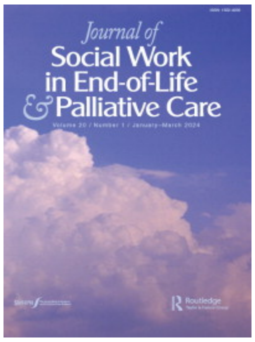

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RESEARCH ARTICLE

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A Prospective Study with Patients and Families on the Usefulness of Accurate Prognosis for Palliative Care Patients

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ABSTRACT

Prediction of life expectancy in terminally ill patients is an important end-of-life care issue for patients, families and mental health workers during the last days of life. This study was conducted to examine the importance/usefulness for patients/families to have an accurate prognosis and its impact on planning their activities prior to death. All patients admitted during a period of one year were included. Patients' and families' viewpoints on the usefulness of an accurate prognosis was documented at admission. There were 285 patients in the cohort. The median time to death was 8 days. Most families (83%) rated the importance of an accurate prognosis as moderately (13%) to very much useful (70%). A total of 42% of patients were able to complete e the questionnaire. Among these, 58% found it moderately to very much useful. For families, having an accurate prognosis influenced the planning of visits (69%), communication/closure (42%) and spiritual needs/funeral arrangements (31%). Patients identified planning of visits (10%), communication/closure (12%), and goals/accomplishments (9%) as very important. Discussing the prognosis and its impact is very helpful for the mental health professionals to have open and honest conversations with patients/families to identify, prioritize and adapt treatment to achieve goals prior to death.

KEYWORDS
Bereavement; cancer; end-of-life planning; Palliative care; prognosis

Introduction

Palliative care hospices serve as sanctuaries of compassion and care for patients with life-limiting illnesses, aiming to improve quality of life and offer support to their families. These specialized care settings focus on pain and symptom management, emotional support, and providing comfort throughout the end-of-life (EOL) journey. While the primary goal of palliative care is

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not curative in nature, it still focuses on enhancing the overall well-being of patients and promoting dignity in their final days. However, an area that has not been extensively explored within EOL care is the importance of an accurate prognosis for both patients and their families (Orlovic et al., 2023; Viganò, Dorgan, Bruera, & Suarez-Almazor, 1999; White, Reid, Harris, Harries, & Stone, 2016).

By providing patients and families with accurate prognostic information, healthcare professionals are better able to tailor their care plans and support services to meet the individual needs of each patient. This could result in improved symptom management, increased satisfaction with care, and potentially longer survival times. Additionally, providing prognostic information could help patients and families to better prepare for the EOL process, which can be emotionally and psychologically challenging. Studies have suggested that a clear communication of prognostic information enables patients and families to set realistic expectations, make well-informed decisions about treatment options, and prioritize their goals and preferences for EOL care (Ghandourh, 2016). These findings highlight the critical role prognostication has in facilitating shared decision-making and promoting patient autonomy within the palliative care context.

Accurate prognosis serves as an essential foundation for patient-centered care in palliative settings. It facilitates effective communication between healthcare providers, patients, and their families, fostering shared decision-making and promoting a sense of control and autonomy. Effective communication between healthcare professionals and family members of patients approaching EOL is crucial for providing high-quality EOL care. Anderson, Bloch, Armstrong, Stone, and Low (2019) highlight the challenges healthcare professionals face in initiating EOL conversations and the need for evidence-based guidance to improve communication strategies in their systematic review.

Researchers have advocated for patient involvement in decision making to be prioritized by healthcare professionals by providing access to accurate information and EOL care options (Josfeld, Keinki, Pammer, Zomorodbakhsch, & Hübner, 2021; Luna-Meza et al., 2021). Ultimately, patient engagement in decision-making leads to improved EOL care management, increased patient satisfaction, and better consideration of their goals and motivations (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014).

Regarding family caregivers, Hebert, Schulz, Copeland, and Arnold (2009) conducted focus groups and ethnographic interviews with 33 family caregivers of terminally ill patients to understand their perspectives on preparing for death and bereavement. The findings revealed four primary themes among caregivers: life experiences, uncertainty, communication and preparedness. Life experiences, including the duration of caregiving/illness, previous planning regarding death, previous experiences with caregiving or death, all of which impacted caregivers' sense of preparedness. However, regardless of these life experiences, all caregivers reported having a sense of uncertainty regarding medical issues, practical matters, psychosocial issues, and religious/spiritual needs. Caregivers needed more than just prognostic information to prepare for their loved ones EOL. Good communication, characterized by clear, reliable information and relationship-centered care, including psychosocial support from healthcare providers, played a crucial role in managing uncertainty and preparing for death and bereavement.

Having an accurate prognosis in a palliative care hospice setting is thus one key aspect of utmost importance for patients and their families. It provides them with valuable information and allows them to make informed decisions regarding EOL care and planning. Accurate prognostic information can help patients and families prepare emotionally, physically, spiritually, and practically for the future, enabling them to prioritize and focus on what matters most to them during this time. The objective of this study, which is part of a large survival study, was to evaluate the usefulness, for patients and families, of knowing the prognosis during the last days of life and to identify its utility in planning the activities that are important to them during their remaining days.

Methodology

Research design

This prospective study included all patients admitted at the Teresa Dellar Palliative Care Residence (TDPCR) (Montreal, Canada) during the span of one year (between June 2021 and June 2022). It is part of a large survival prediction study on terminally ill patients in palliative care residence setting (Bouchard, Iancu, Neamt, et al., 2023). Ethical approval was received from the Faculty of Medicine McGill Institutional Review Board. No patient consent was required given this study did not involve any changes in the standard of care treatment.

Sample and procedures

All patients admitted at the TDPCR during the period of recruitment (until one year duration since the first patient entry or up to a maximum of 300 patients entered) were considered eligible to participate in this study.

The sample size was calculated on the basis of the main study done on "survival prediction of terminally ill patients in palliative care residence setting" (Bouchard, Iancu, Neamt, et al., 2023).

The answers to the FPF questionnaire were obtained by the Supportive Care team and data entered in the Database. A weekly check was done by the research monitoring staff on the compliance/accuracy/completeness of data entry.

Measures

A short questionnaire "Family/Patient Feedback (FPF) questionnaire" was administered during the first week of admission in order to determine the usefulness of an accurate prognosis for patients and families (Appendix I). The FPF consisted of two questions. The first question was a rating scale question asking "How important/useful is it for you to have a relatively accurate prognosis when your family member (or yourself, if patient is able to answer) is admitted at the Residence"? A variation of the Likert scale was used and offered the following options: "not useful", "some usefulness", "moderate usefulness", "very much useful", "unable to answer/does not want to answer". The second question was a binary question in which participants would answer either yes or no to each of the options: "If useful, what would it change in your future activities"? Activities included "planning of visits", "work/life balance", "goals and accomplishments prior to death", "communication and closure", "spiritual needs/funeral arrangements" or "other". Participants who answered "other" were asked to specify their answer.

Data analysis

The inclusion of up to 15 covariates in regression models were anticipated. Given the exploratory nature of this study, there was a target of 10 events per candidate predictor parameter (EPP) to provide adequate power to examine the predictive performance of the models.

The viewpoint of the patient and/or family on the usefulness of having an accurate prognosis was described using the FPF questionnaire. Descriptive statistics were used to summarize responses to items from the FPF questionnaire. Two patient populations were analyzed: patients included in the study and their respective family members. Demographic and other baseline characteristics were summarized for each patient population (cancer and non-cancer). Descriptive statistics included mean, median, interquartile range, frequencies, and proportions to summarize the characteristics of the overall study population and stratified by reason for admission (cancer vs other pathologies).

Results

Patient characteristics

Table 1 presents the comprehensive results of patients categorized as either having cancer or non-cancer conditions. A total of 285 individuals (mostly

Table 1. Patient baseline characteristics.

	Cancer		Non-Cancer		Total	
Characteristic*	Median	(IQR)	Median	(IQR)	Median	(IQR)
Age (years)	80	(68–87)	90	(80–94)	82	(70–89)
Time to death from admission (days)	9	(3–24)	6	(2–12)	8	(3–19)
	N	(%)	**N**	(%)	**N**	(%)
Total	217	(76%)	68	(24%)	285	(100%)
Sex						
Male	94	(43%)	30	(44%)	124	(44%)
Female	123	(57%)	38	(56%)	161	(56%)
Most frequent cancers						
Gastro-intestinal	65	(30%)	–	–	65	(23%)
Lungs/bronchi	45	(21%)	–	–	45	(16%)
Genito-urinary	35	(16%)	–	–	35	(12%)
Breast	21	(10%)	–	–	21	(7%)
Brain	14	(6%)	–	–	14	(5%)
Hematological	11	(5%)	–	–	11	(4%)
Other	26	(11%)	–	–	26	(8%)
Non-cancer pathologies						
Cardiac Insufficiency	–	–	17	(25%)	17	(6%)
Dementia/Alzheimer	–	–	10	(15%)	10	(4%)
COPD/Pulmonary fibrosis/Other pulmonary	–	–	8	(12%)	8	(3%)
Renal Insufficiency	–	–	6	(9%)	6	(2%)
Vasculopathy/severe diabetes	–	–	6	(9%)	6	(2%)
Hepatic Insufficiency (cirrhosis)	–	–	5	(7%)	5	(2%)
Other	–	–	16	(24%)	16	(6%)
Cancer metastases						
Yes	177	(82%)	–	–	177	(62%)
No	40	(18%)	–	–	40	(14%)

IQR: Interquartile range

*96% were Caucasian. Origins: North America (65%); Europe (22%); Asia (6%) and Africa (5%)

Caucasian: 96%) participated in the study of which 42% were able to complete the questionnaire whereas 96% of patients' families completed it. Patients were originally from North America (67%), Europe (22%), Asia (6%) and Africa (5%). Most patients (217 (76%)) had cancer and 68 (24%) were classified as having a non-cancer pathology. The median age for cancer patients was found to be 80 years, with an interquartile range (IQR) of 68-87 years. The median age for non-cancer patients was higher, 90 years (IQR: 80-94 years). The overall median age for all participants was determined to be 82 years (IQR: 70-89 years). The median time from admission to death for cancer patients was 9 days (IQR: 3-24 days), while non-cancer patients exhibited a median of 6 days (IQR: 2-12 days). Combining the data for all participants, the overall median time to death from admission was 8 days (IQR: 3-19 days). In terms of gender distribution, among the entire cohort, 124 participants (44%) were males, while 161 patients (56%) were females. When examining the cancer and non-cancer groups separately, it was observed that 43% of cancer patients were males, while 57% were females. Similarly, in the non-cancer group, 44% were males, and 56% were female.

The most prevalent cancer types among the study participants were gastro-intestinal (30%), lungs/bronchi (21%), genito-urinary (16%), breast

(10%), brain (6%), hematological (5%), and other types (17%). Analyzing non-cancer pathologies, 17 individuals (6%) had cardiac insufficiency, 10 patients (4%) suffered dementia/Alzheimer's, 8 individuals (3%) had COPD/pulmonary fibrosis/other pulmonary conditions, renal insufficiency was present in 6 individuals (2%), vasculopathy/severe diabetes in 6 individuals (2%), hepatic insufficiency (cirrhosis) in 5 individuals (2%), and other pathologies in 16 individuals (6%). Eighty-two percent (82%) of cancer patients had metastases.

Usefulness of accurate prognosis

Patient survey

More than half (58%) of patients (164/285) were unable or did not want to answer the questions. Fifty-six patients (20%) expressed that having a relatively accurate prognosis was very much useful to them; 15 patients (5%) found it moderately useful and a smaller proportion of patients, 8 (3%), indicated some usefulness. (Figure 1a).

Among the 121 patients who were able to answer the question, 56 (46%) said that having an accurate prognosis was very much useful; 15 patients (12%) said that it was moderately useful, and 8 patients (7%) saw some usefulness (Figure 1b).

Family survey

Very few family members refused to answer the questionnaire (4%). Most families, 200 (70%), expressed that having a relatively accurate prognosis was very much useful to them; 38 (13%) found it moderately useful and a smaller proportion of families, 11 (4%), indicated some usefulness. Few families, 21 (7%) reported that having a relatively accurate prognosis was not useful to them. Four responses were missing from the dataset (Figure 2).

Having an accurate prognosis was considered "very much useful" for almost all patients' brothers/sisters (94.7%) (Figure 3). It was very useful in approximately 75% of spouses and patients' children.

Impact on future activities

Patients' viewpoint

In the patient viewpoint, 12% of patients (34 patients) thought that having an accurate prognosis would allow them to have better communication and closure, 10% (29 patients) favored the planning of visits, 9% (25 patients) the goals and accomplishments prior to death and 8% (24 patients) spiritual needs/funeral arrangements (Table 2).

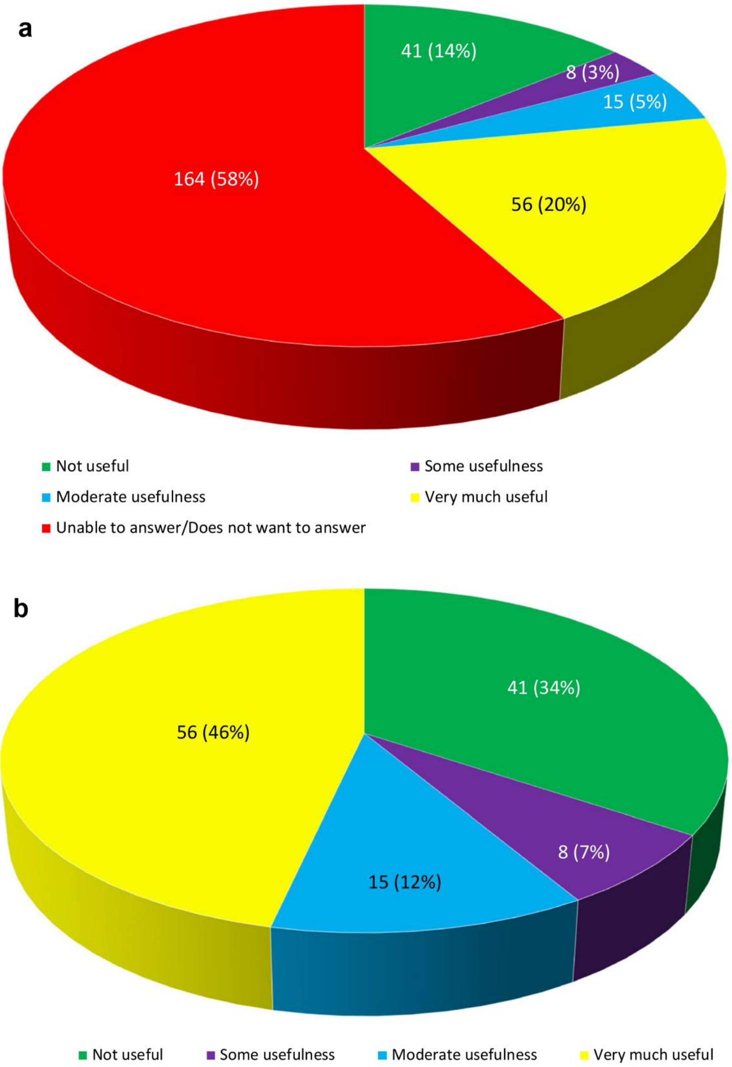

Figure 1. **a.** Usefulness in having a relatively accurate prognosis for patients.
Question asked: How important/useful is it for you to have a relatively accurate prognosis when you are admitted to the Residence?
b. Usefulness in having a relatively accurate prognosis for **patients who were able to answer the question**.
Question asked: How important/useful is it for you to have a relatively accurate prognosis when you are admitted to the Residence?

Families' viewpoint

For the families, the responses were as follows: 197 (69%) families believed that an accurate prognosis would change their planning of visits for domestic or family activities, 69 (24%) families felt that it would have an impact on their work/life balance and compassionate care leave, 18 (6%) families believed that an accurate prognosis would make a difference in goals and

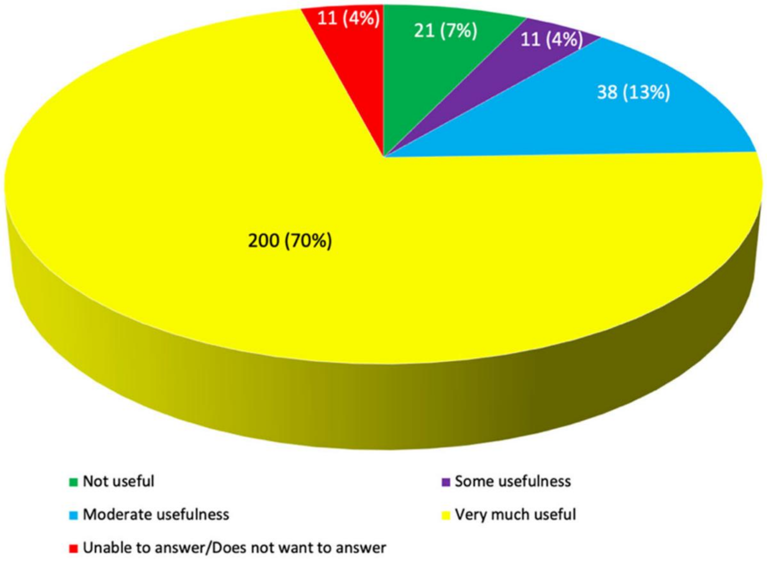

Figure 2. Usefulness in having a relatively accurate prognosis for **families**.
Question asked: How important/useful is it for you to have a relatively accurate prognosis when your family member is admitted to the Residence?

accomplishments prior to death, 119 (42%) families believed that it would facilitate communication and closure (influence their ability to say good-byes and share before death) and 89 (31%) families believed that it would play a role for spiritual needs and funeral arrangements (Table 2).

Overall, in the "Other" category, 32 (11%) patients and 58 (20%) families reported that an accurate prognosis would impact activities beyond the pre-defined options (Table 2).

Discussion

This study explored the importance and usefulness of an accurate prognosis for patients and families in palliative care. In this study, which included a significant number of patients (285 patients) and their families, we were able to demonstrate the importance, particularly for families, of providing a prognosis that is accurate enough to allow them to adjust the care and activities related to their loved one's EOL.

There are several challenges in enabling patients and their families to cultivate prognostic awareness. One challenge is the accurate estimation of prognosis by clinicians, as they range from an underestimate to an overestimate life expectancy (White et al., 2016).

Despite the availability of tools that have been validated in palliative care settings, an element of uncertainty remains and needs to be acknowledged when having conversations with patients and their families (Chu, White, &

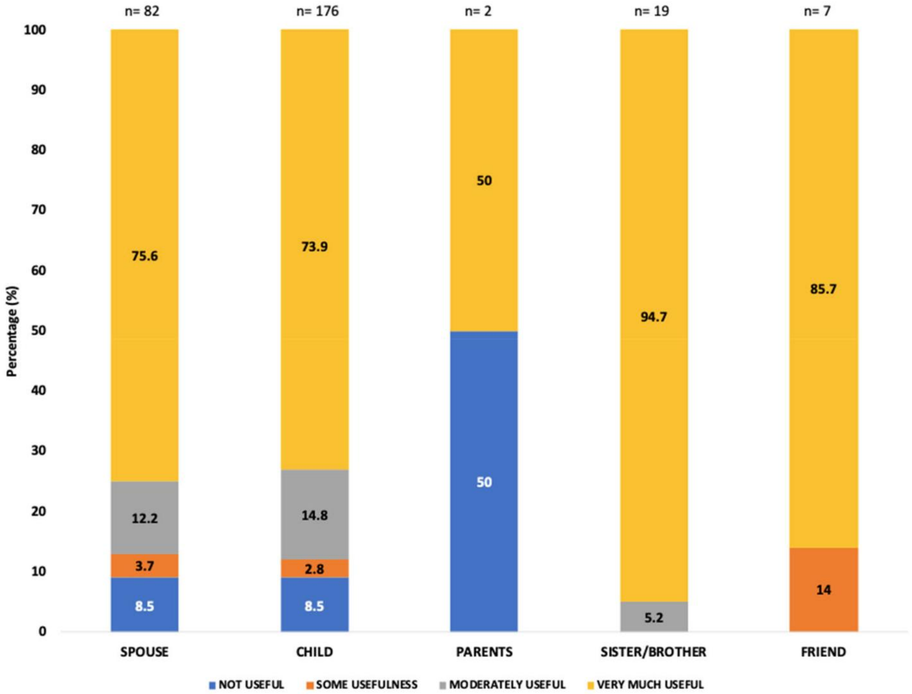

Figure 3. Usefulness of prognosis for relatives and friends according to their relationship with the patient*.
*For some patients, more than one relative per patient answered the questionnaire.

Stone, 2019). Although there is ongoing research to improve the accuracy of prognostication (Bouchard, Iancu, Neamt, et al., 2023), clinicians should be aware of the inherent challenges and use available tools cautiously, especially when caring for patients with advanced cancer or terminal pathologies.

This study showed that most families (including mainly children, spouses and sisters/brothers) wanted to have an accurate prognosis (94%). Most thought that it was useful (87%) mainly to plan their visits, say their last goodbyes to their loved one and arrange for funeral and spiritual needs. This also allowed for families to share their beliefs about death and dying and participate in cultural rituals and customs. Having an accurate prognosis allows patients and families to better prepare for approaching death and address practical matters in a timelier manner. These findings support the importance of open and honest communication between physicians and patients' surrogate decision makers (Evans et al., 2013).

Moreover, families shared that having discussions regarding prognosis earlier in a patient's stay (or sooner in the illness trajectory) provides the opportunity to explore what is most important for the patient and their family, and further assess their specific needs and goals. This is especially relevant for mental health professionals, such as social workers,

Table 2. Impact on activities when having a relatively accurate prognosis.
Question asked: If useful to have a relatively accurate prognosis, what would it change in your future activities?

	Patients		Families	
	Yes N (%)	No N (%)	Yes N (%)	No N (%)
Planning of visits (Domestic/family activities)	29 (10%)	256 (90%)	197 (69%)	88 (31%)
Work/Life Balance (Compassionate Care Leave)	3 (1%)	282 (99%)	69 (24%)	216 (76%)
Goals and accomplishments prior to death	25 (9%)	260 (91%)	18 (6%)	267 (94%)
Communication and Closure (Goodbyes, sharing before death …)	34 (12%)	251 (88%)	119 (42%)	166 (58%)
Spiritual Needs/Funeral arrangements (last rites …)	24 (8%)	261 (92%)	89 (31%)	196 (69%)
Other*:	32 (11%)	253 (89%)	58 (20%)	227 (80%)

*Others include: Psychological welfare, grieving process, avoid loneliness, emotional preparation, knowledge/awareness of situation, suffering delay, spend quality time, change family life outlook, no relevant change, prefer to be oblivious to situation

psychologists, and therapists, who play an essential role in assessing and intervening in the psychosocial domains of care. Mental health professionals can help identify emotional and mental health needs as well as patient and family coping. Discussing prognosis often facilitated conversations on related topics, such as funeral arrangements and advanced care planning. Family members told the social workers that they appreciated having a more accurate prognosis as it allowed them to be realistic and better informed when making plans relative to their loved ones.

Another challenge is assessing patient's existing knowledge and integrating prognostic information. Patients may have conflicting needs regarding prognostic information, wanting their clinicians to be both hopeful and honest. In this study, most patients (58%) either could not answer the questions because of their advanced disease or did not want to discuss their prognosis. Denial and fluctuations in awareness are normal coping mechanisms for patients facing terminal illness, and clinicians must respect these variations (Jackson et al., 2013).

Cultural factors play a significant role in the disclosure of prognostic information with collectivist cultures often limiting such disclosure to protect patients' feelings or maintain hope. Although most patients in this study were Caucasian, several cultures were represented depending upon their origin (North America, Europe, Asia and Africa). The family unit may have a more central role in non-Western cultural groups regarding prognostic awareness and medical decision-making (Applebaum et al., 2014).

Patients and their caregivers want to know how long they have left to live to prepare for their death and make important decisions about their care. The importance of accurate prognostic awareness may facilitate EOL care discussions and contribute to informed and value-based EOL care decision-making, ultimately leading to high-quality EOL care that aligns with patients" preferences, values and goals.

Discussing prognosis and its impact is helpful for mental health professionals and other health care workers involved in the patient's care, as it helps facilitate open and honest discussions with patients/families. When the prognosis is known to everyone, mental health professionals can become involved to help patients and families with legacy projects, last wishes, communication, and spiritual needs.

It would be interesting, in future studies, to further refine our findings by asking the same questions on usefulness of accurate prognosis to families and patients later on during the period of stay at the Residence to evaluate whether its level of usefulness changes with approaching the last days of life. Furthermore, asking multiple family members, *rather than just one,* whether having an accurate prognosis is useful could be explored in future research in order to shed light on whether the familial relationship to the patient influences the desire to have this information.

Limitations

One limitation in this study was that the questionnaire was filled out during patient's admission at the Residence. It did not allow for choosing the best timing for questioning patients and families who could be overwhelmed or in crisis upon their arrival at the Residence. This might explain the difficulty and/or unwillingness for some patients to answer the questions. In addition, the median time for survival was very short; therefore, many patients were in the end-of-stage of the dying process, even some dying during the first 24 hours of admission, hence making it more difficult for them to answer the questionnaire. Also, this study was performed in only one setting with limited number of admissions during the period of one year.

Conclusion

Accurate prognosis is an essential aspect of palliative care that holds great potential to enhance patient and family experiences. By providing patients with a clearer understanding of their illness trajectory, it enables them and their family to make informed decisions, optimize their quality of life, and find peace amidst uncertainty. However, challenges and ethical considerations must be carefully addressed to ensure that the delivery of prognostic information is sensitive, patient-centered, and aligned with cultural diversity. The usefulness of an accurate prognosis in EOL palliative care is of resounding importance for families and patients. Discussing prognosis also enables mental health professionals to have open and honest conversations with patients and families regarding their wishes and goals. It allows mental health professionals to help patients and their loved ones identify their needs, help them organize tasks, and highlight their resources and strengths. With prognostic information, patients have the opportunity to prioritize what is important to them and make the best use of their remaining days.

In conclusion, accurate prognostic information can help patients and families prepare emotionally, physically, and spiritually for the future, enabling them to prioritize and focus on what matters most to them. Prognosis also facilitates effective communication between healthcare professionals, patients, and families, fostering trust and shared decision-making.

Authors' contributions

The authors confirm contributions to this article as follows: study conception and design: SB; data collection MP, PO, ST, ER; Manuscript preparation: SB, MP, PO, ST, ER and CC. All authors reviewed the results and approved the final version of the manuscript.

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References

Anderson, R. J., Bloch, S., Armstrong, M., Stone, P. C., & Low, J. T. S. (2019). Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative Medicine*, *33*(8), 926–941. doi:10.1177/0269216319852007

Applebaum, A. J., Kulikowski, J. R., Jacobs, J. D., Derosa, A., Lichtenthal, W. G., Kolva, E. A., … Breitbart, W. (2014). Conceptualizing prognostic awareness in advanced cancer: A systematic review. *Journal of Health Psychology*, *19*(9), 1103–1119. doi:10.1177/1359105313484782

Bouchard, S., Iancu, A., Neamt, E., et al. (2023). *A prospective study on survival prediction of patients in palliative care. BMJ Supportive & Palliative Care;13:A67*. The Edinburgh International Conference Centre (EICC), Edinburgh, Scotland. doi:10.1136/spcare-2023-PCC.178

Chu, C., White, N., & Stone, P. (2019). Prognostication in palliative care. *Clinical Medicine (London, England)*, *19*(4), 306–310. doi:10.7861/clinmedicine.19-4-306

Evans, N., Pasman, H. R., Vega Alonso, T., Van den Block, L., Miccinesi, G., Van Casteren, V., … Onwuteaka-Philipsen, B., EUROIMPACT, on behalf of, & Smith, T. A. (2013). End-of-life decisions: A cross-national study of treatment preference discussions and surrogate decision-maker appointments. *PloS One*, *8*(3), e57965. doi:10.1371/journal.pone.0057965

Ghandourh, W. A. (2016). Palliative care in cancer: Managing patients' expectations. *Journal of Medical Radiation Sciences*, *63*(4), 242–257. doi:10.1002/jmrs.188

Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement. insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management*, *37*(1), 3–12. doi:10.1016/j.jpainsymman.2007.12.010

Jackson, V. A., Jacobsen, J., Greer, J. A., Pirl, W. F., Temel, J. S., & Back, A. L. (2013). The cultivation of prognostic awareness through the provision of early palliative care in the ambulatory setting: A communication guide. *Journal of Palliative Medicine*, *16*(8), 894–900. doi:10.1089/jpm.2012.0547

Josfeld, L., Keinki, C., Pammer, C., Zomorodbakhsch, B., & Hübner, J. (2021). Cancer patients' perspective on shared decision-making and decision aids in oncology. *Journal of Cancer Research and Clinical Oncology*, *147*(6), 1725–1732. doi:10.1007/s00432-021-03579-6

Luna-Meza, A., Godoy-Casasbuenas, N., Calvache, J. A., Díaz-Amado, E., Gempeler Rueda, F. E., Morales, O., … de Vries, E. (2021). Decision making in the end-of-life care of patients who are terminally ill with cancer - a qualitative descriptive study with a phenomenological approach from the experience of healthcare workers. *BMC Palliative Care*, *20*(1), 76. doi:10.1186/s12904-021-00768-5

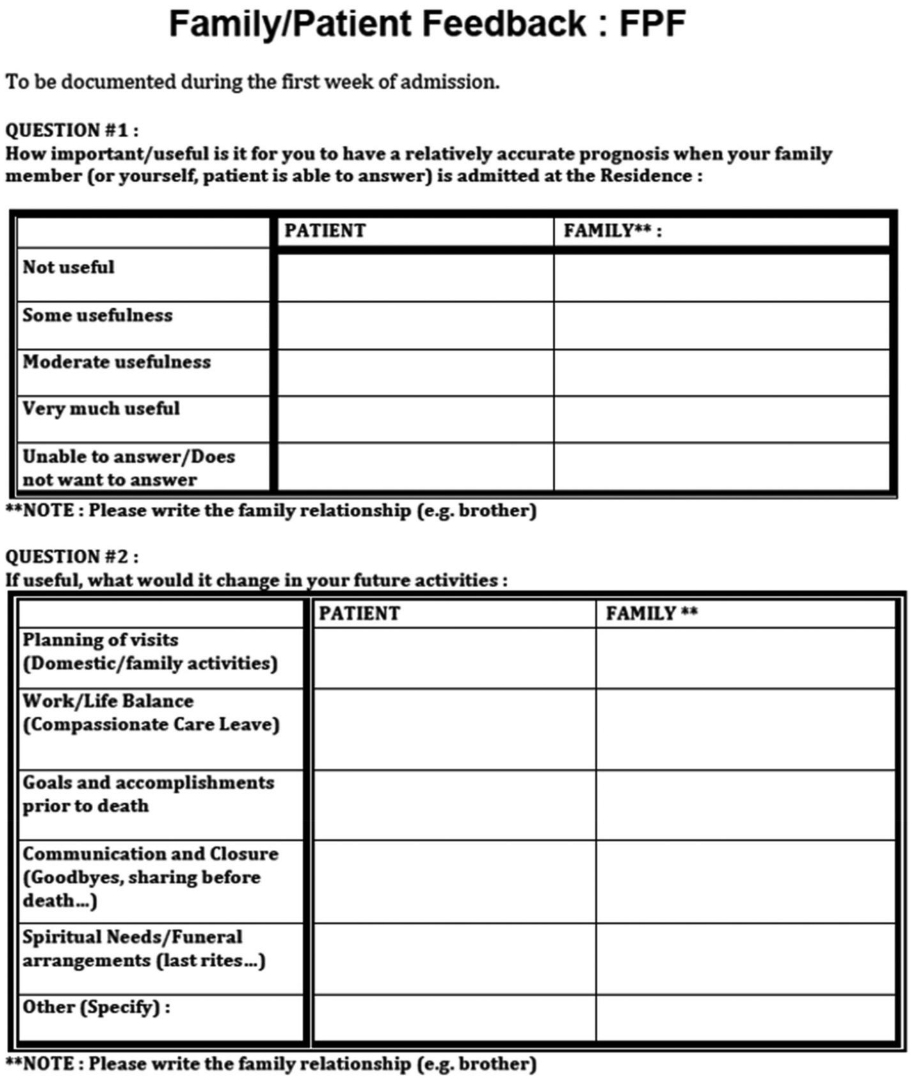
Orlovic, M., Droney, J., Vickerstaff, V., Rosling, J., Bearne, A., Powell, M., … Stone, P. (2023). Accuracy of clinical predictions of prognosis at the end-of-life: Evidence from routinely collected data in urgent care records. *BMC Palliative Care*, *22*(1), 51. doi:10.1186/s12904-023-01155-y

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: A review. *Iranian Red Crescent Medical Journal*, *16*(1), e12454. doi:10.5812/ircmj.12454

Viganò, A., Dorgan, M., Bruera, E., & Suarez-Almazor, M. E. (1999). The relative accuracy of the clinical estimation of the duration of life for patients with end of life cancer. *Cancer*, *86*(1), 170–176. doi:10.1002/(SICI)1097-0142(19990701)86:1 < 170::AID-CNCR23 > 3.0.CO;2-S

White, N., Reid, F., Harris, A., Harries, P., & Stone, P. (2016). A systematic review of predictions of survival in palliative care: How accurate are clinicians and who are the experts? *PloS One*, *11*(8), e0161407. doi:10.1371/journal.pone.0161407

Appendix 1



Family/Patient Feedback : FPF

To be documented during the first week of admission.

QUESTION #1 :
How important/useful is it for you to have a relatively accurate prognosis when your family member (or yourself, patient is able to answer) is admitted at the Residence :

	PATIENT	FAMILY** :
Not useful		
Some usefulness		
Moderate usefulness		
Very much useful		
Unable to answer/Does not want to answer		

****NOTE : Please write the family relationship (e.g. brother)**

QUESTION #2 :
If useful, what would it change in your future activities :

	PATIENT	FAMILY **
Planning of visits (Domestic/family activities)		
Work/Life Balance (Compassionate Care Leave)		
Goals and accomplishments prior to death		
Communication and Closure (Goodbyes, sharing before death…)		
Spiritual Needs/Funeral arrangements (last rites…)		
Other (Specify) :		

****NOTE : Please write the family relationship (e.g. brother)**