

# How does receiving a survival estimate affect the general health and wellbeing of people living with terminal cancer and their carers? Findings from a systematic review of qualitative experiences

Caitlin Spooner<sup>1</sup>, Bella Vivat<sup>1</sup>, Nicola White<sup>1</sup>, Andrea Bruun<sup>1</sup>, Gudrun Rohde<sup>1,2</sup>, Pei Xing Kwek<sup>3</sup>, Patrick Stone<sup>1</sup>

<sup>1</sup> Marie Curie Palliative Care Research Department, University College London, London, UK, <sup>2</sup> Faculty of Health and Sport Sciences, University of Agder, Kristiansand, Norway, <sup>3</sup> University College Dublin School of Medicine, University College Dublin, Dublin, Ireland



## Introduction

We are developing a core outcome set (COS) for palliative cancer care research into prognostication (prediction of survival). Studies in this field often measure a variety of clinical and service-level outcomes, but do not routinely measure outcomes that are important to patients and carers. The experiences of these stakeholders are essential for producing a meaningful COS.

## Aims

To identify and synthesise qualitative data on patients' and carers' experiences of prognostication in palliative cancer care.

## Methods

Five databases were searched up to March 2022. The search included qualitative or mixed methods studies exploring how adult patients and/or carers are affected by prognostication.

Inclusion criteria included:

- Patients with advanced cancer or their informed caregivers
- Discussions about survival length
- Any qualitative study design

Data describing outcomes and experiences of prognostication were extracted and thematically synthesised, using the Core Outcome Measures in Effectiveness Trials (COMET) taxonomy as a framework to develop themes.

We appraised retrieved studies for quality using the Mixed Methods Appraisal Tool (MMAT), but quality was not a basis for exclusion.

## Results

8075 screened → 9 included → 28 themes

### Methodological quality

We assessed the quality as high in four studies, moderate in three, and low in two.

### Qualitative results

We identified 28 themes pertaining to outcomes of prognostication, and organised these into 8 domains:

1. Psychiatric outcomes
2. Spiritual, religious, and/or existential functioning/wellbeing
3. Emotional functioning/wellbeing
4. Social functioning
5. Global quality of life
6. Delivery of care
7. Perceived health status
8. Personal circumstances

## Results continued

The main themes identified were:

### Avoidance/denial

"We were given statistics and we were asked if we wanted to know more, and we both looked at each other and said no." (Informal caregiver)<sup>1</sup>



### Maintaining hope

"I don't mind what I hear, so long as there is a little light at the end of the tunnel you know what I mean? ...a little bit of hope there, yes." (Patient)<sup>2</sup>



### Preparedness for end-of-life

"He had complete knowledge about his condition and hence was very bold and fully prepared to face his death." (Informal caregiver)<sup>3</sup>



### Treatment preferences

"Well, none of us would have made the decisions we did [to continue treatment] if we had known the truth about her illness. I just don't know if the doctors knew, but they must have. Why wouldn't they tell us?" (Informal caregiver)<sup>4</sup>



## Conclusion

We have identified 28 themes as potential candidates for inclusion in the future COS. The next stage of the study will investigate stakeholders' perspectives on these themes and other potentially suitable items for inclusion, identified through linked reviews.

## Impact

Standardising outcome reporting through a COS will improve the comparability of future prognostic research, and match better with patient and carer experiences. This will lead to better evidence synthesis, clinical practice, and ultimately improve access to support for those living with terminal cancer when receiving a prognosis

### References of included studies

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