as sufficient. Four patients perceived the information they received as unsatisfactory. Six other patients reported positive or very positive experiences regarding the information provided to them about their disease. Two patients, however, were reluctant to answer this question. Still, both were of the opinion that they were sufficiently informed.

One patient reported, “[...] I have to say that honestly, at the beginning, I had very little information; I informed myself. And then at the oncology unit, before the chemotherapy, the information was very good. So you will always get informed if you ask what is going on” (P1).

Another patient reported the following experience: “The outpatient clinic was very poor; they are overloaded. Everyone is just interested in cancer. Cancer was interesting for them, but the other, the human being, it was uninteresting” (P17).

3.4 | Theme 3: Lack of information about advance care planning

Eight out of the 18 patients reported having already made an advance directive. Five of them initiated ACP on their own. Three patients reported briefly that this matter had already been settled on their own initiative. With nine of the 18 patients, the topic of a preventive power of attorney emerged after the discussion on advance directives. Two out of nine patients had their children as precautionary authorised persons. Another three patients had their partners as precautionary authorised persons. Two other patients were more averse to the idea of having someone else decide about their situation.

One patient reported, “[...] I have prepared my will, as I do not want certain things” (P1).

Another patient stated that he would like to sign an advance directive right away, and he stated, “Unfortunately, I have not done any of that yet, a mistake on my part. I have to make sure that I get an appropriate form as soon as possible because to be honest, it might happen one day that I will not wake up again.” He added, “[...] the probability is greater than the average” (P13).

3.5 | Theme 4: Positive perception of the stay in the palliative care unit

Fourteen out of the 18 patients linked the question “What needs and wishes do you want to address to your treating team in view of your current situation?” to the team in the PCU. Three other patients

said that they were satisfied with the treatment and care at the unit, but they had nothing to add. Within the entire patient cohort, not one patient expressed with the treatment in the PCU.

A patient mentioned at the beginning of the interview, “And I have to say, honestly, I’ve told everyone else, everything is really taken care of there, it’s like in a five-star hotel. So that’s so humane, yes, I do not know how to express it. Full of love and attention” (P1).

To the question of whether she would like to add something about this subject, the patient answered, “Dying is not unfamiliar to me. But life is not unfamiliar to me either. And if one of these two comes, you take it. And that would be my last word” (P1).

4 | DISCUSSION

Within this manuscript, we describe the results of qualitative interviews conducted with advanced cancer patients in a palliative care setting. Eighteen patients suffering from different types of metastatic cancer were surveyed upon their attitude towards resuscitation. The results of this study revealed four themes, including (a) ambivalence regarding preference or refusal of resuscitation, (b) patient confidence concerning their level of education about their illness, (c) lack of information about ACP and (d) positive perception of the stay in the PCU. Seven out of 18 patients admitted to a PCU desired resuscitation. When asked about their preferences, two out of those seven patients expressed that their desire for resuscitation would depend on the outcome. In the case of physical or mental damage or when they were likely to die on a machine, they would not favour resuscitation. Interestingly, although all patients were suffering from advanced and metastatic cancer and felt well informed about their illness, the patients did not seem to be aware of the severity of their disease. This is underlined by the fact that all patients died within 2 months after the interviews. It was particularly noticeable that some patients, despite having a serious illness, did not want to discuss ACP, and some of them felt that it was not yet time to deal with this topic. Furthermore, many of the patients had already initiated ACP on their own and not upon following professional recommendations. The stay in the PCU was perceived positive.

4.1 | Resuscitation in patients suffering from advanced cancer

The television and media portray resuscitation as a highly successful medical intervention. A survey showed that 50% of surveyed subjects believed that cardiopulmonary resuscitation has at least a 30% chance of successfully resuscitating a hypothetical 60-year-old cancer patient who is in hospice and has exhausted all chemotherapy options (Sundar, Do, & O’Cathail, 2015). Therefore, education about the futility of resuscitation in terminally ill cancer patients seems crucial. The term “futility” describes the meaninglessness or hopelessness of a medical treatment, and it plays an important role in therapy decisions at EOL (Jox, Schaidler, Marckmann, & Borasio, 2012). The results of a study showed that none of the 171 cancer patients in whom cardiac

arrest was anticipated survived (Ewer, Kish, Martin, Price, & Feeley, 2001). This underlines that futile resuscitation should be avoided.

4.2 | Advance care planning

Through ACP, patients may decide for themselves which treatments are taken or omitted. A functioning ACP system also represents an opportunity for healthcare providers concerning medical decisions. Nevertheless, the results of this study also confirm the need for further development of ACP and awareness of its importance, especially because healthcare providers do not always initiate these conversations themselves in a timely manner. Austria is lagging behind in regard to a structured ACP concept and advance care directives. In Austria, only about 5% of the population has an advance care directive, compared to around 43% in Germany. There is ongoing research about ACP. Within a randomised controlled trial, Johnson et al., (2016) aimed to assess the efficacy of a formal ACP intervention in the form of discussing and meeting EOL preferences in patients suffering from cancer and their family members and compared ACP efficacy with that of standard care. The results showed that an ACP intervention did not increase the likelihood that EOL care was consistent with patients' preferences (Johnson et al., 2018). This underscores that ACP is a process that still has to be developed. Nevertheless, ACP interventions were found to increase the frequency of out-of-hospital and out-of-ICU care and increase the use of hospice and palliative care (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Continuously adapting ACP interventions may be necessary to further improve the quality of EOL care. In a study that used an online survey and presented a hypothetical patient with limited life expectancy, 59% of 1.272 surveyed adults did not want to discuss their life expectancy, which underlines the dilemma of identifying patients' preferences regarding ACP or EOL issues (Schoenborn et al., 2018). On the other hand, it is known that physicians sometimes fail to provide accurate prognostic estimates (Christakis & Lamont, 2000). Thus, the question of how to improve communication about these issues remains challenging.

4.3 | Strengths and limitations

What is novel and relevant in our study is that we tried to identify how patients in the PCU perceive the topics of resuscitation and ACP. Conducting interviews on the topic of resuscitation within a palliative care setting is challenging and requires a high degree of sensitivity to avoid patient distress. The issue of resuscitation and questions about the patients' state of knowledge on this topic elicited misunderstanding because some thought they were being asked about their knowledge regarding how to perform a resuscitation. This shows that having a conversation about resuscitation is not a common topic and might need appropriate training. Furthermore, future studies should have interview guides designed with input from the patients to ensure understanding. The limitations of this study are that it was performed at a single-centre and

hospital-based unit, so the results are therefore not generalisable. All patients involved in this study were being admitted to the PCU for the first time. Those who had already been exposed to palliative care might have been more likely to initiate ACP. Although the use of numbers in qualitative research remains controversial, we considered the use of numbers as a process orientation that helped to illustrate our findings.

5 | CONCLUSIONS

This study reveals that the topics resuscitation and ACP remain taboo, even among critically ill patients who are admitted to a PCU. Because of a lack of data regarding the opinions and knowledge of patients on these subjects, this study's results could lead to a better understanding of these issues and thus help overcome the identified barriers. This research further underscores the importance of actively addressing EOL issues to promote patient autonomy.

6 | IMPLICATIONS FOR FUTURE

Defining care goals might be a first step to exploring the time point when EOL discussions should be initiated (Karim, Harle, O'Donnell, Li, & Booth, 2018). Many studies have already been conducted in order to actually induce a change in clinical practice and to increase public and professional awareness about palliative care (Kelley & Morrison, 2015). Obviously, promising study results must be constantly repeated and emphasised (Davis, Temel, Balboni, & Glare, 2015; Ferrell, Temel, Temin, & Smith, 2017; Greer, Jackson, Meier, & Temel, 2013; Temel et al., 2017, 2010). According to a recent study, creating videos about ACP preferences was found to be useful for hospital patients (Quintiliani et al., 2018). Another study demonstrated that information videos about resuscitation were helpful for patients in palliative situations and encouraged EOL discussions (Taubert, Norris, Edwards, Snow, & Finlay, 2018). Interventions to empower seriously ill older adults in an emergency department so that future care goals can be set are well accepted (Ouchi et al., 2018). Furthermore, the surprise question "Would you be surprised if the patient dies within the next year?" can serve to identify patients who might benefit from palliative care (Moroni et al., 2014). Collaboration with general practitioners, who often know their patients for years, is certainly a further important step to improve EOL care.

In summary, healthcare providers need time and support to have frank patient conversations (Masel, Unsel, Adamidis, Roider-Schur, & Watzke, 2018) and to establish and maintain trust-based relationships.

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CONFLICT OF INTEREST

The author(s) have no conflicts of interest.

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