

Building a research agenda together: Involving patients and other stakeholders in defining research priorities in palliative care

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Background

What is known on this topic

- it is important to involve patients and other stakeholders in priority setting in healthcare¹
- however, there is little experience how to do this in a systematic way

INTEGRATE-HTA²

- complex health technologies are necessary for matching the rise in chronic diseases in ageing populations
- INTEGRATE-HTA aims to develop concepts and methods for a comprehensive, patient-centered and integrated assessment for complex health technologies
- palliative care is used as case study to test the methodology

PROJECT

STUDY

the present study develops and tests a method for involving patients and other stakeholders in defining priorities for research in palliative care, with a focus on social learning

¹ Chalmers et al. *Lancet* 2014;383:156-65

² www.integrate-hta.eu

Methods

Data collection

- individual face-to-face interviews with patients and other stakeholders
- invited stakeholders:
 - lay stakeholders
 - professionals
- based on the outcomes; a systematic review of the literature was conducted

Analysis

- notes were taken
- the analysis was based on reconstruction of interpretive frames³, revealing stakeholders
 - problem definitions
 - empirical and ethical background theories
 - judgments of various solutions
 - normative preferences
- MEDLINE, PubMed, Cochrane, Embase, and Cinahl databases were searched to identify relevant articles on interventions to improve spiritual well being in palliative care between 2000 and 2013
- findings were presented to patients and other stakeholders for feedback

³ Fischer 1995; *Evaluating Public Policy*



Results

Participants

- lay stakeholders patients(2)
- professionals general practitioners (2), palliative care specialists (5), chaplains (3), nurses (2)

Individual face-to-face interviews

The concerns came down to they question how research can help patients and their relatives to discover the meaning of life in the presence of incurable disease.

Key issues and concerns revolved around three main themes

1. Transition from a curative to a palliative approach
2. Meaning of life questions
3. Continuity of care



Systematic review

The search yielded 2,305 articles of which 25 articles met all eligibility criteria. Seven of these were qualitative studies, 17 quantitative studies – of which 12 randomized controlled trials – and one mixed-design study. Interventions were diverse and included among others life reviews, meaning-making interventions and music therapies. We found inconclusive evidence that interventions for adults in palliative care may or may not enhance spiritual well-being. The quality of the studies was variable, and significant sources of potential bias were present.

Respondent validation

- the results of studies, identified through the systematic review, did not matched well stakeholders' questions and concerns.
- it is believed that there is no one size fits all, especially in palliative care

Conclusions

This study explored, developed and tested a method to define research priorities

- there is a mismatch between available evidence and stakeholders' concerns
- it is challenging to develop and execute a palliative care research agenda that matches the questions and concerns of patients and other stakeholders
- reconstructing stakeholders interpretive frames and sharing the results among them, may be a means of starting off a social learning process, resulting in more meaningful priorities for research

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