Brief Report

Goal Communication in Palliative Care Decision-Making Consultations

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Abstract

Context. Palliative care (PC) promotes patient-centered outcomes, but the mechanisms underlying these effects remain poorly understood. Identifying, clarifying, and prioritizing patients' goals are conceptually fundamental to the process of patient-centeredness and are the main reasons for PC referral. However, very little is empirically known about the content or process of goal expression in the natural setting of PC.

Objectives. To describe the frequency, types, and determinants of goal expression in PC consultations.

Methods. This was a cross-sectional direct observational study of 72 audiorecorded PC consultations with hospitalized patients (and families) referred for PC goals of care clarification or end-of-life decision making. We coded digital audio files using reliable methods and linked conversation codes to clinical record and brief clinician interview data.

Results. Goal expressions occurred frequently in PC consultations and addressed both length-of-life and quality-of-life domains. The presence of existential suffering in the conversation was associated with substantially more expressions and types of goals.

Conclusion. Goal communication is common in PC decision-making settings and strongly influenced by existential suffering. J Pain Symptom Manage 2015;50:701−706.

Key Words

Goals, existential, decision making, communication, palliative care

Introduction

Goal: the end toward which effort is directed.[1]

Promoting high-quality communication and goal-driven treatment in serious illness are national priorities.[2,3] Palliative care (PC) consultation is one promising clinical context where this appears to be happening.[4,5] However, we know very little empirically about the content or process of these goals of care conversations.

PC clinicians are often asked to help with shared decision making about medical treatments in contexts where seriously ill patients are experiencing diminishing returns from cure or longevity-directed therapies. Understanding the types of clinical outcomes that matter most to patients is fundamental to this relational decision-making process. This often involves an iterative process of identifying, clarifying, and prioritizing what patients want to achieve during their remaining lifetime to guide contemplation of treatment options. For the purposes of this study, we refer to what patients want to achieve as goals. Communicating about goals, however, can be quite challenging for patients or their families in these clinical situations where suffering, fear, and confusion can be substantial. Very little is empirically known about how patients, families, and PC clinicians communicate about goals and the contextual factors that influence this process. Here, we address these important gaps in the science of patient-centered decision making amid serious illness.[6,7]

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Methods

Overview

We directly observed 71 initial inpatient PC consultations to describe the characteristics and determinants of goal expression in the natural setting. We audiorecorded the consultations, briefly interviewed the PC attending physician, and extracted clinical data from the medical record.

Context, Population, and Eligibility

The study was performed in a 750-bed academic medical center in the northeast U.S. with a mature inpatient PC consultation service completing more than 1000 consultations annually. Eighty-one percent of consultations are requested to assist with goals of care clarification or end-of-life decision making (January 2006—January 2010 aggregate data). Reasons indicated by referring teams for the remaining 19% of consultations were to help exclusively with symptom management and/or family support. All PC attending physicians, PC nurse practitioners, and PC physician fellows were eligible to participate. All English-speaking patients who were at least of 21 years (or surrogates if decisional capacity was impaired) and referred for goals of care clarification or end-of-life decision making were eligible to participate.

Data Sources

Recorded Consultations. With prior informed consent from all study participants, we placed digital recorders in unobtrusive locations in the hospital rooms before the clinicians entered and retrieved them at the end of the visit. If the consultation was delayed or the clinicians stepped out of the room during the consultation, those sections were deleted before analysis. Our digital recording hardware and method yielded high-fidelity recordings that allowed the coder to hear even weak voices amid clinical background noises, such as high-flow oxygen, intravenous pumps, and heart rate/respiratory rate monitors.

Medical Records. We extracted the following from the two-page standardized PC consultation form completed for all new consults: patient age, gender, primary diagnoses, referral reason, Palliative Performance Scale (PPS) score, Edmonton Symptom Assessment System score, current mechanical ventilation, bilevel positive airway pressure (BIPAP), artificial nutrition or hemodialysis, and, if present, any advance directives. For nine participants, the PPS was not completed on the consultation form; however, the medical record provided sufficient information to accurately categorize the PPS into low (≤30), moderate (40−50), and high (≥60) categories. We collected the following from the medical record and hospital administrative data: race, insurance type, hospital admit date, and consult date.

Conversation Coding. We developed a communication evaluation tool based on theoretical and empirical understanding of goals communication in advanced illness.[8,9] A detailed codebook provided specific instructions for coding each topic, with precise definitions and examples of what should and should not be coded. Each uninterrupted speaker turn in the conversation, referred to as a *segment*, was coded for the presence of the predefined communication elements. Coders were rigorously trained on the identification and application of the specific communication skills. Training consisted of 30 hours over a two-week period. This method of coding communication segments has been used in multiple studies of physician-patient communication.[10−16]

Coders identified all occurrences of *goal expression* in each conversation, defined as any segment of conversation in which the patient or family member (defined to include friends) expressed something that they wished for the patient to achieve or experience in the future. We included only expressed goals that were explicit (I'd like to have less pain) and not those that might be implied from a statement of current/past experience (My belly hurts). Similarly, we excluded expressions of outcomes that the speaker explicitly characterized as unobtainable (I wish I could have seen my son graduate from college).

We categorized each goal expression into one of five categories: length of life/cure, symptom control, social roles and functioning (including not wanting to be a burden to others[17]), location to live or die, or other. Other most often represented preparing one's financial, legal, or administrative affairs before dying. For exploratory purposes, we coded goal expressions made by the PC team identically to the process described previously, except spoken by a member of the PC team. We subcoded PC goal expressions into two commonly encountered categories: 1) repetition/clarification of a goal stated or implied by the patient/family and 2) suggestion/example of a potential goal.

We coded four other aspects of conversations that might be associated with patient/family goal expression. Two of these—PC team communication about prognoses and patient/family expressions of distressing emotion—are described fully elsewhere.[18,19] For the third, we identified the number of discrete treatment options being identified by the PC team. Treatment options included medications, surgery, cardiopulmonary resuscitation/mechanical ventilation, other life support (e.g., dialysis, total parenteral nutrition, BIPAP), and other therapies (e.g., oxygen, rehabilitation services). Treatments that were