

## Review Article

# Patients' Autonomy at the End of Life: A Critical Review



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## Abstract

**Context.** The predominating definition of autonomy as a capacity to make an independent rational choice may not be suitable for patients in palliative care. Therefrom arises the actual need for more contextualized perspectives on autonomy to promote the quality of life and satisfaction with care of terminally ill patients.

**Objectives.** This review aimed to develop a theoretical structural model of autonomy at the end of life based on patients' end-of-life care preferences.

**Methods.** In this review, we used systematic strategy to integrate and synthesize findings from both qualitative and quantitative studies investigating patients' view on what is important at the end of life and which factors are related to autonomy. A systematic search of EMBASE (OVID), MEDLINE (OVID), Academic Search Complete (EBSCO), CINAHL (EBSCO), and PsycINFO (EBSCO) was conducted for studies published between 1990 and December 2015 providing primary data from patients with advanced disease.

**Results.** Of the 5540 articles surveyed, 19 qualitative and eight quantitative studies met the inclusion criteria. We identified two core structural domains of autonomy: 1) being normal and 2) taking charge. By analyzing these domains, we described eight and 13 elements, respectively, which map the conceptual structure of autonomy within this population of patients.

**Conclusion.** The review shows that maintaining autonomy at the end of life is not only a concern of making choices and decisions about treatment and care but that emphasis should be also put on supporting the patients' engagement in daily activities, in contributing to others, and in active preparation for dying. *J Pain Symptom Manage* 2019;57:835–845. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

Autonomy, palliative care, end of life, terminally ill, quality of life, patient preference

## Introduction

There exists no universal definition of patients' autonomy, and there is no consensus about what it means. At the same time, the dominant emphasis on individual autonomy defined as a capacity to make an independent rational choice, which has a significant influence on principles biomedical ethics,<sup>1</sup> is being criticized for failing to inform nursing and care for seriously ill and older patients.<sup>2</sup> In modern medicine, the liberal emphasis on individual freedom and resistance to a controlling authority<sup>3</sup> is represented in legal disputes articulating patients' rights to receive care consistent with their preferences.<sup>4</sup>

The critics of the mainstream bioethical approach argue that, on the one hand, the principle of autonomy does not distinguish between “respecting autonomy” and “promoting autonomy”<sup>5</sup> and, on the other hand, that this limited understanding of autonomy as the capacity to make individual choices ignores the important role that autonomy plays in the constant process of adaptation to opportunities and limitations in the interaction with the world.<sup>6</sup>

There is growing evidence reflecting the general priorities and preferences of people in advanced stages of life-threatening illnesses.<sup>7–9</sup> The diversity of the results supports the suggestion that end-of-life

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needs are multidimensional<sup>10</sup> and strictly individual. Interview- or questionnaire-based research usually generates a list of items that are considered important by most participants. The list encompasses different domains of experience (physical, psychological, social, and spiritual), which gives an image of how the advanced disease impacts the functioning and understanding of everyday life. There is a strong agreement that the key for improvement of end-of-life care is to make the care consistent with patient preferences by an individualized process of decision making.<sup>11</sup>

The legal concept of informed consent and advanced directives grounded in the ethical principle of individual autonomy has been implemented to reach this goal. But some studies show that this decision-making approach does not match the needs of many patients and their families.<sup>12,13</sup> Therefrom arises the actual need for more contextualized perspectives on autonomy that would be more suitable for the situation of patients at the end of life and would help to promote the quality of their life and satisfaction with received care.

Mars<sup>6</sup> identifies different conceptualizations of autonomy in the context of chronic physical illness. First of them is defined by Dworkin.<sup>14</sup> For Dworkin, autonomy constitutes a critical rational reflection of desires. However, the advocates of relational autonomy<sup>15</sup> argue that such reflection is not necessarily rational but may involve emotions, imagination, and creativity. They stress the importance of relationship and social interdependence, only through which autonomy can be shaped. Agich<sup>16</sup> argues that patients' capacity for reflection of their desires can be jeopardized by chronic illness, and he proposes a model of actual autonomy, which is built upon everyday activities by accommodation and adaptation to the new circumstances in structures of meaning. He also describes how the perception of autonomy simply as of individual freedom and self-determination can cause conflicts in the context of the patients' dependence on others, which can be manifested as the denial of need, hostility to the carers, and the feelings of guilt for being a burden.<sup>16</sup>

Hedgecoe's critique<sup>17</sup> of the classic bioethics model of autonomy points out significant differences between theoretical bioethical analyses and the ethical reasoning that takes place in real clinical situations. He suggests using empirical social science in bioethics to get the bioethical discussion more empirically rooted.

### *Aim*

This review aims to develop an evidence-based, structural model of autonomy of patients at the end of life by analyzing end-of-life care preferences related

to autonomy, as expressed by the patients themselves in available literature.

### *Method*

A systematic review strategy was used to integrate and synthesize the findings from both qualitative and quantitative studies. This design was chosen to gain broader knowledge by including studies investigating patients' preferences from both methodological perspectives. Combination of quantitative and qualitative data is recommended when the aim is to build a theoretical model, rather than to generalize knowledge by comparing the results of particular reviewed studies,<sup>18</sup> which applies to our study. As this is a review study, ethics approvals were not required.

The interpretation of the results was based on the concept of autonomy as developed by Agich,<sup>16</sup> stressing the importance of interdependent and social factors in understanding and promoting the autonomy of frail people. To develop a theoretical model of autonomy of people at the end of life, we decided to analyze the studies of the patients' preferences, and to identify which of those preferences are connected with autonomy understood as a meaningful adaptation to the new circumstances and situations at the end of life.

In the analysis, the demands of the integrative review method were met.<sup>19</sup> Open and axial coding techniques and constant comparison method<sup>19</sup> were used to achieve synthesis by subsuming the concepts identified in the primary studies into a higher-order theoretical structure.

### *Eligibility Criteria*

In this review, based on the Agich model explained previously, we understand autonomy as a concept expressed by patients' preferences so the search was designed to gather studies on patients' preferences. The term autonomy itself was intentionally not included in the search strategy. Qualitative and quantitative studies were included if they provided primary data from patients with advanced stage of chronic diseases and were published between 1990 and 2015 in English, French, and Czech peer-reviewed journals. Papers that did not provide primary data from the patients—reviews, editorials, letters, primary data from health professionals—were excluded, although they were used for double-checking references to identify studies potentially missed by the initial search.

Studies providing primary data gained from family members were not included because the main goal of this study was to derive definitions of autonomy exclusively from the patients' perspective. Studies focusing on one specific preselected aspect of

Table 1  
Search Strategy

1. preferences, priorities, values, attitude to death - combined with OR
2. patients, family, caregiver - combined with OR
3. terminal care, palliative care, end of life - combined with OR
4. English, French, Czech - combined with OR
5. 1 AND 2 AND 3 AND 4

patients' priorities, for example, treatment priorities or place of death preferences were also excluded, as well as papers about advance directives or advance care planning that did not provide further specific information about patients' priorities.

### Search

Key terms used in search strategy are summarized in Table 1. The following databases were used: EMBASE (OVID), MEDLINE (OVID), Academic Search Complete (EBSCO), CINAHL (EBSCO), PsycINFO (EBSCO). We identified 5524 articles through database searching and 16 studies through other sources. After removing duplicates, abstracts screening, and assessment for eligibility (Fig. 1), we finally included 19 qualitative and eight quantitative studies (two of them<sup>20,21</sup> reporting on one study) in the review (Table 2) providing data from 2924 patients with advanced chronic disease. Reference lists of identified

studies were manually searched to identify other potentially relevant articles.

### Findings

Two core structural domains of autonomy as viewed from the perspective of patients at the end of life were identified—"being normal" and "taking charge." Both domains could be thematically summarized as "active participation in normal life while dying." Each of the two domains is further analyzed from two perspectives that emerged from the analysis: perceptual perspective and activity perspective (Fig. 2). The perspective of perception builds upon the preferences that describe the patients' feelings and perceptions that allow them to feel autonomous in the way as a meaningful adaptation to their situation. The perspective of activity is focused on the preferences that allow patients to actively shape their life at its end (e.g., to manage their time, help others, fulfill their needs).

Based on Agich's model of the autonomy of everyday experience that derives from both affective and rational ways of relating to the world, these two domains take into account the circumstances and clinical realities of people with advanced disease. That reveals specific aspects of the autonomy of people in this

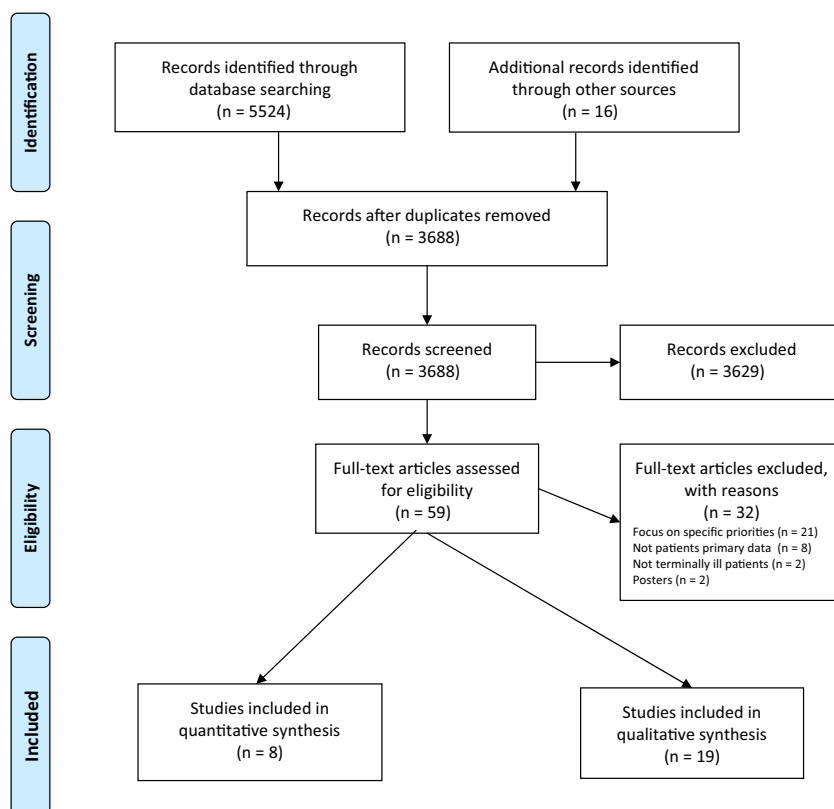


Fig. 1. PRISMA flow diagram.

Table 2  
Summary of Included Studies

Author	Year	Methods	Participants	No. of Patients	Age	Gender	Thematic Outcomes
Carter	2004	Qualitative	10 cancer patients	10	80% above 50	70% female	Personal factors (participation in daily activities, lack of energy), interpersonal responses, future issues (loss of meaning of plans, reconsider life priorities), perception of normality, taking charge (ability to define and actualize needs, process of adaptation, accepting assistance from others)
Aspinal	2005	Qualitative	10 palliative care patients, 65 caregivers	10	Above 18		Seven themes identified as most important: symptom management, choice and control, dignity, quality of life, preparation, relationship, continuity. Patients prioritized issues around preparation, relatives and professionals empathized symptom management, relationship, and quality of life.
Steinhauser	2000	Qualitative	14 patients, 61 caregivers	14	26–77, mean age 48	60% female	Six thematic outcomes: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, affirmation of the whole person
Vig	2003	Qualitative	Advanced heart disease or cancer patients	26	52–86, mean 71	100% male	Three thematic outcomes: living while dying, anticipating a transition to active dying, receiving good health care. Rating importance: 1, being able to do things for myself; 2, spending time with family and friends; 3, control of pain
Volker	2004	Qualitative	Seven advanced cancer patients	7	46–76, mean 59	85% female	Six thematic outcomes: protection of dignity, control of pain and other symptoms—pain under control, management of treatment, management of how remaining time is spent, management of impact on family, control over the dying process
Piamjariyakul	2014	Qualitative	30 ethnic minority patients with advanced cardiovascular illness	30	13 p. below 70 y., 17 beyond 70 y.	66% female	Five thematic outcomes: importance of family involvement in care, being pain free, having a comfortable environment for death, wanting no procedures for prolonging life, desiring a relationship with a professional for end-of-life decision making
MacPherson	2012	Qualitative	10 COPD patients	10	58–86	90% male	Five thematic outcomes: information provision, discussion about the future, decision making, planning for future, place of care
Clayton	2005	Qualitative	19 advanced cancer patients, 24 caregivers	19	36–83, median 68	74% female	Four thematic outcomes: treatment decision at the end of life, discussing future symptoms, preferences for place of death, discussing the terminal phase
Goodman	2013	Qualitative	18 patients with dementia	18	68–92, median 84.7	72% female	Three thematic outcomes: “dementia and decision making”—having dementia combined with living in nursing home makes them accepted that decisions are made by others, “everyday relationships,” “place and purpose”—loses have impact on their purpose of life
Horne	2012	Qualitative	25 lung cancer patients, 19 caregivers	25	47–85	72% male	Four thematic outcomes: facing death when it comes (focus on living in the present, “carry on as normal”), planning for death not dying, disclosure of the prognosis, clinical discussion about future.
McIlfatrick	2006	Qualitative	Eight palliative care patients, 16 caregivers	8	50–88, mean 74	62% female	Four thematic outcomes: to define palliative care, coordination, communication, and continuity of care. Social support, community care, and long-term planning.
Thomas	2009	Qualitative	Two advanced cancer patients	2	67	50% female	Four thematic outcomes: accept the theme of dying, desire to engage in normal activities, independent decision making, choice of place of death
Payne	1996	Qualitative	18 advanced cancer patients, 20 caregivers	18	30–81, mean 65	50% female	Thematic outcomes: descriptions of a “good death”—dying in one’s sleep, dying quietly, with dignity, being pain free, and dying suddenly.
Gardner	2009	Qualitative	10 elders with advanced lung or cardiac disease, 10 caregivers	10	64–100, mean 85	50% female	Four thematic outcomes: challenges (to experience physical and functional decline, participate in normal daily activities, accepting dependence, difficulties to cope with uncertain future), worries (pain and suffering, becoming a burden), concerns about end-of-life care (consistent and responsive care, being treated with dignity and respect, as whole person), living with dying (focus on living, having a measure of control in their lives, and choice in the care)

Singer	1999	Qualitative	126 patients (48 CKD, 40 HIV, 38 residents of long-term care facility)	126	20->85, mean 55	62% male	Five thematic outcomes: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control over end-of-life decision, relieving burden (three domains—physical care, witnessing death, substitute decision making), strengthening relationships with loved ones.
Pierson	2002	Qualitative	35 AIDS patients	35	Mean 41	91% male	11 thematic outcomes: symptom management, quality of life (without suffering, not having a prolonged life), having loved ones around, dying process (while sleeping, being awake, fear of violent death), place of death, sense of resolution (dying without unresolved issues, say goodbye, time to prepare), control over treatment (being involved in decision, to cease treatment if they want), spirituality, physician-assisted suicide (to escape unbearable pain), medical care (good access, good relationship, whole person approach), acceptance of death (by patients and by loved ones)
Goldsteen	2006	Qualitative	13 terminally ill patients, 26 caregivers	13	39–83, mean 64	77% male	Five thematic outcomes: awareness and acceptance, open communication, living life till the end (normal life, deal actively with the situation), taking care of final responsibilities (funeral, bereavement), dealing adequately with emotions
Ek	2008	Qualitative	Eight advanced COPD patients	8	48–79	63% female	Five thematic outcomes: common structure (limited living space, changed lifestyle, challenged self-image), lacking physical strength, forgoing normal activities (increasing dependence, influence on family), being socially and existentially alone, experiencing meaninglessness
Romo	2014	Qualitative	20 palliative care patients	20	67–97	65% male	Two thematic outcomes: maintaining a sense of control (sense of control without being in control, focusing on living, being comfortable), decision making in the context of ambiguity (uncertain future, contextuality of decisions)
Miccinesi	2012	Quantitative	88 advanced cancer patients	88	Mean 66.3	63% female	Thematic outcomes: 77% declared to be willing to talk about what it is important at the end of life in case of worsening of their conditions, 31% prefer to be left alone in difficult moments, 67% choose home as the preferred place of death, 63% think it is preferable to die in a state of unconsciousness induced by drugs 40% consider very important to find any meaning at the end of life, 50% responders declare to believe in any kind of life after death.
Rocker	2008	Quantitative	118 advanced COPD patients	118	Mean 73.3	53% female	Thematic outcomes: not being kept alive on life support when there is little hope for meaningful recovery (54.9% of respondents), symptom relief (46.6%), provision of care and health services after discharge (40.0%), trust and confidence in physicians (39.7%), not being a burden on caregivers (39.6%).
Heyland	2005	Quantitative	440 advanced disease patients, 160 caregivers	440	Mean 71.2	51% male	Thematic outcomes: 56% to have trust and confidence in doctors, not to be kept alive on life support, 44% to complete things and prepare for life's end, information about disease communicated in honest manner, 42% to adequate plan of care, not to be physical or emotional burden to family, 39% to have relief of symptoms.
Steinhauser	2000	Quantitative	340 seriously ill patients, 1022 caregivers	340	Mean 68	78% male	Thematic outcomes: 26 items were consistently rated as being important (>70% responding that item is important) across all groups, including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, being treated as a 'whole person. Eight items received strong importance ratings from patients but less from carers, including being mentally aware, having funeral arrangements planned, not being a burden, helping others, and coming to peace with God.
Heyland	2010	Quantitative	361 patients with advanced disease, 193 caregivers	361	Mean 76.6	52% male	Thematic outcomes: high-priority areas from the perspective of patients—sense of dignity, good care in absence of informal carer, health care workers work as a team, compassionate and supportive doctors and nurses.

(Continued)

Table 2  
Continued

Author	Year	Methods	Participants	No. of Patients	Age	Gender	Thematic Outcomes
Downey	2009	Quantitative	352 advanced disease patients, 318 nonpatients	352	Mean 69.3	53% female	Thematic outcomes: top five priorities for at least 25% of respondents—spending time with family and friends, pain control, breathing comfort, maintaining dignity and self-respect, being at peace with dying, human touch, avoiding strain on loved ones, avoiding life support.
Heyland	2006	Quantitative	440 advanced disease patients, 160 caregivers	440			Thematic outcomes: 56% to have trust and confidence in doctors, not to be kept alive on life support, 44% to complete things and prepare for life's end, information about disease communicated in honest manner, 42% to adequate plan of care, not to be physical or emotional burden to family, 39% to have relief of symptoms.
Reinke	2013	Quantitative	376 COPD patients	376	Mean 69.4	97% male	Thematic outcomes: symptom control, preparation for death (financial part, avoid strain the family, feeling at peace, say goodbye), spending time with family and friends, personal concerns (maintaining dignity and self-respect, being touched).

situation and allows us to understand their needs better.

*Being Normal.* First major domain of our structural model of patients' autonomy in a state of advanced illness is "being normal."

From the perceptual perspective, this domain consists of the perception of the normality of the body in contrast with the changes of the body<sup>22,23</sup> emerging due to physical symptoms (pain, dyspnea, weight loss) and the progression of the disease. Good management of current symptoms as well as of the future development or the dying itself was mentioned in most studies as one of the most important concerns. The need for human touch<sup>24,25</sup> is pointed out in some studies as something important that is lost and missed due to progression of the disease. Human touch was interestingly valued as more important by COPD patients than by other hospice patients.<sup>24</sup> Another important aspect of this domain is physical strength—the perception of having enough energy or strength to do everyday activities, or, on the contrary, experiencing the lack of energy<sup>22,23,25</sup> plays an important role in the perception of dependence.

From the activity perspective, following aspects of patients' preferences are strongly connected with their understanding of being autonomous: there is a strong wish or yearning to continue in normal daily activities,<sup>23,26–28</sup> pronounced as "living while dying",<sup>29</sup> "to carry on as normal" or "to strive in roles",<sup>30</sup> and "to focus on living".<sup>27,31,32</sup> While for some patients it means to live in the present and not to think about the future,<sup>22,30,32</sup> for other patients an important part of being normal, which "gives sense of meaning",<sup>29</sup> seems to consist in making plans for the future, making daily plans,<sup>29</sup> making plans for the remaining time<sup>33</sup> or even making unrealistic plans.<sup>34</sup> Other activity, which seems to be important to the patients and which is often dispraised by carers in the circumstances of dependence and disability, is helping others or contributing to others, either family members or other patients or staff, by passing on knowledge and experiences, giving gifts, spending time together.<sup>33, 35–36</sup>

*Taking Charge.* The need for active control over one's own life is pronounced in the second domain of this model of patients' autonomy, which we call "taking charge." We argue that this active control taken by patients must not be understood only as their capacity to make a rational independent choice, mainly in the situation of advanced disease and dependence on others, and that the results of the studies on patients' end-of-life care preferences show more differentiated view on this issue. Here again, we identified those preferences in which their fulfillment does not lead only

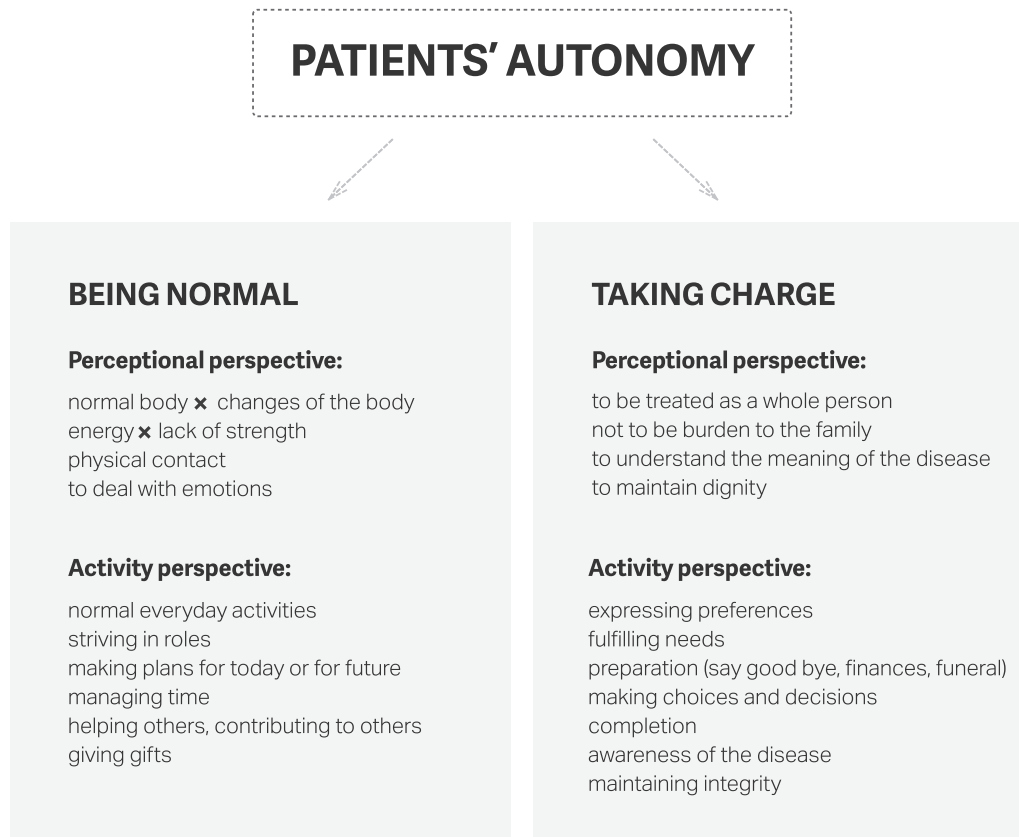


Fig. 2. Structural model of autonomy for patients at the end of life.

to better quality of life, but which can also contribute to better understanding of patients' autonomy. Based on the findings of this study, we propose that this domain can also be comprehended from two perspectives.

The perception perspective of this domain describes the prerequisites for active participation or obstacles that hinder it. Being treated as a whole person is mentioned in some studies,<sup>24,32,34,35,37</sup> mostly related to the relationship with health care providers, but by further exploration, it is always connected with preserving or protecting one's dignity,<sup>24,25,27,33,38,39</sup> being treated with respect and with mutual trust,<sup>29</sup> and being treated as an individual<sup>40</sup> by others in general. If we put those preferences in relation to autonomy then its interindividual characteristics become more evident. Another important aspect in this domain is the patients' feeling of being a burden to their family<sup>24,34,39,41</sup> or society. This can either compromise the patient's autonomy and lead to the erosion of their self-confidence, of their will to act, of their will to discuss difficult topics,<sup>30</sup> or of their willingness to choose a surrogate decision-maker<sup>42</sup> so as not to frighten the family. Or, on the contrary, it can support the patient's autonomy by strengthening the effort to diminish this negative impact on the family, for example, by preparing an adequate plan of care<sup>21,24</sup> or preparing the others for one's death.<sup>29,33</sup>

Activity perspective of "taking charge" provides a picture of autonomy, which is close to the traditional understanding of this term in bioethics. But further analysis of patients' preferences shows that we can expand the range of strategies by which patients pursue their goal of having the preparation for the end of life under control beyond the dogma of independent decision making. Rather, it is defined in many different ways. In Carter's study,<sup>22</sup> where "taking charge" was identified as a central theme, active engagement in the control over the dying process was expressed by participants as "adoption to a range of coping strategies." In other studies,<sup>33,40</sup> the control over the dying process was understood more in the sense of control over decision-making concerning treatment,<sup>32,33,36,37,43</sup> care, and social interactions.<sup>40,42</sup> Romo<sup>31</sup> identifies four different strategies patients use to express their preferences and make their choices: 1) direct articulation of what they want, 2) third-party analogy—expressing the preference by rejecting someone else's decision, 3) adaptive denial—accepting that the disease will progress, but "putting further thoughts in background," 4) engaged avoidance—actively avoiding to think of the end of life and one's choices.

The preparation for the period near death constitutes the second factor of taking charge. Many studies



argue that to be prepared is part of good dying.<sup>27,29,34,35</sup> The preparation for dying and death itself is often connected with the awareness of the disease or the need for being provided with information. There are many reasons why patients want to know what to expect from the process of dying,<sup>35</sup> why they want to be able to anticipate the transition to active dying,<sup>29</sup> and to discuss the future.<sup>27,34</sup> Among the most important motivations, there is a desire to minimize the burden for their family after their death, to have the financial and relational affairs settled,<sup>27,29,33</sup> and to prepare the relatives for the burial and bereavement.<sup>28</sup> Based on our analysis, we argue that this is a fundamental aspect of personal autonomy, which does not figure in the traditional concept of autonomy.

Broader motivation for the preparation for the last stage of life is connected with spirituality and the search for meaning at the end of life. Resolving conflicts, reviewing one's life, saying good-bye to relatives, and being in peace with God<sup>20,37–39,44</sup> can apparently provide this sense of meaning<sup>22</sup> for some patients at the end of life.

## Discussion

In this review, we have developed a structural model of autonomy from the perspective of seriously ill people. We summarized the results relevant to the phenomenon of autonomy from the studies on patients' end-of-life care preferences and divided them into two thematic groups. By analyzing the thematic outcomes of the studies from the perceptual point of view, on the one hand, and from the activity point of view, on the other hand, we identified several important aspects of the patients' understanding of autonomy, mainly in the activity point of view, which can help to better understand the complexity of this concept.

The model of autonomy at the end of life built upon the patients' care preferences shows autonomy as a meaningful comprehension of patients' physical, emotional, and social situation and the role they play in this situation. An important review on the evolution of the understanding of the concept of self-determination (taken as a synonym to autonomy) in palliative care was published by Bakitas,<sup>45</sup> where some attributes of self-determination described are similar to the ones in our model: for example, possessing physical and emotional strength, the need of information, and the desire for control. Bakitas further highlighted the concept of self-determination as a manner of protection of patients from coercion and violation of their rights, which is relevant for involving palliative care patients in the research.

Recent literature reviews on patients' end-of-life preferences can also present a valuable contribution to our discussion. These surveys analyze similar data but with the intention to summarize patients' preferences, not with special focus on the concept of autonomy. Virdun et al.<sup>7</sup> analyzed in their systematic review eight quantitative studies reporting on 3117 family members and 1141 patients dying in hospital settings and identified four domains considered important for them: effective communication and shared decision making; expert care; respectful and compassionate care; and trust and confidence in clinicians. By further exploration of those domains, we can see that most of them are concerned with how the patients should be treated to relieve their suffering, and contrary to our findings, there is only a narrow part concerned with the patients' active engagement, mostly in the domain of effective communication (to prepare for the end of life) and shared decision making (making choices about the treatment, nominating a surrogate decision-maker). The explanation for that could be that the studies in Virdun's review were exclusively from hospital settings.

In Meier's review<sup>8</sup> of 36 mostly qualitative studies on the definition of good death from the perspective of different stakeholders, there is a broader list of items (11 themes and 34 subthemes) considered important at the end of life. The active engagement of patients, which is an important aspect of our model, was often pronounced as accepting death and saying good-bye as a part of life completion, having a sense of control over treatment choices, and maintaining independence. Living as usual, maintaining hope, pleasure, and gratitude, and physical touch were also mentioned in some studies.

Rodriguez-Prat et al. in the systematic review<sup>46</sup> about the relationship between autonomy and dignity at the end of life described dignity as a part of the patients' identity and the decrease of their dignity at the end of life due to the loss of functionality. Some aspects of dignity in this study are similar to the aspects found in perceptual perspectives in our autonomy model. But the description of autonomy as a determining factor of perceived dignity in the Rodriguez-Prat review is limited to the traditional understanding as the desire for having control over the dying process and the desire for self-determination. Dignity and autonomy may overlap in some aspects, but they still represent two distinctive concepts, which have their specific complexity.<sup>47</sup>

Upon our findings, it seems that maintaining autonomy is not only a concern of making choices and decisions about the treatment and care but that emphasis should be also placed on supporting the



patients in their daily activities, contribution to others, and active preparation for dying.

Our analysis was inspired by the ethical framework for long-term care proposed by Agich.<sup>16</sup> He argues that to acknowledge autonomy, it is important to treat a person as an individual with personal experiences, history, and needs but also to support his active engagement in their fulfillment. Applying this model in the setting of end-of-life care allowed us to focus on the patients' activity in a broader context and also to delineate the differences from long-term care, such as the emphasis on the active preparation for dying or on the awareness of the disease.

We believe that the aspects of autonomy presented in our findings are often mentioned by patients, but their significance is not recognized or understood as related to autonomy by carers and researchers for two reasons. First, there is a strong general opinion that autonomy means independent and rational decision-making, and second, the seriously ill patients can be seen as more or less passive recipients of care, and the social interaction and the mutual contribution of patients and carers to each other is undervalued. To acknowledge and to support these aspects of autonomy, the conception of autonomy based on everyday experience and everyday activities and interactions can encourage the patients to be as active as possible; it can relieve their stress and minimize the fear of being a burden. This fear, often mentioned by seriously ill patients,<sup>7,27,36</sup> is not only a source of stress, but it can also be a motivation for requesting assisted suicide or euthanasia.<sup>48–50</sup> We believe that the understanding of autonomy presented in this study can be a plausible contribution to this discussion, in which autonomy understood as simple self-determination usually serves as pro-euthanasia argument.

This review has several limitations. First, the search was restricted to peer-reviewed articles written only in English, French, and Czech. Second, studies providing data from bereaved family members and health care professionals were excluded, although they can inform the debate about patients' autonomy, especially in the final days of the patients' lives, when it is difficult to get direct information from the patients themselves. Third, the quality of selected studies was not evaluated by a specific tool, such as Effective Public Health Practice Project Quality Assessment Tool or Cochrane Collaboration Risk of Bias Tool. Fourth, although all studies included in the review were focused on patients' preferences at the end of life, their specific objectives (preferences, good death, quality of life) and also their populations were different (advanced cancer, COPD, neurological disease).

## Conclusions

Supporting the autonomy of patients is considered an important principle of care at the end of life, and the results of this review highlight that autonomy should not be reduced to the simple process of decision-making. Future research should address the presented conceptual model of autonomy from the perspective of family members and professional caregivers to apprehend how they understand the autonomy of their seriously ill relatives or patients and to investigate more deeply the interconnectedness of those perspectives.

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**Which aspects of care are considered important by patients with advanced disease, their relatives and physicians? A cross-sectional study.**

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Short title: **Important aspects of care for seriously ill patients.**

## **ABSTRACT**

### **Objective**

To understand what is important for patients with advanced chronic diseases and to avoid misunderstandings in end-of-life communication is crucial for advance care planning. The aim of the study was to discover what the patients, their relatives, and physicians consider top priorities.

### **Methods**

The study was a cross-sectional survey of seriously ill patients (n=170), their relatives (n=108), and physicians (n=113). Participants were asked to rank 40 aspects identified previously as important at the end of life. Descriptive statistics were used to examine the distribution of responses. The significance of differences among respondent groups was explored by Levene and Bonferonni tests ( $p<.05$ ). The influence of other independent variables was observed by regression models.

### **Results**

Most factors were considered important in all three groups. Significant differences ( $p<.05$ ) between group rankings were found in items connected to informational needs, feelings of energy, and sense of usefulness, where patients placed more importance on these aspects compared to their relatives and physicians.

### **Significance of the Results**

Although there was general agreement between groups, several aspects of care that might be underestimated by patients' relatives and physicians were revealed. Professionals in palliative care should be aware of these potential differences and support patients in incorporating their needs into advance care plans.

**KEYWORDS**

end-of-life care, patient needs, palliative care, patient preferences, decision-making, informational needs, prognostic awareness, patients, relatives, physicians

**BACKGROUND**

Understanding what is important for patients with advanced disease and what they want to know about their illness is a crucial prerequisite for effective advance care planning. There is solid evidence that the preferences and priorities of patients in the advanced stages of life-threatening diseases are multidimensional and individual and have an important influence on end-of-life care[1-3]. Making decisions in advanced disease is a complicated process that involves patients, healthcare professionals, and the patient's loved ones, who are responsible for ensuring that the patient's best interests and priorities are met [4-6]. The role of loved ones becomes even more important as the disease progresses [7].

People's end-of-life healthcare preferences and priorities are based on what is important to them as individuals nearing the end of life in general. In a notable study by Steinhauser et al. [8], various aspects were identified as important at the end of life by patients, their doctors, and their families. The study revealed agreement among the groups on several issues related to symptom management, decision-making preferences, end-of-life planning, and preserving dignity. However, there were also notable differences in opinions on some items. Differences in healthcare preferences between patients, physicians, and caregivers are not uncommon. For instance, in the Slevin et al. study [9] on attitudes towards chemotherapy for metastatic cancer, patients were more likely than their doctors to support radical treatment, even when the chances of benefit were minimal. In a review by Bélanger et al. [10] on shared decision-



making in palliative care, it was found that doctors were accurate in predicting their patients' attitudes towards shared decision-making in less than 45% of cases.

When discussing end-of-life priorities, patients' information needs play a crucial role. Their information preferences are closely linked to their ability to participate actively in the decision-making process. To participate actively, patients must be aware of the incurability of their illness, treatment goals, and prognosis. Uncertainty or a lack of accurate prognostic awareness can impact patients' priorities, preferences, and decisions regarding further medical interventions [11].

The aim of this study is to examine what patients with incurable illnesses and limited life expectancy, their relatives, and physicians consider important, with a particular emphasis on their informational requirements, and to compare their viewpoints.

## **METHODS**

### **Study Population**

The study participants were adult patients (18 years or older) recruited from April to August 2018 in two university hospitals and two smaller medical facilities in the Czech Republic. Patients and physicians in the sample were identified by 7 collaborating physicians in these facilities. Inclusion criteria for patients in the study were a diagnosis of an advanced incurable disease with a life expectancy less than 1 year, estimated by collaborating physicians using the "surprise question" method, and being cognitively able to complete the structured interview or questionnaire [12]. Relatives were nominated directly by the patients and consequently invited to participate in the study.

Physicians were identified through collaborating physicians who worked in the facilities included in the study, physicians working with patients with advanced incurable diseases

### **Study design**

This study is a cross-sectional questionnaire survey among seriously ill patients, their relatives, and physicians. Eligible patients were contacted during their hospitalization by their physicians. The relatives of the eligible patients were contacted during their visit in the hospital. All participants provided written informed consent, and the study was approved by the Ethics Committee of the Center for Palliative Care and by local ethics committees at every hospital included in the study. Data were collected through face-to-face structured interviews with patients and by a self-administered questionnaire for relatives and physicians. The reasons for refusing participation were documented. The researchers didn't have access to information that could identify individual participants during or after data collection. This study was a part of the IMPAC project conducted by the Center for Palliative Care, the project aimed to develop an integrative model of prognostic awareness.

### **MEASUREMENT**

The survey asked participants to rate the importance of 40 factors that could be considered important in the terminal stage of a chronic incurable disease. These factors were identified in the non-published qualitative pre-study, consisting of 19 semi-structured interviews with advanced cancer patients and one focus group with healthcare providers in which participants discussed priorities in the care of patients with advanced disease at the end of life. Selected items were piloted with 30 oncology and non-oncology hospice patients and their relatives to test the content and face validity. The participants in our study rated all 40 factors on a 5-point Likert scale considering their importance (the translation of the questionnaire is attached in

Appendix 1). Basic demographic data were also collected: age, education and spirituality in all three groups; main diagnosis and life expectancy estimated by physicians in the patients' group; relationship to patients in relatives; specialization and experience in palliative care in physicians. Prognostic awareness was defined as an understanding of the illness regarding its curability and was measured by question *Do you consider your disease/disease of your relative as A) curable, B) incurable*[13,14]. Answer B) was identified as accurate prognostic awareness.

## ANALYSIS

The distribution of all 40 items was examined, including frequency, mean, median, standard deviation, variance, and quartiles. All items could range from 1 (completely unimportant) to 5 (extremely important). Because of the specific distribution of responses, items were sorted by comparing the mean ranking score in each respondent group. Differences in ranking between respondents' groups were explored through analysis of variance. The significance of the differences between groups ( $p < .05$ ) was examined by the Levene test, and the Bonferonni test was used for an exact determination of the differences.

Prognostic awareness was measured in patients' and family members'. Answers were analyzed by the chi-square tests to explore correlations with independent variables: sex, age category, education, spirituality, and in the patients' group, also with the diagnosis and life expectancy.

Logistic regression was used for items with significant differences in group ranking. Due to the specific distribution of ranking (respondents evaluated most items as important or extremely important), the scale used in the items was reduced to "not important" (which included "completely unimportant", "slightly unimportant" and "neither important nor

unimportant") and "important" (for "important" and "extremely important" ranking). Odds ratios (OR) and 95% confidence interval (CI) are presented only for significant covariates. The statistical significance of models was controlled by Fischer's exact test, and the significance of the effect of individual variables was controlled by t-tests ( $p < .05$ ). Because some variables were strongly associated with the respondent group (such as education with the physicians' group) or were measured only in a particular group (such as diagnosis or prognostic awareness in the patients' group), their effect on the full sample could not be evaluated; a separate analysis of those variables was conducted in each respondent group. STROBE guidelines were consulted to enhance the clarity of the reported study, and the STROBE checklist for cross-sectional studies is attached in Appendix 2.

## **RESULTS**

### **Participant sample**

Based on the sample size calculation using Cochran's formula[15] we aimed for the sample size of 385 in each group. This goal was not achieved completely, but the size achieved (patients = 170, relatives = 113, physicians = 108) was sufficient to conduct the required statistical analysis according to similar studies[14,16]. Response rate (RR) was of 87 %; participation in the study was refused by 21 patients (RR 89 %), 16 relatives (RR 67 %) and 1 physician (RR 99 %). Non-responders were mostly women (n=30). Reasons for refusing to participate were lack of interest (mainly in the relatives' group) or physical and psychological barriers (in the patients' group). 41 patients did not give their permission to contact relatives, either because they thought it would be too burdensome for them or because they did not want them to answer the questions in the survey. A flow chart describing the selection of the study population is attached in Appendix 3. Descriptive statistics of participants is summarized in Table 1.

### **Rating of importance**

The median value for 38 of 40 items was 4 "important" or 5 "extremely important". Variance in all items across all respondent groups in our sample was relatively small (only 7 items had a variance of 1.0 or more). Table 2 shows the distribution of items where the mean ranking was 4.0 or more, which means that the average answer was "important" or "extremely important" and the variance of answers was small. Items were sorted by the average mean of ranking; items with means  $\geq 4.0$  in all three respondent groups are highlighted in bold. The median value in two items (*Spending as much time as possible with family and friends*, *To be free of pain*) was "extremely important" and had the lowest variance at the same time (0.398 and 0.283). Only two items (*Keeping a job*, *Having the opportunity to contact a chaplain*) had the median value "neither important nor unimportant" and had the highest variance (1.684 and 1.800).

### **Differences among patients, their relatives, and physicians**

A descriptive analysis of the distribution implied differences in results among the three groups of respondents. Differences based on the group affiliation were found in 11 items (Tab. 3). Furthermore, the Bonferroni test showed homogeneity of the groups of relatives and physicians; there was just one item that differed significantly (*Having the opportunity to contact a chaplain*). On the other hand, there is a significant distinction between the patient group and the physicians, or relatives or both in all 11 identified items. Patients' ranking of importance was higher for all items than that of the other participants except for the items *Having enough privacy for conversation with the doctor*, *Having an opportunity to contact a chaplain*, *To be free of pain* and *To be free of shortness of breath*.

### **Multivariate analysis**

Except for three items (*Having enough privacy for conversation with the doctor, To be free of pain, To be free of shortness of breath*), intergroup distinctions persisted even after the merging of categories on the response scale and after conducting multivariate logistic regression controlling sex, age, and spirituality.

**Not to be a burden:** patients (OR, 5.236; CI 2.527-10.849) more likely ranked this item higher than other groups; other variables had no significant effect.

**Not to depend on help from other people:** patients (OR, 5.315; CI, 2.722-10.378) and physicians (OR, 1.996; CI, 1.002-3.975) are more likely to rank this item higher. There is important prognostic awareness in the patient group as well, as accurate prognostic awareness predicts a lower ranking for this item (OR, 0.332; CI, 0.118-0.939).

**To be useful:** patients (OR, 6.143; CI, 3.289-11.474) and younger people (OR, 0.978; CI 0.961-0.996) are more likely to consider this item important. In the relatives' group, education was also important (OR, 0.452; CI 0.281-0.729); relatives with higher education are less likely to consider this item as important.

**Getting information from the doctor even if it is bad:** patients (OR, 2.918; CI, 1.358-6.268) are more likely to rank this item as important, while physicians were more likely to rank this item as less important (OR, 0.347; CI, 0.161-0.751). The age of the respondent was also significant for the ranking of these items (younger people, especially physicians, are more likely to consider this item important, OR, 0.972; CI 0.952-0.993). Men, especially from the relatives' group, are more likely to rank it higher as well (OR, 0.496; CI, 0.258-0.851).

**Having the opportunity to contact a chaplain:** patients (OR, 0.382; CI, 0.202-0.722) were less likely to rank this item as important. Spirituality was significant as well; religious people (OR, 0.293; CI 1.178-0.481) are more likely to rank this item higher than others.



**To be free of shortness of breath:** younger people are more likely to rank this item as important (OR, 0.963; CI, 0.934-0.992), especially in the group of patients and physicians.

**Not to be bedfast:** patients (OR, 2.986; CI, 1.327-6.720) are more likely to rank this item as important, while physicians (OR, 0.474; CI, 0.222-1.012) are more likely to rank it as unimportant.

### **Prognostic awareness and information needs**

No significant correlation between prognostic awareness and ranked items was found. An analysis of variance found a significant difference between the participant groups, as relatives were more often aware of the patients' prognosis than the patients themselves. Because prognostic awareness in general is usually connected to informational preferences[17], multivariate logistic regression analysis was conducted additionally for three items focused on informational needs and preferences that were not analyzed in the previous multivariable analysis.

**To decide how much information about health status one wants to get:** the model shows that younger respondents (OR, 0.968; CI, 0.947-0.989) and patients (OR, 2.793; CI, 1.300-6.002) consider this item more likely as important. On the other hand, physicians (OR, 0.349; CI 0.158-0.769) are less likely to rank this item as important.

**Getting information from the doctor about time prognosis:** younger people are more likely to consider this item as important (OR, 0.969, 0.952-0.986).

**Getting information from the doctor about illness trajectory:** younger people are more likely to consider this item as important (OR, 0.975; CI 0.957-0.993).

## **DISCUSSION**

Decision-making in the advanced stages of chronic disease can pose a challenge not only for patients and their relatives but also for physicians, who must comprehend their patients' needs and values and assist them in making decisions. The study presented here demonstrates that the majority of priorities are similarly ranked among patients, their relatives, and physicians. All respondents considered good symptom management to be critical for maintaining a good quality of life while living with an advanced disease. Other items that were deemed important in all three groups are related to family and friends, family well-being, and spending time together. These findings support the results of Steinhauser et al. [8].

The item "To be free of pain" had the highest mean ranking among all three groups. This is not surprising given that physical pain is a universal experience and people naturally want to avoid it [18]. However, the presented study offers new insights, as patients rated this item as less important than physicians did. This may be due to physicians' biomedical focus and assumptions that physical symptoms are more important than emotional or psychosocial factors [19]. Nevertheless, pain management is still considered a crucial aspect of end-of-life care, and dealing with pain is known to be one of the most stressful parts of care [20]. The study highlights that physical pain is just one of the many factors, including anxiety, psychological, social, spiritual, and financial distress, that contribute to the overall quality of life of patients [21].

The presented study also revealed significant differences between patients, their relatives, and physicians, which may impact communication and understanding among the triad. Despite patients being the focal point of the physician-patient-relative triad, the perspectives of physicians and relatives were found to be more similar to each other than to those of patients. While the study supports Steinhauser's findings that items such as "not being a burden" or "being useful" are more important to patients than to physicians, it also highlights greater

differences between patients and their relatives than between patients and physicians. These differences may stem from variations in the study population (hospitalized patients and their relatives), cultural setting, attitudes towards the healthcare system, involvement in the decision-making process, or levels of respect for professional authority.

The item "Getting information from the doctor even if it is bad" revealed the most significant difference among the three respondent groups. The study findings indicate that physicians and relatives do not perceive the sharing of bad news with patients as a priority to the same extent as patients themselves. This discrepancy in understanding patients' informational needs may result in avoiding such topics during healthcare conversations, leading to misunderstandings among patients, physicians, and families. These results are consistent with Bruera et al.'s findings [23] that European physicians believe only a minority of patients wish to know that they are in the terminal stage of their illness. However, our study also revealed that while patients expressed their preference for being informed about bad news, the majority of them did not want to know specific details of their prognosis or disease progression. Physicians face the challenging task of balancing which information to convey and which to withhold, requiring advanced communication skills and a deeper understanding of their patients beyond standard practice[4].

Despite the assumption that patients' informational preferences are associated with their prognostic awareness, this study did not find a significant correlation between patients' prognostic awareness accuracy and variables related to their information needs. Although younger patients and relatives reported that health-related information was more important to them, this was not associated with more accurate prognostic awareness, suggesting that their information needs were not met. These findings are consistent with previous studies [16,24]. The question remains as to how patients with accurate prognostic awareness learned about

their prognosis, as there is evidence that patients who estimated their prognosis based on symptoms have a worse quality of life than those who learned about their prognosis through open discussion with their physicians [25].

The study has several limitations that need to be acknowledged. Firstly, the inclusion criteria were based on the surprise question, which is subjective and may depend on physicians' ability to use this method accurately. Thus, some relevant patients may have been missed or irrelevant patients included in the study. Secondly, the selection of patients invited to participate in the study could have been influenced by the physician's perception of the seriousness of the patient's condition, potentially introducing selection bias. Additionally, differences in preferences among patients could be influenced by the stage of their disease, which was not captured in this study. Therefore, any changes in preferences due to the progression of the disease may not have been captured by the cross-sectional design of this study. These limitations highlight the need for further research using more objective and standardized methods to assess patients' preferences at different stages of their disease.

## **CONCLUSION**

The study presented herein demonstrates a broad consensus among patients, their family members, and physicians regarding the important factors for end-of-life care. Nevertheless, significant disparities were identified, indicating that patients' relatives and physicians may underestimate certain aspects of care, as compared to patients' own perspectives. This phenomenon underscores the risk of forming alliances between relatives and clinicians and highlights the need for clinicians to act as facilitators during conversations about care goals. They should strive to support both patients and their caregivers in clarifying their views on what they consider essential. Future research should aim to uncover the underlying reasons for these divergent priorities, with a focus on obtaining insights from patients from specific

cultural backgrounds or with specific clinical requirements that have not yet been well documented.

## **ETHICS AND CONSENT**

This study was submitted as part of a larger study and was approved by the Ethical Committee of the Center for Palliative Care on 23rd March 2015.

Following local ethical committees at hospitals involved in the data collection provided ethical approval of the study:

Ethics committee of University Hospital of Královské Vinohrady ref. EK-VP/50/0/2017

Ethics Committee of the Regional Hospital in Liberec, ref. EK/175/2017

Ethics Committee of the University Hospital of Motol, ref. EK-992/18

Ethics Committee of the Ples Hospital, ref.17-26722Y.

All participants were given written information about the purpose of the study and they provided written or verbal consent. All participants were informed about the possibility of withdrawing from the study at any time they would feel like it and that this withdrawal would not affect their treatment in any way.

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# Association between prognostic awareness and quality of life in patients with advanced cancer

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## Abstract

**Purpose** Despite the current guidelines supporting open communication about serious news, the evidence about the impact of prognostic awareness on the quality of life in cancer patients is not clear. The aim of this study was to assess the association between quality of life and prognostic awareness in patients with advanced cancer.

**Methods** This was a cross-sectional study which involved patients ( $n = 129$ ) with incurable advanced cancer (estimated by oncologist using 12-month surprise question). Data were collected at oncology departments at 3 hospitals using structured interview in which patients were asked about their quality of life (using Integrated Palliative Outcome Scale—IPOS and a single-item global measure), prognostic awareness, information needs and demographics.

**Results** Only 16% of the sample was completely aware of prognosis and 57% was partially aware. Accurate prognostic awareness was significantly associated ( $p = 0.02$ ) with lower level of quality of life between (when measured by both the IPOS and the single-item scale) patients with accurate prognostic awareness ( $M = 37.1$ ; 10.4) and partially aware ( $M = 31.9$ ; 9.1) and unaware patients ( $M = 30$ ; 7.4). Detailed analysis showed that significant difference between groups was found only for physical symptoms subscales ( $p = 0.002$ ), not for emotional and communication subscales.

**Conclusion** Prognostic awareness was found to be negatively associated with physical domain of quality of life, but not with emotional and communication domains. More research is needed on personality factors that might influence the development of prognostic awareness and quality of life.

**Keywords** Quality of life · Palliative care · Advanced cancer · Prognostic awareness · Prognostic · Understanding

## Abbreviations

IPOS Integrated Palliative Outcome Scale  
PA Prognostic awareness  
SICP Serious Illness Care Programme

## Introduction

The majority of patients suffering from advanced cancer want to know their diagnosis and prognosis. However, their relatives and physicians' views on patients' informational needs may differ [1–3]. Relatives and physicians tend to underestimate patients' information needs, even though they acknowledge that patients have the right to be informed about their condition [1, 4]. Being informed about the prognosis means that patients can understand the seriousness of their current health condition [5], their shortened life expectancy and the incurability of their disease [6]. Accurate prognostic awareness can help patients receive goal-concordant end-of-life care [7], including a higher chance of completing advance directives and discussing treatment options with physicians [8–10]. Effective communication is an essential prerequisite for developing accurate prognostic awareness. However, many other factors such as age, education and patients' values also play an integral role [4, 11–13]. Available evidence suggests that despite the current

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communication standards in oncology, most patients with advanced cancer keep an inaccurate perception of the curability of their condition and the goal of their treatment even while receiving palliative care [6, 14–16].

Being truthfully informed about diagnosis and prognosis shall be considered as the fundamental right of patients [17, 18], and many studies have shown that more accurate prognostic awareness may be associated with the better quality of life and less depression and anxiety [19, 20] [21, 22]. However, other studies have reported that being aware of the terminal condition may cause patients psychological distress, decrease their quality of life, increase anxiety and depression, and even shorten their survival [16, 23–27]. Such contradictory findings may stem from the fact that the available studies used different and often non-standardised methods of how prognostic awareness shall be assessed, asking patients to identify their current health status or indicating the curability of their condition, using open- as well as close-ended questions or scales [6, 11]. In comparison, assessing the quality of life and psychological distress is less challenging as a wide range of standardised tools is available for patients with advanced health conditions, including cancer [28]. Nevertheless, the tools applied in palliative care differ in their measurement properties. Moreover, many instruments have issues with construct validity, reliability, responsiveness still require to be adequately evaluated [29].

The complexity of prognostic awareness (PA) and the wide range of research methods used in this field contribute to the unclear evidence of whether it is suitable for patients to know the truth about their prognosis. Given that it continues to be a significant challenge both clinically and research wise, this study aimed to investigate the association between PA and quality of life in patients with advanced cancer. This study aims to test the hypothesis of a negative association between accurate prognostic awareness and quality of life.

## Methods

### Study design and participants

The STROBE statement was used to guide the study's reporting; the STROBE checklist is available in Appendix 1. It was a cross-sectional study using data from patients with advanced cancer. Patients were recruited in oncology wards in three hospitals (one secondary hospital and two university hospitals) in the Czech Republic. All three hospitals are located in the capital city, and all provide care to patients with various types of cancer. Data were collected from September 2018 to February 2019. The study included patients with incurable, advanced cancer. Inclusion criteria for patients comprised a diagnosis of advanced cancer, limited prognosis and cognitive ability to participate in a

structured interview. The limited prognosis was indicated by the attending oncologists using the 12-month surprise question, meaning that the physicians answered adversely to the question: "Would it surprise me if this patient dies in the next 12 months?" [30, 31]. Suitable patients were recruited by their treating physicians. Experienced researchers (KP, AT, AH) collected data, and in doing so, they followed a structured interview protocol. During the structured interview, the researchers asked patients three questions regarding their prognostic awareness, information needs, demographics and quality of life (see Appendix 2 for the structure of the interview protocol). The study was a part of a multi-centre longitudinal cohort IMPAC study, focussed on repeated measurement of prognostic awareness.

### Study measures

#### Quality of life

Two different methods measured the quality of life. The first was a validated Czech version of the Integrated Palliative Outcome Scale (IPOS) [32], and the second was a single-item global quality of life scale [33]. The IPOS consists of ten questions and covers the following topics: physical symptoms, well-being, patient and family distress, practical concerns and information needs [32]. The total score range was 0–68 points, with higher scores indicating a worse quality of life. Confirmatory factor analysis of the IPOS has established a three-factor structure—physical, emotional and communication subscales [34]. The IPOS was explicitly developed for palliative care patients and has had excellent reliability and validity, as confirmed by several studies [32, 34–37].

In the single-item global quality of life scale, patients answer the following question: "How would you rate your overall quality of life during the past week?", rating their quality of life on a seven-point scale, where 1 means "very poor" and 7 means "excellent"; i. e., the higher the score, the better the quality of life [33]. The global measure has been reported to have good reliability and validity for measuring the quality of life [33, 38, 39]. In the present study, this scale was used for data triangulation.

#### Prognostic awareness

Prognostic awareness was measured using three different methods that have been used in previous research [5, 40, 41]. Patients were asked three close-ended questions, each focusing on a different aspect of prognostic awareness. First, they were asked to define the seriousness of their illness ("How would you describe your current health care status?", with the following options: "Relatively healthy", "Ill, but not seriously", "Seriously ill, but my life is not currently at risk",

“Seriously and terminally ill”), followed by a question about their own perception of the curability of their illness (“What is the probability that your disease will be cured?”, answering on a percentage scale of 0–100%). The last question focussed on the goal of their current treatment (“What is the primary goal of your cancer treatment?” with the following answer options: “To cure my disease”, “To prolong my life although the disease can no longer be cured”, and “To relieve symptoms”). The patients were considered as prognostically aware if they answered “I am seriously and terminally ill” to the first question if they indicated in their second answer that the probability of being cured was less than 10%. For the final question, patients were considered prognostically aware if they answered that their treatment goal was to prolong their life or relieve symptoms. (see Appendix 2 for a complete description of the methods applied.) Patients were considered prognostically aware if they answered all three questions using answers consistent with their actual health care status (incurable advanced cancer with a possible survival time of less than 12 months). If they used these answers only in one or two questions, we considered them as partially aware.

### Statistical analysis

Frequencies and proportions were used for descriptive statistics. Differences in quality of life were assessed using ANOVA test with Fisher’s LSD post hoc test in three groups of patients based on a composite measure of prognostic awareness with three groups (aware, partially aware, unaware). Correlations between demographics and quality of life were assessed using a *T*-test for independent sample (religiosity, gender), ANOVA (diagnosis, education) and Pearson correlation coefficient (age). The correlation between the three close-ended questions measuring prognostic awareness and quality of life was also assessed using the *T*-test for independent samples. In addition, multivariate regression was conducted to examine the associations of quality of life with prognostic awareness after controlling for confounding factors which was revealed using ANOVA. Multivariate regression was done for total IPOS score and IPOS physical subscale. Composite measure of prognostic awareness was entered into the model as dummy variables. Unaware group was set as a reference category. All analyses were performed using IBM SPSS 27 software.

## Results

### Demographics

The sample consisted of 137 patients; however, but for 8 patients data were missing, so the analysis was based on

**Table 1** Demographics

Gender	59 women (46%) 70 men (54%)
Age	M=64.8 (SD=9.2)*
Diagnosis	21% lung cancer 21% gastrointestinal cancer 11% breast cancer 12% urinary tract cancer 15% ovarian/prostate cancer 20% other
Education	10% elementary school 70% secondary school 20% university
Religiosity	37% yes

\*Age did not differ in men and women ( $p=0.08$ )

129 patients. The demographics of the sample are indicated in Table 1.

### Prognostic awareness

The majority of the sample (57%) was partially aware of their prognosis, 16% of patients had accurate prognostic awareness and 27% were unaware. Gender, age, hospital type, diagnosis, education, religiosity or having enough information about their condition had no significant association with the level of prognostic awareness.

### Prognostic awareness vs quality of life

The mean of quality of life measured by the IPOS reached 32.2 (SD=9.1), and  $M=4.7$  (SD=1.5) using the single-item global measure. The quality of life measured by the IPOS differed significantly between groups ( $p=0.02$ ;  $\omega^2=0.03$ ), and post hoc analysis showed unaware and partially aware patients had a significantly better quality of life compared to aware patients ( $M=30$ ; SD=7.4 and  $M=31.9$ ; SD=9.1 versus  $M=37.1$ ; SD=10.4). The difference between unaware and partially aware patients was not significant. The difference in the score of more than five points can also be considered as a relevant difference, likely to indicate a significant change in patients’ health condition [34]. The quality of life measured by single-item measure was also considerably higher ( $p=0.005$ ;  $\omega^2=0.03$ ). Post hoc analysis showed major differences between all three groups of patients. Unaware patients experienced a better quality of life ( $M=5.2$ ; SD=1.3) than partially aware patients ( $M=4.6$ ; SD=1.3), who furthermore enjoyed a significantly better quality of life than aware patients ( $M=3.9$ ; SD=1.8). Using three close-ended questions measuring prognostic awareness, we were able to identify a significant association with quality of life

**Table 2** Quality of life and prognostic awareness

	Aware M(SD)	Partially aware M(SD)	Unaware M(SD)
IPOS total score	37.1 (10.4)	31.9 (9.1)	30 (7.4)
Single-item measure	3.9 (1.8)	4.6 (1.3)	5.2 (1.3)
IPOS physical subscale	21.1 (6.6)	18.3 (5.3)	15.9 (4.4)
IPOS emotional subscale	10.8 (4.9)	8.7 (3.6)	8.6 (3.5)
IPOS communication subscale	5.1 (2.9)	4.8 (2)	5.6 (2.2)

**Table 3** Multiple regression

	IPOS total score		IPOS physical subscale	
	Regression $\beta$ coefficient (95% IC for B coefficient)	<i>p</i> value	Regression $\beta$ coefficient (95% IC for B coefficient)	<i>p</i> value
PA	–		–	
<i>Aware</i>	0.28 (1.92 to 11.79)	0.007*	0.33 (2.03 to 7.9)	0.001*
<i>Partially aware</i>	0.13 (– 1.37 to 5.94)	0.218	0.23 (0.39 to 4.67)	0.021*
<i>Unaware</i>	Ref		Ref	
Age	– 0.08 (– 0.25 to 6.34)	0.386	– 0.04 (– 0.13 to 0.08)	0.617
Gender	0.17 (– 0.02 to 6.34)	0.052	0.13 (– 0.44 to 3.29)	0.134
Religiosity	0.09 (– 1.5 to 5.04)	0.286	0.11 (– 0.7 to 3.16)	0.210

only for the question related to the patients' health status ( $p=0.001$ ). Furthermore, this fact confirmed the assumption that unaware patients experienced a better quality of life ( $M=30.1$ ;  $SD=8.1$ ) compared to aware patients ( $M=35.7$ ;  $SD=9.8$ ).

### IPOS subscales

We have analysed the association of IPOS subscales with prognostic awareness. It became evident that there was a significant difference between groups only for the physical symptoms subscale ( $p=0.002$ ;  $\omega^2=0.04$ ), but not for the emotional ( $p=0.063$ ;  $\omega^2=0.01$ ) and communication subscales ( $p=0.281$ ;  $\omega^2=0.002$ ) (see Table 2).

Demographics factors such as the diagnosis type ( $p=0.7$ ), gender ( $p=0.07$ ), religiosity ( $p=0.25$ ), age ( $R=0.04$ ) or education ( $p=0.5$ ) had no significant association with quality of life.

### Multiple regression

The results of multiple regression are presented in Table 3. We have determined that only prognostic awareness was a reliable predictor of quality of life. It was a slightly stronger predictor for the physical subscale than the IPOS total score (standardised B 0.33 versus 0.28).

## Discussion

The study focussed on the association between prognostic awareness and quality of life among patients suffering from advanced cancer. Our findings indicate that accurate prognostic awareness in this population is significantly associated with worse quality of life. This fact was confirmed using two different methods for measuring patients' quality of life and a composite indicator of prognostic awareness based on the most commonly used tools for assessing this phenomenon. Compared with unaware and partially aware patients, the

standard deviation of the quality-of-life measure scores was higher in patients with accurate prognostic awareness, suggesting more significant variation in this group of patients.

However, our analysis of the IPOS subscales has corroborated that the worse quality of life reported by patients aware of their prognosis relates only to worse physical symptoms, not to emotional distress or other aspects of quality of life.

Several studies have reported a negative relationship between accurate prognostic awareness and overall quality of life [16, 24, 26, 27, 42, 43]. Similar to our findings, at least one study [44] has shown that emotional aspects of quality of life did not significantly differ between prognostically aware and unaware patients. However, the total score and the scores for the other subscales (such as physical activities, role limitations, cognitive activities) differed. Indeed, findings from previous studies support these results, as they also determined that accurate prognostic awareness was related to shorter survival [15, 43], worse performance status [41, 45] or physical well-being [46], suggesting that patients with more severe health impairment at the end of their lives better understood their poor prognosis. While we did not identify a significant association between PA and emotional well-being in our study, the tendency was similar to several studies that contradicted our results by detecting a substantial negative correlation of accurate PA with emotional quality-of-life domains [24, 42]. Moreover, several



studies identified a negative relationship between accurate PA and depression and anxiety [16, 23, 26, 41].

On the other hand, several studies have corroborated the correlation between accurate prognostic awareness and a better quality of life [9, 21, 47, 48]. Regarding the emotional quality-of-life sphere, it seems that such an association may be more complicated and possibly influenced by confounding factors. Ray and her colleagues [9] have determined that the association of PA and quality of life was affected by peacefulness. If patients were aware and peaceful, they were less sad and enjoyed a better quality of life. Other studies have corroborated that the emotional quality-of-life domain related to the patients' acceptance of diagnosis and prognosis [49] and their coping strategies [26]. On the other hand, Kim et al. [43] found that depression did not function as a confounding factor, as the significant association between worse quality of life and accurate prognostic awareness remained even when the level of depression was statistically controlled. This evidence suggests that patients' personality might be a crucial factor affecting the prognosis acceptance and playing a key role in the relationship between quality of life and PA. Another fundamental factor influencing the relation between prognostic awareness and quality of life is how the physicians convey diagnosis and prognosis [9, 11, 15]. However, only 8% of our participants recalled discussing hospice or end-of-life care, so the data did not allow us to examine the correlation between communication and prognostic awareness.

The different results regarding the association between quality of life and prognostic awareness may also be explained by the fact that the inclusion criteria for patients suffering from advanced cancer varied between different studies: some included all patients undergoing chemotherapy [50], patients at stage III or IV [24] or stage IV, unresponsive to current treatment [49], patients with metastases or first-line chemotherapy failure [9] or with metastases and low-performance status [16], or not receiving treatment with curative intent [26, 42]. Other studies have used prognosis estimation provided by physicians based on the surprise question [43]; such was the case in the present study. In addition, it is also important to note that the studies mentioned above [8, 9, 21, 22, 42–44, 48, 49] used different instruments to measure the quality of life, which means that the operationalisation of the domains differs and, thus, the comparability of the results is limited [51].

## Limitations

There are several limitations of this study. First, its design was cross-sectional, preventing us from making any assumptions about the causal relationship between prognostic awareness and the quality of life. Randomised controlled

trials using specific communication interventions to improve prognostic awareness (e. g., SICP [52] programme) and measure the quality of life would be needed to answer this question. Our sample was relatively small, and our results' effect is considered limited [53]. Another limitation of the study is the lack of information on other potential confounders, such as the patients' medical records, hospitalisation history or treatments specifications. Our results concerning the association between accurate prognostic awareness and worse physical quality of life could also be supported by measuring patients' functional condition using specific additional tools, such as the Palliative Performance Scale, which we did not apply. Similarly, emotional or informational needs could be measured by other additional tools. At the same time, the IPOS is a validated and widely used measure for assessing perceived symptom burden in all three domains. The burden of additional questionnaires and their impact on this vulnerable population should also be considered. The convenience sampling method applied in the study may have caused selection bias, as patients with higher emotional distress may not have wanted to participate in research. We also did not ask patients how long they were aware of their terminal prognosis, which might also affect their quality of life.

## Conclusion

This study has corroborated that the physical domain of quality of life in patients suffering from advanced cancer is negatively related to accurate prognostic awareness. Such an association is not significant for the emotional and communication domains. Our findings suggest that accurate understanding of prognosis and reduced life expectancy do not necessarily correlate with a worse emotional status, and that the worse reported quality of life of prognostically aware patients is explicitly related to their worse physical condition. Therefore, the mere prognostic disclosure does not have to be associated with emotional distress of the patient, and physicians do not have to worry about that [4]. The relationship between patients' prognostic awareness, their quality of life and emotional well-being is highly complex. Therefore, a meta-analysis of the current evidence on specific factors, such as depression and anxiety, would be helpful in better understanding their mutual associations. Future research should also focus on personality traits, as they may constitute an overlooked key factor facilitating the development of prognostic awareness and quality of life in patients with advanced cancer.

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**Availability of data and materials** The datasets used during the study are available from the corresponding author on reasonable request.

## Declarations

**Conflict of interest** All authors declare that they have no conflict of interests related to submitted manuscript.

**Ethical approval** This study was approved by the Ethical Committee of Center for Palliative Care (ref. 1–2732015). The local ethical committees at all hospitals involved in the data collection also approved the study (Ethics Committee of the Institute for Clinical and Experimental Medicine and Thomayer Hospital, ref. G-18–57 13782/2018; Ethics Committee of the General University Hospital, Prague, ref. 1033/18 S; Ethics Committee of the Hospital at Bulovka, ref. 4.2.2019/9034/EK-Z).

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## ORIGINAL ARTICLE

# Prognostic awareness in advanced cancer patients and their caregivers: A longitudinal cohort study

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## Abstract

**Objective:** The aim of this study was to analyse longitudinal development of prognostic awareness in advanced cancer patients and their families.

**Methods:** This was a longitudinal cohort study, involving 134 adult cancer patients, 91 primary family caregivers and 21 treating oncologists. Key eligibility criterion for patients was life expectancy less than 1 year (estimated by their oncologists using the 12-month surprised question). Structured interviews, including tools to measure prognostic awareness, health information needs, and demographics were conducted face to face or via phone three times over 9 months. Forty-four patients completed all three phases of data collection.

**Results:** Only 16% of patients reported accurate prognostic awareness, 58% being partially aware. Prognostic awareness of both patients and family caregivers remained stable over the course of the study, with only small non-significant changes. Gender, education, type of cancer, spirituality or health information needs were not associated with the level of prognostic awareness. Family caregivers reported more accurate prognostic awareness, which was not associated with patients' own prognostic awareness (agreement rate 59%, weighted kappa 0.348, CI = 0.185–0.510).

**Conclusions:** Prognostic awareness appears to be a stable concept over the course of the illness. Clinicians must focus on the initial patients' understanding of the disease and be able to communicate the prognostic information effectively from the early stages of patients' trajectory.

## KEYWORDS

advance care planning, cancer, communication, family, oncology, patient care planning, prognosis, psycho-oncology

## 1 | BACKGROUND

Current guidelines on communication with patients with advanced cancer emphasize the focus on patients' autonomy and the shared decision making.<sup>1–3</sup> When the disease advances, patients must make decisions about their future care by taking into account both potential risks and benefits of another line of treatment as well as their limited life expectancy, using their values and preferences as the

guiding tools.<sup>4</sup> Accurate information about prognosis and the expected trajectory of their disease is fundamental to ensure that patients are well positioned to make these difficult decisions.<sup>5</sup>

The concept of prognostic awareness refers to patients' level of understanding of the terminal nature of their disease. There is a number of methods how the prognostic awareness is measured, usually focussing on asking patients to indicate the likely chance that their cancer will be cured, estimating their life expectancy or



assessing the seriousness of their illness.<sup>6</sup> The available evidence shows that strikingly low number of advanced cancer patients understand their prognosis well—the mean prevalence of accurate prognostic awareness in a recent large international meta-analysis was 49.1% (95% CI: 42.7%–55.5%, range: 5.4%–85.7%)<sup>7</sup>—and most of them usually see their situation as overoptimistic compared to their physicians. Accepting the bad news and being able to make decisions reflecting the poor prognosis is a very complex process, involving a number of factors such as the patients' coping style, doctor/patient relationship, clinicians' communication skills or the hope and ability to accept the stage of the illness in family members.<sup>8,9</sup> At the same time, the available evidence shows that most patients prefer to be informed about their diagnosis and prognosis, even if it is poor, and their preferences for health information are not related to their level of prognostic awareness.<sup>10–12</sup> Several studies also showed that accurate prognostic awareness can positively influence achieving goal-concordant care at the end of life.<sup>13–15</sup> Although we could expect some specific factors being associated with prognostic awareness of patients in the Eastern Europe, recent systematic reviews did not find any research published on prognostic awareness from this region.<sup>6,7,9</sup>

Family caregivers need reliable information about patients' status to emotionally, cognitively and behaviourally prepare for their role<sup>16</sup> and lack of prognostic awareness might negatively impact their quality of life.<sup>17</sup> Some studies found family caregivers reporting more accurate prognostic awareness compared to their patients,<sup>11</sup> suggesting that prognostic awareness in caregivers is not associated with their anxiety, depression or emotional preparedness for death.<sup>18,19</sup> On the other hand, Kang et al.<sup>20</sup> found that better prognostic awareness in family caregivers can positively impact the patients' quality of life but can also lead to worse quality of life and more depression in caregivers themselves.

As Jackson et al.<sup>21</sup> state in their landmark paper, “patients gradually develop prognostic awareness through an incremental cognitive and emotional process” (p. 894). With regard to this process and the gradual development of prognostic awareness, there is a striking lack of longitudinal research on prognostic awareness, with most studies reporting only cross-sectional data.<sup>6,9</sup> Therefore the primary aim of this study was to analyse the possible changes in prognostic awareness of advanced cancer patients over time. The secondary aim was to explore the association between prognostic awareness of patients and their family caregivers.

## 2 | METHODS

The Integrative Model of Prognostic Awareness in patients with advanced Cancer (IMPAC) study was researching factors influencing prognostic awareness in patients with advanced cancer. This paper reports the primary analyses of the project, a multi-centre longitudinal cohort study, involving patients and their caregivers. Data were collected in three university hospital oncology departments in Prague, Czech Republic, from September 2018 till September 2019 and

ethics approval was granted by the research ethics committee at each of the three sites (for reference numbers see Supplementary Appendix 1). The STROBE checklist for cohort studies is attached in Supplementary Appendix 2.

Participants were recruited from September 2018 till February 2019 to allow at least two follow-up measurements over 9 months after recruitment. The study included patients with advanced cancer and their relatives. Inclusion criteria for patients were a diagnosis of an incurable advanced cancer (assessed by their treating physician using the 12-month surprise question<sup>22</sup>) and cognitive ability to participate in a structured interview in Czech language (as perceived by treating oncologists, no formal evaluation used). No further exclusion criteria were applied. All eligible patients at the three sites were invited during the study period. Patients were asked to identify their primary family caregiver to be contacted as part of the study in the consent form. Written informed consent was obtained from all patients during the baseline data collection, which was a face-to-face interview in the hospital, either in the outpatient clinic or during patient's hospitalization. Baseline interviews with family caregivers were in 83% by phone and in 17% in-person. Follow up measurements with patients as well as their caregivers and physicians were conducted either in person or by phone. After each interview with the patients, their family caregivers and treating oncologist were contacted to complete their measurements. All interviews were conducted by experienced researchers (Loučka Martin, Houska Adam, Poláková Kristýna, Houska Adam, Vlčková Karolína) following a structured protocol focussing on the variables described below.

### 2.1 | Prognostic awareness

Prognostic awareness was measured by three most widely used tools, involving multiple choice questions:

1. How would you define your current health status? (based on Prigerson<sup>23</sup>)?
  - a. relatively healthy
  - b. ill, but it is not serious
  - c. seriously ill but not terminal
  - d. seriously ill and terminal
2. What is the probability of your illness to be cured? (based on IGEO<sup>24</sup>)?

Participants were asked to indicate the likely chance of curability of the disease on visual scale 0%–100%.

3. What is the primary goal of your current cancer treatment? (based on Shin<sup>25</sup>)?
  - a. to completely cure my disease
  - b. to prolong my life (although the disease itself can no longer be cured)
  - c. to relieve my symptoms

Patients were perceived as prognostically aware if they answered the first question with the option (d) seriously ill and terminal, the second question by indicating the probability of being cured as less than 10%, and the third question by choosing either the option (b) to prolong their life or (c) to relieve symptoms. Family caregivers were asked the same three questions as patients, referring to their relatives' health status (see Table 1).

Expecting different outcomes of each particular method to assess prognostic awareness, we developed a new composite measure, compiling the scores of all three questions with potential outcome 0 for no correct answers in any of the three questions (patient not aware), one point for at least one accurate answer (patient partially aware), and two points for all questions answered accurately (patients considered to be aware of their prognosis).

## 2.2 | Health information needs

Patients and their family caregivers were asked three questions regarding their information needs:

1. "How important it is for you to have the information about future development of your disease/disease of your relative (to know the prognosis)?" answering on a Likert-scale (very important–important–not important–not important at all).
2. "Did you speak about the seriousness of your health status with your loved ones?", answering yes/no.
3. "Do you feel you are getting enough information about your illness from your physicians?", answering (a) I would like to have

more information, (b) I have as much information as I want, (c) I would prefer to have less information.

Family caregivers were asked the same questions as patients with focus on "your relative's disease/illness/health status". Patients and family caregivers were also asked if they recall any conversations with their clinicians about hospice, advanced directives or code status. Demographics were also collected (gender, age, education, spirituality). Ethnicity was not enquired as the Czech population is very homogenous with only about 5% of population representing other races or ethnicities. Due to the poor availability of hospice care, patients were not screened for receipt of hospice care and no patients in the study received hospice care.

At each data collection time, data from physicians were also collected. Physicians were asked the same question about the primary goal of current treatment as patients and if they had a conversation about patients' wishes for end-of-life care. Physicians' age, specialization, spirituality and self-assessed level of palliative care knowledge were recorded.

## 3 | ANALYSIS

Prognostic awareness was analysed separately using each of the three methods described above and also by using a composite measure described above. In order to test the consistency of the composite measure across the three data collection phases, McNemar-Bowker test of symmetry was used.<sup>26</sup> This method allows to test pairs of related data, so every measure was compared to each other; therefore Bonferroni corrections for multiple testing were used ( $p = 0.05/3 = 0.02$ ). Chi-square and Fisher tests or Fisher-Freeman-Halton (extension of Fisher exact test for contingency table  $2 \times 3$ ) were used to analyse the associations between composite measure of prognostic awareness and confounder variables. Kappa weighted coefficient was used for assessing agreement between patient, family caregiver and physicians on a question regarding patients' condition. All analyses were conducted in IBM SPSS 27.

## 4 | RESULTS

The study sample at baseline included 137 patients and 91 relatives. Only complete participant datasets were used in the analysis, excluding three patients and three relatives with some missing data. At baseline, 21 physicians provided their reports for 120 patients. The second data collection after 3 months was completed by 77 patients, and 44 patients completed the third data collection 6 months after baseline. Changes in prognostic awareness have been calculated for the whole sample and specific longitudinal analysis was conducted with the cohort of patients who completed all three measurements. There were slightly more women in the longitudinal cohort (52% vs. 44%) and gastrointestinal cancer was the most common diagnosis in the longitudinal cohort (39% vs. 20% in the

TABLE 1 Changes in caregivers' prognostic awareness over time

	T1 (N = 88)	T2 (N = 28) <sup>a</sup>	T3 (N = 18)
<b>Composite measure</b>			
Aware	24(27%)	5 (18.5%)	4 (22%)
Partially aware	51 (59%)	15 (55.5%)	9 (50%)
Not aware	13 (14%)	7 (26%)	5 (28%)
<b>Specific measures</b>			
How would you describe your relative's current health status?			
Aware	52 (59%)	13 (46%)	10 (56%)
Not aware	36 (41%)	15 (54%)	8 (44%)
What is the probability of his/her illness to be cured?			
Aware	31 (34%)	9 (33%)	5 (28%)
Not aware	57 (66%)	18 (67%)	13 (82%)
What is the primary goal of your relative's current cancer treatment?			
Aware	64 (73%)	20 (71%)	13 (72%)
Not aware	24 (27%)	8 (29%)	5 (28%)

<sup>a</sup>One family caregiver did not answer the second question, composite measure is therefore reported only for 27 family caregivers in the second phase.



TABLE 2 Description of the sample

	Patients (N = 134)	Relatives (N = 88)	Patients in the longitudinal analysis (N = 44)
<b>Gender</b>			
Male	75 (56%)	22 (25%)	21 (48%)
Female	59 (44%)	66 (75%)	23 (52%)
<b>Age</b>			
Mean	64.8 (SD = 9.2)	53 (SD = 12.5)	64.5 (SD = 9.4)
<b>Diagnosis</b>			
Lung cancer	27 (20%)		6 (13.6%)
Gastrointestinal cancer	27 (20%)		17 (39%)
Breast cancer	14 (11%)		6 (13.6%)
Urinary tract cancer	16 (12%)		3 (6.8%)
Ovarian/prostate cancer	19 (14%)		5 (11%)
Other cancer	31 (23%)		7 (16%)
<b>Relationship to the patient</b>			
Partner		44 (50%)	
Son/daughter		38 (43%)	
Other		6 (7%)	
<b>Education</b>			
Elementary	14 (10%)	3 (3.5%)	4 (9%)
Secondary	93 (70%)	62 (70.4%)	32 (73%)
University	27 (20%)	23 (26.1%)	8 (18%)
<b>Do you consider yourself to be a religious or spiritual person?</b>			
Yes	49 (36.5%)	35 (40%)	16 (36%)
No	85 (63.5%)	53 (60%)	28 (64%)

whole sample). Overall, the demographic differences between the sample and the longitudinal cohort were not statistically significant (for details see Table 2). The reasons for dropout were patients' death (38.6%), did not want to continue (30.7%), could not be reached (16%), transport to hospice (9%), patient unable to communicate (5.7%). Complete baseline data were available for 88 family caregivers, but only for 28 and 18 caregivers in the second and the third data collection.

#### 4.1 | Prognostic awareness

We found significant differences in the level of prognostic awareness based on which tool was used. At the baseline, 34% of patients reported accurate prognostic awareness being asked the first question ("How would you describe your current health status?"), 22% when asked the second question ("What is the probability of your illness to be cured?") and 67% of patients reported accurate prognostic awareness when measured by the third question ("What is the primary goal of your current cancer treatment?").

Using the composite measure, 16% of patients were aware, 58% were partially aware and 26% were not aware of their prognosis at the baseline. The level of prognostic awareness remained stable in the whole sample over the repeated measurements (Table 3), with only small non-significant changes ( $p = 0.285$ ). No statistically significant differences (Bonferroni correction reflected) were equally found in the longitudinal cohort of the 44 patients who completed all three data collections (McNemar-Bowker test T1 vs. T2:  $p = 0.706$ , T1 vs. T3:  $p = 0.172$  T2 vs. T3:  $p = 0.037$ ). Gender, education, spirituality and type of diagnosis were found not to be statistically significant in any of the analyses. If not stated otherwise, composite measure was used in all analyses described below.

Prognostic awareness in our sample was not significantly related to whether patients completed all the three measurements or withdrew from the study (chi square  $p = 0.14$ ). Prognostic awareness at baseline was also not related to the fact whether patient died during the study or not (Fisher-Freeman-Halton  $p = 0.054$ ), nor with any other reason for dropout. The agreement rate between patients and physicians on answers to the question about the primary goal of

TABLE 3 Changes in patients' prognostic awareness over time

	Total sample			Longitudinal cohort (N = 44) <sup>a</sup>		
	T1 (N = 134)	T2 (N = 77)	T3 (N = 45)	T1	T2	T3
Composite measure						
Aware	21 (16%)	12 (16%)	11 (24%)	7 (16%)	8 (18%)	11 (25%)
Partially aware	78 (58%)	38 (49%)	21(47%)	21 (48%)	19 (43%)	21 (48%)
Not aware	35 (26%)	27 (35%)	13 (29%)	16 (36%)	17 (39%)	12 (27%)
Specific measures						
How would you describe your current health status? <sup>b</sup>						
Aware	46 (34%)	28 (36%)	17 (37%)	13 (30%)	17 (39%)	17 (39%)
Not aware	88 (66%)	49 (64%)	28 (63%)	31 (70%)	27 (61%)	27 (61%)
What is the probability of your illness to be cured? <sup>c</sup>						
Aware	30 (22%)	19 (25%)	13 (29%)	11 (25%)	10 (23%)	13 (30%)
Not aware	104 (78%)	58 (75%)	32 (71%)	33 (75%)	34 (77%)	31 (70%)
What is the primary goal of your current cancer treatment? <sup>d</sup>						
Aware	90 (67%)	48 (62%)	31 (69%)	25 (57%)	25 (57%)	31 (70%)
Not aware	44 (33%)	29 (38%)	14 (31%)	19 (43%)	19 (43%)	13 (30%)

<sup>a</sup>Patients who completed data collection at all three times.

<sup>b</sup>McNemar-Bowker T1 versus T2:  $p = 0.346$ ; T1 versus T3:  $p = 0.344$ ; T2 versus T3:  $p = 1.0$ .

<sup>c</sup>McNemar-Bowker T1 versus T2:  $p = 1.0$ ; T1 versus T3:  $p = 0.625$ ; T2 versus T3:  $p = 0.375$ .

<sup>d</sup> McNemar-Bowker T1 versus T2:  $p = 1.0$ ; T1 versus T3:  $p = 0.146$ ; T2 versus T3:  $p = 0.031$ .

treatment was 47%, weighted kappa 0.117, at the second phase it was 73% (data available for 48 dyads), weighted kappa 0.192, at the third phase it was 73% (data available for 36 dyads), weighted kappa 0.182. The estimation of prognosis was not associated with the accuracy of patients' prognostic awareness.

## 4.2 | Health information needs

There was no association found between participants' answer to "How important it is for you to have the information about future development of your disease/disease of your relative (to know the prognosis)?" and their prognostic awareness (Fisher test  $p = 0.264$ ). Five percent of patients reported prognostic information not to be important for them, 31% to be important, 64% to be very important.

Eighty-one percent of family caregivers reported speaking about the seriousness of their health status with their loved ones, but there was no association found with patient's prognostic awareness (Fisher-Freeman-Halton  $p = 0.876$ ). However, it was significantly associated with prognostic awareness of family caregivers (Fisher-Freeman-Halton  $p = 0.014$ ). Less family caregivers with accurate prognostic awareness reported having this conversation (62.5%) compared to partially aware (91%) and unaware caregivers (85%). Seventy-seven percent of patients reported speaking with their relatives about their health condition but this was not associated with their prognostic

awareness ( $p = 0.579$ ) or prognostic awareness of family caregivers ( $p = 0.186$ ).

Having enough information was not associated with the accuracy of patients' prognostic awareness (Fisher-Freeman-Halton  $p = 0.677$ ). Sixteen percent of patients in the sample would like to have more information, while 84% had enough information. Patients' prognostic awareness was not associated with recollection of discussion about hospice ( $p = 0.118$ ), advance directives ( $p = 0.357$ ) or DNR ( $p = 0.158$ ), although less than 8% of patients in the sample recalled such discussions. Physicians reported that they have talked with patients about their wishes regarding end-of-life care in 25% of all cases, which was not significantly associated with the level of patients' prognostic awareness (Fisher-Freeman-Halton exact test  $p = 0.531$ ). The reasons for not having these conversations with the rest of the patients were: no appropriate opportunity so far (34%), fear of losing hope and cooperation of patients (32%), patients did not want to talk (12%), family did not want us to talk with patients (2%) or other reasons (20%).

## 4.3 | Caregivers' perspective

Slightly more family caregivers than patients reported accurate prognostic awareness (27% fully aware, 59% partially aware, 14% unaware) when measured by the composite measure (Fisher-Freeman-Halton  $p < 0.001$ ). The agreement rate between patients

and their relatives was 59%, weighted kappa 0.348 (CI = 0.185–0.510), in 41% of the sample there was not agreement on prognostic awareness and there was no case when caregiver would be unaware and patient aware. Gender, education, religiosity, age or relationship to the patient were not associated with relatives' prognostic awareness. Being informed about prognosis was very important for 89% of relatives, important for 7% and not important for 4% of relatives. Relatives with accurate prognostic awareness reported higher importance of being informed about prognosis than relatives who were partially or not aware (Fisher-Freeman-Halton  $p = 0.034$ ). There was no significant association between relatives' prognostic awareness and their satisfaction with how much information they had (Fisher-Freeman-Halton  $p = 0.92$ ).

The longitudinal analysis did not reveal any significant changes in the prognostic awareness of family caregivers; however, the sample was very small in the second and third measurement (there were only 9 caregivers providing the data in all three phases).

## 5 | DISCUSSION

The results of this study suggest that prognostic awareness in advanced cancer patients is a rather stable and firm concept, which is not influenced by prognostic awareness of family caregivers and clinical or demographical factors. In our sample, most patients were not aware, or only partially aware of their prognosis. In similar longitudinal Taiwanese study,<sup>27</sup> prognostic awareness remained also stable, although almost 60% of their sample were accurately aware of their prognosis already at baseline. Our study suggests that patients tend to keep their prognostic awareness regardless its accuracy.

The stability of prognostic awareness might be explained by the fact that oncologists in our sample discussed end of life care issues with only 25% of patients and less than 10% of patients recalled any conversation about hospice, advanced directives or code status. This number could be considered low and communication about these issues could help patients develop more accurate prognostic awareness<sup>28</sup> but other studies showed that patients very often do not recall these discussions (38%<sup>28</sup>–82%<sup>12</sup> of advanced cancer patients reported having no discussion about prognosis with their physician). Without more information from patients' medical records and their caregivers it can be difficult to find out whether these conversations actually happened, to validate patients' recollections.

The stability of prognostic awareness might be also related to the personality of patients. Achieving the accurate prognostic awareness requires accepting poor prognosis, limited life expectancy or incurable nature of the disease. This is a challenging task for patients who often use various coping strategies to adapt to the life-changing experience of cancer disease.<sup>29</sup> Some patients might choose to keep inaccurate prognostic awareness as part of their coping, although our results showed that most patients wish to receive correct information about their prognosis while not

understanding its meaning. A potential explanation of this conflict, also identified in other studies,<sup>10</sup> can be related to psychological factors and personality traits, such as optimism<sup>30</sup> or specific coping style of patients.<sup>29</sup>

Similarly, agreement between patients and family caregivers regarding the patients' prognosis was not very high (59%), with family caregivers being more accurate (27% vs. 16% fully aware). In a recent South Korean study,<sup>15</sup> family discussion about advance care planning was positively associated with patients' better illness understanding. In our sample, 81% of family caregivers reported discussions with their patients about the seriousness of their disease but it was not associated with prognostic awareness of patients, only caregivers themselves. Surprisingly, the aware caregivers less often reported having the conversation with their patients. This suggests that being aware of patient's prognosis can be a challenging barrier for relatives to start this conversation with their loved ones.

Our results highlight the importance of choosing an adequate tool to assess prognostic awareness. Due to the significant differences in responses when asking patients about the seriousness of their health status versus them correctly indicating the goal of their treatment, it is apparent that both researchers and clinicians must carefully consider and operationalize what is the aim of their conversation. In their recent work, Tzuh et al.<sup>19</sup> highlighted the difference between emotional and cognitive prognostic awareness. Grey et al.<sup>18</sup> also discuss behavioural aspect of being aware of prognosis. It is possible that patients and their caregivers would cope with different aspects of prognostic reality differently and measurements should take this into account. Using a composite measure, including several indications of prognostic awareness and assessing patients' understanding in more than just binary variable proved to be helpful in the analysis and was also used in other recent studies.<sup>15,25,28</sup> However, a validated "gold standard" tool to assess prognostic awareness still remains to be developed through future research.<sup>6</sup>

### 5.1 | Study limitations

This study has several limitations. The sub-sample of participants who completed all three data collections was rather small (in patients as well as family caregivers), so it is possible that with a larger sample more significant differences would be identified. However, the results of the longitudinal analysis were supported by the fact that the level of prognostic awareness was not related to whether the patient died or not during the study and also by cross-sectional analysis of cases at each data collection. Another limitation is that we used a convenience sampling method without recording the number and reasons for not participating in the study, that might have left the patients with different levels of prognostic awareness out of the study scope. Another limitation is that our study focused on patients who were already in the advanced stage of the disease. Stability of the prognostic awareness

might be influenced by factors related to earlier experience with the disease and its treatment, which were not covered by our study. We also did not record some variables which might potentially explain the stability of prognostic awareness such as optimism or coping styles. More research is needed to explore the role of psychological factors on the development of prognostic awareness. Longitudinal studies should include the early stages of disease trajectory as they might be crucial for the initial development of prognostic awareness.

## 5.2 | Clinical implications

The results of this study highlight the need for honest and effective communication about prognosis early in the disease trajectory. Clinicians should use the ask-tell-ask principle and other techniques to ensure that patients understand their situation correctly, if they wish to be informed.<sup>4,31</sup> Our results also highlight the need to ask specifically about prognostic awareness as the correct understanding of the goal of treatment does not necessarily mean that patients would understand the seriousness of their illness or their prognosis. Family meetings could be a good opportunity to level the prognostic understanding of patients and their family caregivers, who can support further advance care planning.

## 6 | Conclusions

Prognostic awareness is a complex phenomenon, influenced by a number of factors. It seems to be a stable concept, influenced by individual psychological factors rather than clinical or demographical context. As it can significantly influence patients' ability to engage in advance care planning, more research about determinants and the ways how to improve prognostic awareness is needed. Due to the difficult recruitment and the likely drop-out rates, larger longitudinal studies are required to further improve our knowledge in this area.

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### CONFLICT OF INTEREST

Authors have no conflicts of interests to declare.

### AUTHOR CONTRIBUTIONS

Martin Loučka conceived the study. Martin Loučka, Anna Tuckova, Kristyna Polakova, Adam Houska, Karolina Vlckova, Martin Mateju and Zuzana Donatova collected the data. Anna Tuckova, Karolina Vlckova and Martin Loučka analysed and interpreted the data. Martin Loučka drafted the manuscript. All authors contributed and approved the final version of the manuscript.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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# Optimal participation in decision-making in advanced chronic disease: perspectives of patients, relatives and physicians

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**Background:** Making decisions about health care issues in advanced illness is difficult and the participation of patients and relatives is essential. Most of the studies on shared decision-making focus on the interaction between patient and physician (dyadic interaction), while the role of relatives in triadic decision-making remains less explored. The aim of the study was to investigate the perceived importance of the role of the patient, the physician and the relative in the decision-making from their respective perspectives.

**Methods:** Patients (n=154) with advanced disease, their relatives (n=95) and physicians (n=108) were asked to rank the importance of their roles on the scale from 0 to 10. Differences between respondent groups were examined by ANOVA. A typology of answers was constructed for dyadic and triadic relations and analyzed by descriptive statistics and the chi-square test.

**Results:** Physicians rated the importance of patients' role in decision-making significantly higher [mean 9.31; 95% confidence interval (CI): 9.07–9.55] than did patients themselves (mean 7.85; 95% CI: 7.37–8.32), while patients and relatives rated higher the importance of the physicians' role (mean 9.29; 95% CI: 8.98–9.59 and mean 9.20; 95% CI: 8.96–9.45, respectively) than did physicians themselves (mean 8.35; 95% CI: 0.06–8.65). In the analysis of the patient-physician dyadic interaction, patients ranked their role as equally important (44.1%) or more important (11.2%) than the role of physicians. Physicians (56.5%) thought patients should play a more important role. When relatives were included in the analysis, patients either preferred equal role of the three actors (30.2%) or prioritized the role of the physician and the relatives (16.8%), while physicians and relatives prioritized the role of the patient (54.6% and 29.0%, respectively). All results were statistically significant (P<0.05).

**Conclusions:** Physicians and relatives tend to accentuate the active role of patients, while patients mostly prefer shared decision-making. Physicians seem to underestimate the importance of the role of relatives, compared to patients and relatives for whom the participation of relatives in the decision-making is of greater importance. A triadic decision-making model that acknowledges the importance of all three actors should be implemented in decision-making process in advanced illness.

**Keywords:** Decision making; end of life; palliative care; advanced disease; autonomy; participation

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## Introduction

Making decisions about health care in the complex situation of advanced serious illness is a difficult process where clinical evidence is often limited (1). Psychosocial factors and the preferences of patients and their families appear to play an important role in achieving beneficial and reasonable outcomes. Therefore, the patients' and relatives' involvement in those decisions is desirable as a key feature of a patient-centered care (2). Although the patients' participation in decision-making is generally acknowledged by health care providers (3,4), its realization is hindered by significant barriers. For example, ICU physicians may focus more on physiological and technical parameters rather than on patient's preferences (5). Relatives, on the other hand, may argue that involvement in decision-making would be too stressful for the patient (6) and that differences in opinion regarding the actual decision-making are a strong factor contributing to intra-family conflicts (7).

In the complex situations of a serious illness, it is often not possible to make a fully informed decision because the course of the illness of the individual patient is difficult to predict and the decisions must be made provisionally to achieve intermediate goals (1). For that reason, a linear concept of shared decision-making, proposed by Charles *et al.* (8) as a four-step process—(I) the involvement of the patient and the physician; (II) information sharing between the two parties; (III) the expression of treatment preferences on each side; (IV) a consensus over a treatment plan—might not be efficient enough for the patients to make good decisions. For Epstein *et al.* (1), the process is a more dynamic and iterative one and must involve a support in constructing the patient's preferences by reflecting on the communication process itself, specifying how much information a patient wants to get and how relatives should be involved in the decision-making.

There are different ways to measure patient preferences for decisional control (9) used in quantitative studies, such as CPS (The Control Preferences Scale by Degner) (10) or API-D (autonomy preference index-D) (11), where the results of the decisional control preferences are usually presented as either active (decision made by the patient), shared (decision made by the patient and the physician together) or passive (decision made by the physician).

In the systematic review on patients' preferences for their participation in the decision-making in palliative care setting, Bélanger *et al.* (12) found that between 68% and

87% of patients prefer either a shared or an active role in the decision-making. Similar results were found for older adults—33% for a shared and 49% for an active role (13). In a recent international multicenter study of 1,490 patients with advanced cancer, the preferences for shared, active and passive decisional control were 33%, 44% and 23%, respectively (14). Evidence also shows that, in most cases, physicians may not be able to predict the patients' preference for decision-making (15). Studies on shared decision-making often focus on the dyadic interaction between the patient and the physician, while the role of family members or relatives and the preferences for their involvement in the decision-making remain much less explored and so do the measure instruments (16). Laidsaar-Powell *et al.* (17), in their systematic review, summarized, *inter alia*, the attitudes of the patients, the relatives and the physicians toward the triadic shared decision-making structure. The results suggest that approximately one third of patients believe that all three parties should have an equal role in the decision-making, one third would prefer the physician to have the major role and one third of patients would prefer to make decisions by themselves. Regarding the role of the relatives, more than half of physicians and relatives believed that relatives should play a more important role in the decision-making process than they actually do. Results of a recent mixed-method study on the triadic decision-making showed important disagreements among physicians, patients and relatives about the relatives' decision-making preferences and their influence on the final decision (16). In a retrospective view on the decision-making process, patients and relatives felt that physicians had more influence than the physicians themselves felt to be the case. The disagreement between patients and caregivers about the decision-making preferences was another common phenomenon emerged from this study. In general, the triadic process of decision-making and the views of patients, physicians and relatives on the roles of each other in that process are very little understood, and research data are scarce. This study brings an original analysis of three different perspectives on engagement of patients, physicians and relatives in decision-making in the situation of an advanced disease. We present the following article in accordance with the STROBE reporting checklist (available at <http://dx.doi.org/10.21037/apm-20-2368>).

The aim of this study is to explore the perspectives of patients with advanced chronic disease, of their relatives and of their physicians on the role each of them play in the process of health care decision-making.



## Methods

This study was a part of the IMPAC project (Integrative model of prognostic awareness in advanced cancer)—a multi-method study of prognostic awareness in advanced cancer patients.

### Study population

Participants were recruited from oncology and non-oncology departments of four hospitals in the Czech Republic (two University hospitals, two regional hospitals).

Inclusion criteria for patients were a diagnosis of advanced incurable disease, life expectancy less than one year as estimated by their physicians using the “surprise question” method (18), and the cognitive ability to participate in the survey. The study also included relatives of eligible patients and physicians working in data collection sites—treating physicians of eligible patients and their colleagues.

### Study design

This study was conducted in accordance with the Declaration of Helsinki (as revised in 2013) and was conducted with approval from the Ethics Committees of all hospitals included in the study and by Ethics Committee of research institution Center for palliative care, Prague, Czech Republic, ref. 27/5/2015.

Eligible patients were contacted during hospitalization by their physicians, eligible relatives were contacted during their visits in hospital: those who agreed to participate were then introduced to a trained researcher, who informed them about the purpose of the study, and informed consent was taken from all the respondents. The survey was administered as a face-to-face structured interview for patients and a self-administrated questionnaire for relatives and physicians.

The part of the questionnaire analyzed in this paper was focused on how respondents perceive the role of patients, relatives and physicians in the health care decision-making process. Participants were asked to rank how important, from their own point of view, should the role of the patient, the physician and the relative be on a scale from 0 to 10, with the possibility to rank all actors with the same score (*Figure 1*). The study also collected basic demographic data—age, sex, education and spirituality for all groups, and diagnosis and prognostic awareness for the patient group.

Prognostic awareness was defined as understanding the illness’ curability and was measured by the question “Do you consider your disease as curable or incurable?”, where the answer “incurable” was considered as the accurate prognostic awareness.

### Statistical analysis

The distribution of responses for the option “patient”, “physician” and “relative” was examined, the differences between respondent groups (patient/relative/physician) were observed by analysis of variance, the significance of these differences ( $P=0.05$ ) was examined by the Levene test in IBM SPSS 21.

For the next analysis, a typology of answers was constructed for each participant. First, the option “patient” was considered as a central category (patient autonomy is perceived as the level of the patient’s participation in the decision-making process in relation to the physicians’ and the relatives’ role) and three categories of combinations of answers were constructed: the patient’s voice is more important than that of the others (active role), the patient’s voice is equal to that of the others (shared decision-making) and the patient’s voice is less important than that of the others (passive role). Second, for the analysis of the triadic relation of the decision-making process, a typology of nine possible combinations was constructed. The distribution and relations among these variables were examined, the significance of the results was observed by the chi-square test ( $P=0.05$ ) and adjusted residuals.

## Results

Sample size was adequate to provide necessary statistical power in each of three groups (patients =170, relatives =113, physicians =108), response rate was 91%; 16 patients and 19 relatives refused to participate. Non-responders were mostly women ( $n=30$ ). The most common reason for refusing interview was lack of interest (mainly in group of relatives) or physical and psychological barriers (in group of patients). We enrolled 154 patients, 108 physicians and 94 relatives. The participants’ demographics are summarized in *Tables 1,2*. The mean age of the patients and relatives was 68.7 and 57.5, respectively; 64.9% of patients had cancer. Forty-eight percent of the patients believed that their disease was curable. The most common kinship status of the relatives was daughter (40.0%), spouse (22.0%) and son (13.0%). The physicians’ specializations were most often internal medicine

In the course of your illness, important decisions concerning health care have to be made. Often, the doctor, the patient and his family are involved in this decision-making process. From your point of view, how important those three actors should be in this decision-making process?												
For each of the actors, indicate the degree of importance on a scale from 0 to 10 (0—this opinion in decision-making about health care is completely unimportant for me, 10—this opinion is the most important for me):												
a)	Patient	0	1	2	3	4	5	6	7	8	9	10
b)	Physician	0	1	2	3	4	5	6	7	8	9	10
c)	Relative	0	1	2	3	4	5	6	7	8	9	10

**Figure 1** Survey question concerning decision-making.

**Table 1** Demographics of patients and relatives

Characteristics	Patients (n=154)	Relatives (n=94)
Sex, male	50.0%	25.5%
Age, mean, years	68.7	57.5
Diagnosis		
Cancer	64.9%	–
Non-cancer	35.1%	–
Education		
Elementary school	15.7%	8.5%
High school	34.0%	14.9%
High school with degree	31.4%	40.4%
Graduate degree	19.0%	36.2%
Religion		
Religious	40.8%	45.6%
Non-religious	59.2%	54.4%

**Table 2** Demographics of physicians

Characteristics	Physicians (n=108)
Sex, male	43.5%
Age, mean, years	40.3
Religion	
Religious	44.8%
Non-religious	55.2%
Medical specialty	
Internal medicine	37.0%
Oncology	17.6%
Cardiology	13.0%
Geriatrics	10.2%
Neurology	10.2%
Other	12.0%
Palliative care skills	
Excellent	0.9%
Very good	13.9%
Good	37.0%
General	38.9%
Basic	8.3%

(37.0%), oncology (17.6%) and cardiology (13.0%). The physicians rated their palliative care skills as: excellent (0.9%), very good (13.9%), good (37.0%), general (38.9%) and basic (8.3%).

When asked to rank the importance of each of the three roles in the decision-making process on a scale from 0 to 10, the patients attributed the most important role to the physicians [mean 9.29; 95% confidence interval (CI): 8.98–9.59], then to themselves (mean 7.85; 95% CI: 7.37–8.32) and then to their relatives (mean 7.41; 95% CI: 6.94–7.88). The relatives rated the importance in the decision-making in the same sequence—physicians mean 9.20 (95% CI: 8.96–9.45), patients' mean 8.80 (95% CI: 8.44–9.16) and relatives' mean 7.49 (95% CI: 7.06–7.93). On the other hand, from the physicians' point of view, the most important role should be played by patients (mean 9.31; 95% CI:

9.07–9.55), followed by physicians themselves (mean 8.35; 95% CI: 8.06–8.65) and finally by relatives (mean 6.40; 95% CI: 6.05–6.75) (Table 3).

Although all participants put the scores higher than 7 to all three “actors” (patients, physicians, and relatives), we found statistically significant differences between the respondent groups. The physicians indicated that the role of the patients in the decision-making should be stronger (mean 9.31; 95% CI: 9.07–9.55) than the patients

**Table 3** The role of patients, physicians and relatives in decision making on scale 0–10

Group of respondents	Who should decide	Mean	SD	95% CI
Patients perspectives	Patients	7.85	2.963	7.37–8.32
	Physicians	9.29	1.912	8.98–9.59
	Relatives	7.41	2.937	6.94–7.88
Physicians perspectives	Patients	9.31	1.256	9.07–9.55
	Physicians	8.35	1.555	8.06–8.65
	Relatives	6.40	1.849	6.05–6.75
Relatives perspectives	Patients	8.80	1.751	8.44–9.16
	Physicians	9.20	1.197	8.96–9.45
	Relatives	7.49	2.153	7.06–7.93

SD, standard deviation; CI, confidence interval.

themselves ranked it (mean 7.85; 95% CI: 7.37–8.32). On the other hand, when asked about the role of physicians, both the patients and the relatives rated the role of the physicians in the decision-making significantly higher (mean 9.29; 95% CI: 8.98–9.59 and mean 9.20; 95% CI: 8.96–9.45 respectively) than did the physicians themselves (mean 8.35; 95% CI: 8.06–8.65). The role of the relatives was considered to be stronger by the patients and the relatives themselves (mean 7.41; 95% CI: 6.94–7.88 and mean 7.49; 95% CI: 7.06–7.93 respectively) than by the physicians (mean 6.40; 95% CI: 6.05–6.75).

In the analysis of the dyadic interactions, we used the three categories of the patients' decisional control preferences (active, shared and passive) and here we found correlations between the respondent groups and their preferences. When we compared the preferred involvement of patients *vs.* physicians in the dyadic decision-making, patients preferred to be active in 11.2%; to have a shared input into the decisions with their physician in 44.1%; and to be passive and let the physician have the strongest word in 44.7%. As for physicians, the majority (56.5%) thought that patients should play the most important role in the decision-making and 26.9% preferred the decision-making to be shared. As for relatives, most of them believed that in the dyadic patient-physician decision-making, patients should be active (31.9%) or should have a shared role (23.4%) in the decision-making with their physician, and 44.7% of relatives believed that the physician should have the strongest word. The strongest positive correlations were found between being a patient and a preference for shared decisions, and between being a physician and a preference

for active decisions of the patients (*Table 4*). The strongest negative correlations were found between being a physician and passive decisional preferences of patients, and between being a patient and an active decisional preference of patients (*Table 4*).

When we compared the preferred involvement of the dyad of patients - relatives, 47.4% of patients thought that they should have equal word in the decision-making as their relatives, 34.2% of patients would prefer to be more active than their relatives and 18.4% of patients would prefer their relatives to be more active in the decision-making than they themselves. A large majority of physicians (93.5%) believed that patients should be more active than relatives, 5.6% of physicians were for shared decision between patients and relatives and only 0.9% of physicians would ascribe a more active role to relatives than to patients.

Most relatives (58.1%) would also prefer an active role of the patients but more than one third (34.4%) found the shared decision-making between patients and relatives the most acceptable option, and only 7.5% of relatives would like to be more active in the decision-making than the patients. The strongest positive correlations were found between being a patient and preferences for active decisions of patients and shared decisions of patients and relatives, and between being a physician and preferences for active decisions of patients (*Table 5*). The strongest negative correlations were found between being a patient and a stronger role of the relatives than the patients, and between being a physician and a stronger or shared role of relatives (*Table 5*).

Analyzing the attitudes of the participants towards the triadic decision-making, there are nine possible

**Table 4** The attitudes of participants toward dyadic decision making: patient-physician

Group of respondents	Who should decide	N	%	P <sup>a</sup>
Patients perspectives	Patient	17	11.2	***
	Physician	68	44.7	**
	Both of them	67	44.1	***
Physicians perspectives	Patient	61	56.5	***
	Physician	18	16.7	***
	Both of them	29	26.9	N.S.
Relatives perspectives	Patient	30	31.9	N.S.
	Physician	42	44.7	*
	Both of them	22	23.4	*

<sup>a</sup>, adjusted residual standardised analysis: \*, P<0.05; \*\*, P<0.01; \*\*\*, P<0.001. N.S., not significant.

**Table 5** The attitudes of participants toward dyadic decision making: patient-relative

Group of respondents	Who should decide	N	%	P <sup>a</sup>
Patients perspectives	Patient	52	34.2	***
	Relative	28	18.4	***
	Both of them	72	47.4	***
Physicians perspectives	Patient	101	93.5	***
	Relative	1	0.9	***
	Both of them	6	5.6	***
Relatives perspectives	Patient	54	58.1	N.S.
	Relative	7	7.5	N.S.
	Both of them	32	34.4	N.S.

<sup>a</sup>, adjusted residual standardised analysis: \*\*\*, P<0.001. N.S., not significant.

**Table 6** The attitudes of participants towards triadic decision making

Type of interaction	Patients, n (%)	Physicians, n (%)	Relatives, n (%)
Patient < relative + physician	25 (16.8)	1 (0.9)	7 (7.5)
Patient + relative < physician	22 (14.8)	0 (0)	14 (15.1)
Relative < patient < physician	21 (14.1)	17 (15.7)	21 (22.6)
Patient = relative = physician	45 (30.2)	4 (3.7)	15 (16.1)
Patient + physician > relative	20 (13.4)	25 (23.1)	6 (6.5)
Patient + relative > physician	5 (3.4)	2 (1.9)	3 (3.2)
Patient > relative + physician	11 (7.4)	59 (54.6)	27 (29.0)

combinations of interactions (*Table 6*). The most significant preference of the patients was either an equal role of the three actors (30.2%) or a more active role of the physician and the relative than the role of the patient (16.8%). For physicians, the most preferable type of interaction was an active role of the patient compared to the physician and the relative (54.6%). The least preferable types of interaction were those with the most active role of the physician compared to the patient and the relative (either physician + relative > patient or physician > patient + relative). The relatives also highlighted the active role of the patient compared to the physician and the relative (29.0%), but it was less statistically significant.

In the analysis of the sociodemographic and illness-related factors, we have found a significant association between age and the active role of the patients, with

younger participants preferring a more active role of patients. This is due to lower mean age in the group of physicians. Analyzing each group of the respondents separately, we have not found any association between the role in the decision-making and age, education, spirituality, diagnosis and the patients' prognostic awareness. Also, we have not found any significant association between physicians' views on decision-making and their specialty and between relatives' views on decision-making and their kinship status towards the patients.

## Discussion

Our results show a difference in attitudes toward decision-making between patients, physicians and relatives. Physicians and relatives tend to accentuate the active role of patients

either in dyadic or triadic interactions, while patients mostly prefer shared decision-making both in dyadic interaction with physicians and triadic interaction patient-physician-relative. Physicians also seem to underestimate the importance of the role of relatives in the decision-making in general while patients and relatives would prefer a more active participation of the relatives in the decision-making.

Comparing our results of patients' views with the study by Nolan *et al.* (19), the most important difference can be found in the dyadic patient-physician decisional preferences, where, in Nolan's study, 15% of patients preferred a passive role compared to 44.7% in our study, and 34% of patients preferred an active role compared to 11.2% in our study. Regarding the patient-relative dyad, in Nolan's study, 50% of the patients preferred an active role in decision with their relatives, compared to 34.2% in our study; 44% of patients preferred a shared decision compared to 47.4% in our study; and 6% preferred a passive role compared to 18.4% in our study. Similar to our results, Nolan found no significant association between sociodemographic variables and the decision-making preferences.

In Yennurajalingam's international study of 11 countries (14) there is also a stronger inclination towards an active role of patients in the patient-physician dyad (25% *vs.* 11.2% in our results), but almost similar in the patient-relative dyad (37% *vs.* 34.2%). In the triadic interaction, Yennurajalingam's study results also show that patients would opt for a more active (44%) attitude towards the decision-making than in our results (24.2%), but Yennurajalingam's comparison is made between the group of patients on the one hand and the group of physicians and relatives put together on the other, whereas in our study, the three groups are analysed separately, giving nine possible combinations of interactions. Also, the two above mentioned studies focused only on the views of the patients on the decision-making process, while our study compares the views of the patients, the physicians and the relatives.

In the study of LeBlanc *et al.* (16), the patients, physicians and relatives were asked to look at the triadic decision-making process retrospectively. Partial results of this study show that 46% of patients and 41% of relatives felt that the decision had been entirely influenced by physicians, while among physicians, only 17% thought they had such an active role. Interestingly, we have found similar numbers when asking about attitudes. 44.7% of patients and 44.7% of relatives thought physicians should play the most active role in the decision-making while only 16.7% of physicians thought that way. That may imply how attitude can have

impact on this process and its evaluation.

Patients in all studies mentioned in the discussion as well as patients in our study were either patients with palliative care needs or patients with limited prognosis. Even though our results do not show any association between patients' view of decision-making process and their prognostic awareness, the generalization of these results to other group of patients would require further research with specific patient population (e.g., different diagnosis) or a larger sample.

Although many physicians believe that they are already providing enough space for the patients to participate in the decision-making, in reality, shared decision-making demand more profound changes of attitudes of all parties involved in the process (20). The understanding of autonomy as a capacity to make an independent rational choice based on the information provided by the physician, and not paying enough attention to the interdependence and the social context of the patients' decisional preferences, mainly in the situation of advanced illness (21), are some of the main barriers of those changes. The person-centered approach, a well-defined concept integrated in other disciplines such as psychiatry and geriatrics, but taken as rather implicit and not much studied in palliative care (22), takes into account the patient as a person with her whole life experience and within her social relations. One of the main goals of this approach is to help patients to make meaningful decisions based on person's individual narrative and life's experience (23) through the process of shared decision-making. To support shared decision-making does not mean merely to provide information or knowledge and to restrain the physician's effort to push through his own view on what is in the patient's best interest (24). It also requires to reflect on the power imbalance in the patient-physician relationship; to redefine the patient's role; and to help the patients to engage in the process on the basis of their own values and life experiences; and to involve their significant others if the patient desires. Recent studies imply that special communication trainings (20) and trainings focused on goals of care conversations (25) and shared decision-making consultations (26) are important to change physicians' attitudes towards more person-centered care.

The results presented in this study lead to the interpretation that physicians do want to provide more space in the decision-making but they often do not know how, and that patients do want their relatives to be more engaged as a support, because the patients do not know what to expect from an expert-lead consultation and therefore do need more support.

This study has several limitations. First, the main



method used in this study was an original questionnaire, not previously tested for its psychometric properties. The method was only piloted for face validity and feasibility in a small group of patients, clinicians and relatives (<10 in each group). The second limitation is the small sample of the study, which limits especially the interpretation of the triadic interactions—here nine combinations were found and the count in some of the combinations was very low. Though statistically the results presented here are significant, their clinical significance may be questionable due to the small sample size. A qualitative study could bring further insight into the differences in the perceived roles among patients and their caregivers. The small sample size also does not enable detailed analysis of the association between the role in decision-making and the type of diagnosis, type of kinship status of relatives, type of specialty of physicians etc. A third limitation is the fact that physicians recruited for the study were not only the physicians taking care of the recruited patients, but also other physicians taking care of seriously ill patients in general. For that reason, we talk about the attitudes of three groups of respondents more than about the actual triads. And finally, participants were asked to think about the roles in a decision-making process concerning health care issues in general. Although all patients were in an advanced state of an incurable disease, the question of health care issues may have different meaning for each of them.

## Conclusions

Physicians should assess patients' preferences for the decision-making process and for their relatives' involvement. This study confirms that attitudes towards participation in the decision-making in the situation of advanced stage of incurable disease differ significantly between patients, physicians and relatives, and that physicians expect more active involvement from patients than do relatives and patients themselves. This study also shows that physicians underestimate the role of the relatives as expected by the patients and the relatives themselves. More research is needed to elucidate into greater depth the process of decision-making within the triad of actors—patient, physician and relative—and the factors that influence patients' and relatives' preferences for decisional control.

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