

# Association Between Quality of Life and Prognostic Awareness in Patients with Advanced Cancer

Karolína Vlčková (✉ [k.vlckova@paliativnicentrum.cz](mailto:k.vlckova@paliativnicentrum.cz))

Centre For Palliative Care <https://orcid.org/0000-0003-2004-9656>

Kristyna Polakova

Centre For Palliative Care

Anna Tuckova

Centre For Palliative Care

Adam Houska

Centre For Palliative Care

Martin Loucka

Centre For Palliative Care

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## Research Article

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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 % (N= 129) 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; 3.9) and partially aware (M= 31.9; 4.6) and unaware patients (M= 30; 5.2). 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 does not have to be associated with increased emotional distress to patient, which many clinicians fear and therefore tend to avoid or postpone prognostic disclosure. More research is needed on personality factors that might influence the development of prognostic awareness and quality of life.

## Introduction

Majority of patients with advanced cancer want to know their diagnosis and prognosis, but the views of their relatives and their physicians on patients' informational needs can be different [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]. Prognostic awareness means that patients can understand the seriousness of their current health status [5], their shortened life-expectancy and the incurable nature of their disease [6]. Having an accurate prognostic awareness can help patients to receive a goal-concordant end of life care [7], including higher chance of completing advance directives and having discussion about possible treatment options with physicians [8–10]. Effective communication is a necessary prerequisite for the development of accurate prognostic awareness, although many other factors such as age, education and patients' values also play an important role [4, 11–13]. Available evidence suggests that despite current standards of communication in oncology majority of patients with advanced cancer keep 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 is considered as the fundamental right of patients [17, 18] and a number of studies showed that more accurate prognostic awareness can be linked to better quality of life and less depression and anxiety [19, 20] [21, 22]. However, other studies reported that being aware of terminal condition may be a cause of psychological distress for patients, decreasing their quality of life, increasing anxiety and depression and even shorten survival [16, 23–27]. These contradictory findings can be caused by the fact that available studies used different and often non-standardized methods of how is prognostic awareness assessed, asking patients to identify their current health status or indicating the curability of their condition, using open-ended as well as closed questions or scales [6, 11]. On comparison, assessing the quality of life and psychological distress represent less of a challenge as there is a wide range of standardized tools available for patients with advanced health conditions, including cancer [28]. Nevertheless, the tools for use in palliative care differ in their measurement properties, and many have issues with construct validity, reliability, responsiveness or still require to be adequately evaluated [29].

The complexity of prognostic awareness as well as the wide variety of research methods used in this field contribute to the unclear evidence whether it is good for patients to know the truth about their prognosis. As this remains an important challenge from both clinical and research point of view, the aim of this study was to explore the association between PA and quality of life in patients with advanced cancer.

## Methods

### Study design and participants

STROBE statement was used to guide reporting of the study, the STROBE checklist is available in Appendix 1. This was a cross-sectional study using data from patients with advanced cancer. Patients were recruited at oncology departments in three hospitals (one secondary hospital and two university hospitals) in the Czech Republic. Data were collected from September 2018 till February 2019. The study included patients with incurable, advanced cancer. Inclusion criteria for patients were a diagnosis of advanced cancer, limited prognosis, and cognitive ability to participate in a structured interview. The limited prognosis was indicated by treating oncologists using the 12-month surprise question, which means that the physicians answered positively on the question: ‘Would I be surprised if this patient died in the next 12 months?’ [30, 31]. Eligible patients were recruited by their treating physicians. Data were collected by experienced researchers (KP, AT, AH) who followed a structured interview protocol. During the structured interview, researchers asked patients three questions about their prognostic awareness, questions on their information needs, demographics, and quality of life (the structure of the interview protocol is in Appendix 2). This study was a part of a multi-centre longitudinal cohort IMPAC study, which was focused on repeated measurement of prognostic awareness.

### Study measures

Quality of life

Quality of life was measured by two different methods. 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]. IPOS consists of 10 questions and covers the following domains: physical symptoms, wellbeing, patient and family distress, practical concerns, and information needs [32]. The range of sum score is 0–68 points, and a higher score means a worse quality of life. Confirmed factor analysis of IPOS found a 3-factor structure – physical, emotional and communication subscales [34]. IPOS was developed specifically for palliative care patients and has got excellent reliability and validity, which was 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 past week?’, assessing their quality of life on a 7-point scale, where 1 means “very poor”, and 7 means “excellent”, therefore the higher score, the better quality of life [33]. This global measure was also found to have good reliability and validity for measuring the quality of life [33, 38, 39]. In this presented study, the scale was used for data triangulation.

### Prognostic awareness

Prognostic awareness was measured with 3 different methods which were used in previous research [5, 40, 41]. Patients were asked 3 closed-ended questions, each focused on different aspect of prognostic awareness. Firstly, they were asked to define the seriousness of their illness (‘How would you describe your current health care status?’ with options: ‘relatively healthy’; ‘ill, but not seriously’; ‘seriously ill, but my life is not currently in danger’; ‘seriously and terminally ill’), following by question about their own perception of the curability of their condition (‘How likely is that your disease will be cured?’ answering on a percentual scale 0-100 %). The last question was focused on the goal of their current treatment (‘What is the primary goal of your cancer treatment?’ with options ‘to cure my disease’; ‘to prolong my life, although the disease can no longer be cured’; ‘to relieve symptoms’). Patients were considered as prognostically aware if they answered the first question as ‘I am seriously and terminally ill’, the second question if they indicated the probability of being cured as less than 10 %. For the final question, patients who answered that the goal of their treatment is to prolong their life or relieve symptoms were identified as prognostically aware. (see Appendix 2 for a full description of the used methods). Patients were considered as prognostically aware if they answered all 3 questions correctly, as partially aware if they answer one or two questions correctly.

## Ethics

Written consent was obtained from all participants. 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)

## Statistical analysis

Frequencies and proportions were used for descriptive statistics. Differences in quality of life were assessed using ANOVA test with Fischer's LSD post hoc test. Associations between demographics and quality of life were assessed using T-test for independent sample (religiosity, gender), ANOVA (diagnosis, education) and Pearson correlation coefficient (age). In addition, multivariate regression was conducted for verifying the predictors of quality of life. All analyses were conducted in IBM SPSS 27.

## Results

The sample consisted of 137 patients, but data were completed only for 129 patients. Demographics of the sample is in Table 1.

Table 1

<b>Gender</b>	<b>59 women (56 %)</b>
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

Most of the sample (57 %) was partially aware of their prognosis, 16 % of patients had accurate prognostic awareness, and 27 % were unaware. Gender, age, diagnosis, education, or religiosity were not significantly associated with the level of prognostic awareness. Mean of quality of life measured by IPOS was 32.2 (SD = 9.1) and by single-item global measure was M = 4.7 (SD = 1.5).

The quality of life measured by IPOS was significantly different between groups ( $p = 0.02$ ;  $\omega^2 = 0.03$ ) and post hoc analysis showed unaware and partially aware patients had 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). Difference between unaware and partially aware patients was not significant. Difference between groups are also clinically relevant difference [34].

The quality of life measured by single-item measure was also significantly higher ( $p = 0.005$ ;  $\omega^2 = 0.03$ ). Post hoc analysis showed significant differences between all three groups of patients. Unaware patients had a better quality of life ( $M = 5.2$ ;  $SD = 1.3$ ) than partially aware patients ( $M = 4.6$ ;  $SD = 1.3$ ) who also had a significantly better quality of life than aware patients ( $M = 3.9$ ;  $SD = 1.8$ ).

Table 2

	<b>Aware M(SD)</b>	<b>Partially aware M(SD)</b>	<b>Unaware M(SD)</b>
IPOS sum 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)

Detailed analysis of subscales of IPOS showed that significant difference between groups was present only for the physical symptoms subscale ( $p = 0.002$ ;  $\omega^2 = 0.04$ ), and not for emotional ( $p = 0.063$ ;  $\omega^2 = 0.01$ ) and communication subscales ( $p = 0.281$ ;  $\omega^2 = 0.002$ ) (see Table 2).

Demographics factors like the type of diagnosis ( $p = 0.7$ ), gender ( $p = 0.07$ ), religiosity ( $p = 0.25$ ), age ( $R = 0.04$ ) or education ( $p = 0.5$ ) were not significantly associated with quality of life.

The results of multiple regression are reported in Table 3. We found that only prognostic awareness was a significant predictor for quality of life, and it was a slightly stronger predictor for physical subscale than for the sum score of IPOS (standardised B -0.30 versus - 0.24).

Table 3

	<b>IPOS sum score</b>		<b>IPOS physical subscale</b>	
	<i>Regression B coefficient (95 % IC)</i>	<i>p-value</i>	<i>Regression B coefficient (95 % IC)</i>	<i>p-value</i>
PA	-0.24 (-5.89 to -0.80)	<b>0.011*</b>	-0.30 (-4.08 to -1.10)	<b>0.001*</b>
Type of diagnosis	0.03 (-1.80 to 2.44)	0.767	0 (-1.22 to 1,22)	0.996
Age	-0.08 (-5.89 to -0.80)	0.398	-0.04 (-0.13 to 0.08)	0.624
Education	-0.04 (-2.24 to 1.37)	0.633	-0.07 (-1.46 to 0.62)	0.424
Gender	0.17 (-0.15 to 6.36)	0.061	0.11 (-0.66 to 3.16)	0.197
Religiosity	0.10 (-1.38 to 5.31)	0.248	0.11 (-0.70 to 3.23)	0.205

## Discussion

This study focused on the association between prognostic awareness and quality of life among patients with advanced cancer. Our findings indicate that accurate prognostic awareness in this population is significantly associated with worse quality of life. This was confirmed by using two different methods for measuring patients' quality of life and a composite measure of prognostic awareness based on the most widely used tools for measuring this phenomenon. However, our detailed analysis showed that the worse quality of life reported by patients who are aware of their prognosis might be influenced only by worse physical symptoms rather than by emotional distress or other aspects of quality of life.

A number of studies 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] showed that the emotional aspects of quality of life were not significantly different between prognostically aware and unaware patients, but the sum score and the score in other subscales (such as physical activity, role limitation, cognitive activity) differed. These results are also supported by findings from previous studies which found that accurate prognostic awareness is associated with shorter survival [15, 43], worse performance status [41, 45] or physical wellbeing [46], suggesting that patients with more severe health impairment near the end of life have better understanding of their poor prognosis. Although in our study we did not find significant association between PA and emotional wellbeing, even though the tendency was similar as in several studies which contradict our results as they found a significant negative association of accurate PA with emotional domains of quality of life [24, 42]. Moreover, several studies identified a negative relationship of accurate PA and depression and anxiety [16, 23, 26, 41].

On the other hand, there are several studies which found that accurate prognostic awareness is associated with a better quality of life [9, 21, 47, 48]. Regarding emotional domain of quality of life, it seems that this association might be more complicated and possibly influenced by confounding factors. Ray and her colleagues [9] found that the association of PA and quality of life was influenced by peacefulness, and if patients were aware and peaceful, they were less sad and had better quality of life. Other studies found that the emotional domain of quality of life was associated with the patient's acceptance of diagnosis and prognosis [49] and also with coping strategies [26]. On the other hand, Kim et al. [43] found that depression did not work as confounding factor as the significant association between worse quality of life and accurate prognostic awareness remained even if the level of depression was statistically controlled. This evidence suggests that the personality of patients might be an essential factor which can influence the acceptance of prognosis and play a crucial role in the relationship between quality of life and PA.

Different results regarding the association of quality of life and prognostic awareness might be also explained by the fact that the inclusion criteria for patients with advanced cancer were different across studies: some of them included all patients undergoing chemotherapy [50], patients on stage III or IV [24] or stage IV with unresponsiveness to current treatment [49], patients having metastasis or failure of first-line chemotherapy [9] or having metastasis and low performance status [16] or not receiving treatment

with curative intent [26, 51]. Other studies used the estimation of prognosis by physicians with the surprise question [43]; this was the case of this presented study. Additionally, it is also important to note that the above-mentioned studies [42–44, 49, 8, 9, 48, 21, 22] used different tools for measuring quality of life which means that operationalisation of domains is different and comparability of the results is limited [52].

## Limitations

There are several limitations of this study. First, the design of this study was cross-sectional, which did not allow us to make any assumptions about the causal relationship between prognostic awareness and the quality of life. Randomised controlled trials using specific communication intervention aimed at improving prognostic awareness (e.g. SICP [53] programme) and measuring quality of life would be needed to answer this question. Our sample was rather small and the effect size of our results is considered to be small [54]. Convenience sampling method used in the study could have led to selection bias, when the patients with higher emotional distress may have not wanted to participate in this research.

## Conclusion

This study found that quality of life in advanced cancer patients is negatively associated with accurate prognostic awareness. Detailed analysis showed that this association was significant only for physical domains of IPOS and not for emotional and communication domains. Our findings suggest that accurate understanding of prognosis and the shortened life expectancy does not have to be necessarily connected to a worse emotional state and that worse reported quality of life of prognostically aware patients might be caused specifically by their worse physical condition. Therefore, prognostic disclosure itself does not have to cause emotional distress to patient, and clinicians do not have to be afraid of that [4]. The relationship between patients' prognostic awareness, quality of life and their emotional well-being is very complex and a meta-analysis of current evidence around specific factors such as depression and anxiety would be useful to better understand their mutual associations. Future research should also focus on personality traits as they might be the omitted key factor which facilitate the development of both prognostic awareness and quality of life of patients with advanced cancer.

## Abbreviations

IPOS – Integrated Palliative Outcome Scale

PA – prognostic awareness

SICP – Serious Illness Care Programme

## Declarations

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## **Conflicts of interests**

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

## **Availability of data and materials**

The datasets used during the study are available from the corresponding author on reasonable request.

## **Authors' contribution**

KV contributed to the data collection, investigation, data analysis and overall writing of the manuscript. KP contributed to the data collection, investigation, data analysis and overall writing of the manuscript. AT and AH contributed to data collection and editing of the manuscript. ML contributed to conceptualization, funding acquisition, data collection and editing of the manuscript. All authors have read and approved the manuscript.

## **Ethics 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)

## **Consent to participate**

Written consent was obtained from all participants.

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