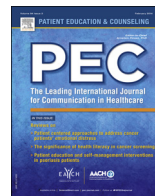




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## Review

# A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work?

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### ABSTRACT

**Objective:** To identify and synthesise evidence for interventions targeting end-of-life communication.  
**Methods:** Database, reference list and author searches were conducted to identify evaluations of end-of-life communication-focussed interventions. Data were extracted, synthesised and QALSYST quality analyses were performed.

**Results:** Forty-five studies met inclusion criteria. Interventions targeted patients ( $n=6$ ), caregivers ( $n=3$ ), healthcare professionals (HCPs  $n=24$ ) and multiple stakeholders ( $n=12$ ). Interventions took various forms including communication skills training, education, advance care planning and structured practice changes. Substantial heterogeneity in study designs, outcomes, settings and measures was apparent and study quality was variable.

**Conclusion:** A substantial number of end-of-life communication interventions have been evaluated. Interventions have particularly targeted HCPs in cancer settings, though patient, caregiver and multi-focal interventions have also been evaluated. While some interventions were efficacious in well-designed RCTs, most evidence was from less robust studies. While additional interventions targeting patients and caregivers are needed, multi-focal interventions may more effectively remove barriers to end-of-life communication.

**Practice Implications:** Despite the limitations evident in the existing literature, healthcare professionals may still derive useful insights into effective approaches to end-of-life communication if appropriate caution is exercised. However, additional RCTs, implementation studies and cost-benefit analyses are required to bolster arguments for implementing and resourcing communication interventions.

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**1. Introduction**

Communication regarding prognosis and end-of-life care and decision-making can be challenging for all stakeholders. Doctors frequently avoid life expectancy discussions [1], often for fear of destroying hope or the therapeutic relationship [2]. Patients' readiness to discuss such issues is variable, and depends on factors such as degree and length of exposure to their disease, having had time to adjust, coping style and spirituality [3]. Consequently doctors and patients may "collude" to avoid these discussions [4]. Communication about end-of-life care often first occurs during acute hospital admissions near death [5], when the patient may be too sick to participate in decisions about their end-of-life care. Research showing that as few as 14% of doctors know patients' preferences regarding pain management or place of death, [6] and that many patients receiving palliative chemotherapy do not understand it is unlikely to cure them [7], suggests such discussions can be too late, or of poor quality.

Caregivers also play a crucial role in end-of-life patient care, typically acting as medical decision surrogates in addition to providing physical and emotional care, yet they often report unmet information needs regarding this role along with patients' prognosis [8]. Patients and caregivers can have somewhat divergent information needs as the patient's illness progresses, with caregivers preferring more information and patients preferring less [9]. However health professionals may be reluctant to provide caregivers with information they do not also provide to the patient, particularly while the patient remains competent [10]. Yet caregivers often need information prior to the patient becoming incompetent in order to prepare them for the patients' death as well as their role as caregivers.

Despite doctors' concerns about discussing prognosis and end-of-life care, evidence suggests that increased information provision on these topics does not increase anxiety [11,12]. Insufficient information may even heighten anxiety by raising patients' suspicions that doctors are withholding potentially frightening information [12,13]. If asked, the majority of patients with incurable cancer say they want prognostic information and to discuss end-of-life care [14,15] and their end-of-life priorities often relate to effective communication [16]. High quality end-of-life communication is also associated with less aggressive patient treatment patterns and better quality-of-life [17–19] and improved caregiver bereavement outcomes [20].

Despite the challenges and potential good outcomes of end-of-life communication, relatively few studies have evaluated interventions designed to improve end-of-life communication. Furthermore, insufficient synthesis of the evidence has occurred to

allow consensus regarding whom to target, how interventions should be conducted, how to best assess efficacy and, overall, whether such interventions work. Previous systematic reviews have explored communication interventions targeted at one stakeholder group only or without a specific focus on the rather unique end-of-life context [21,22]. Others have focussed on end-of-life communication as a whole, without specific attention being given to communication interventions [9].

The aim of this systematic review is therefore to assess and synthesise the available evidence for interventions targeting both end-of-life communication and any or all stakeholders in such communication. The goals of the review were to: (a) summarise the type and structure of interventions explored to date for different stakeholders (b) identify the outcomes and measures used to assess effectiveness; and (c) evaluate the evidence-base for these various interventions.

**2. Methods**

*2.1. Search strategy*

The review was restricted to evaluations of interventions that:

- a) Include primarily end-of-life focussed content or are designed/ relevant for a population for whom end-of-life focussed topics (e.g., end-of-life care, prognosis) are pertinent
- b) Place a primary emphasis on changing an aspect of communication (i.e., utilize a mode of action such as information provision/education to impact upon communication)
- c) Include a communication-related outcome

A search of MEDLINE, PsychINFO, and CINAHL databases was conducted based on the search strategy in Fig. 1, limited to articles published between 1950 and March 2014. Search results were divided between 2 authors (AW and SB) and screened with reference to the inclusion criteria outlined above. Development, feasibility and pilot studies were excluded where no evaluation of the impact of interventions on participant outcomes was conducted.

Uncertainty regarding inclusion/exclusion of articles was resolved through iterative discussion between AW and SB, referencing the inclusion criteria. Reference lists of included articles were examined for relevant articles and author searches were performed for prolific first, second and last authors of identified articles (>2 included articles). Finally, citations of all included articles were examined for additional relevant articles.

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