Original Article

Exploring the Topics Discussed During a Conversation Card Game About Death and Dying: A Content Analysis

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Abstract

   Context. Substantive discussions between loved ones are necessary for effective advance care planning. Although multiple tools are currently in use for promoting conversations, the content and clinical relevance of the conversations they stimulate is unknown.

   Objective. To describe the content and clinical relevance of conversations that occur during a nonfacilitated end-of-life conversation game.

   Methods. Using convenience sampling, we scheduled adult volunteers to participate in an end-of-life conversation game (2−6 individuals per game; $n = 68$). Participants discussed 20 questions about death, dying, or end-of-life issues. Games lasted up to two hours and were audio-recorded, transcribed, and analyzed using a conventional qualitative content analysis approach to identify emerging themes.

   Results. Participants ($n = 68$) were primarily Caucasian (94%), females (68%), with mean age of 51.3 years (SD 0.7). Seventeen games were analyzed. Four primary themes emerged during game conversations: 1) the importance of people, relationships, and the roles played during end-of-life decision making, 2) values, beliefs, and preferences related to end-of-life care and the dying period, 3) considerations about preparing for the aftermath of one's death, and 4) the relevance of stories or experiences for informing one's own end-of-life preferences.

   Conclusions. Topics discussed during a nonfacilitated end-of-life conversation game are substantive and address important issues for advance care planning.   J Pain Symptom Manage 2016;■:■−■. © 2016 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words
Advance directives, communication, medical decision making, end-of-life care, palliative care, terminal care

Introduction

   Advance care planning (ACP) is process that involves discussing end-of-life issues, clarifying values and goals about care, designating a surrogate decision maker, and documenting preferences via advance directives.[1] Although federal regulations and clinical guidelines have long promoted ACP due to its positive impact on patients and families,[2−5] fewer than a third of adults in the U.S. have had end-of-life conversations

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with loved ones.[1,3,6,7] This may be, in part, due to discomfort with discussions about end-of-life issues, societal taboos about death and dying, and avoidance of considering one's own mortality.[8–12] Still, discussing end-of-life issues is a priority for patients and physicians,[13] and interventions that effectively overcome barriers to ACP are needed.

Many tools are available to help individuals start conversations with their families and physicians,[14–16] yet there is little evidence base supporting the efficacy of these tools.[17] In particular, little is known about what individuals actually talk about during the resulting conversations. To address this gap in knowledge, we conducted a qualitative content analysis of a conversation game that engages individuals in end-of-life discussions.

A conversation game was chosen as the intervention because games have been shown to be effective tools for engaging individuals in emotionally sensitive discussions about such topics as cancer, sexual health, post-traumatic stress disorder, and anxiety.[18–22] By design, games are fun and engaging, and hence well suited for promoting desired health behaviors. By creating safe, structured activities for tackling tough issues, games offer a promising approach to overcoming various barriers and/or stigmas associated with discussing death and dying.

We previously demonstrated that a nonfacilitated conversation card game about end-of-life issues, *My Gift of Grace*,[23] stimulated engaging, realistic end-of-life conversations that participants found highly satisfying.[24] Here, we describe the major topics discussed during game sessions and discuss the implications for stimulating substantive discussions about death and dying.

Methods

Intervention

My Gift of Grace is an end-of-life conversation card game consisting of 47 questions that prompt a group of players to consider issues about death and dying and then discuss them with the group.[23] The game is played by taking turns reading the cards aloud, players writing their answers, and then sharing with the group. Players may opt to skip questions if they wish. Players exchange game chips to express gratitude to other players or reward thoughtful responses. The "winner" of the game is determined by a pregame coin flip (whose result is not revealed until the game ends). If heads, the player with the most chips "wins," and if tails, the player with the least chips "wins."

The questions were developed by the game designers from a series of 13 focus groups of over 100 patients and caregivers and in-depth interviews with clinicians. For this study, the research team surveyed another group of clinicians and researchers ($N = 8$) to select and order 20 game questions with consideration to pace, emotional depth, and expected conversation content (Table 1). Games continued until all 20 questions were answered or two hours elapsed.

Data Collection

Using flyers, we recruited a convenience sample of 70 adults living in areas surrounding Hershey, Pennsylvania ($n = 57$; 14 games) and Lexington, Kentucky ($n = 13$; four games). The Institutional Review Boards at both institutions approved all study procedures. Eligibility criteria included the following: 1) English-speaking, 2) >18 years, 3) without hearing impairment, and 4) able to sit and engage in conversation

Table 1
Conversation Game Questions

Question
1) Write down any fears you have about playing this game.
2) Write down any hopes you have about playing this game.
3) If you had 3 months to live, what would you give yourself permission to do? Choose one thing per month.
4) Who have not you talked to in more than six months that you would want to talk to before you died?
5) Name the three person committees who should be consulted on any decisions made about whether to continue life-saving care if you can't communicate. Circle the name and head of the committee.
6) When you think about care at the end of your life, do you worry more about: a) not getting enough care, b) getting overly aggressive care, c) other.
7) In order to provide you with the best care possible, what three nonmedical facts should your doctor know about you?
8) What are the first three words you think of when you hear the word "hospice?"
9) If a nurse asked you whether you were a spiritual person, what would you say?
10) If you could control only one thing about the place you spend your last hours of life, what would it be?
11) Think of the last disagreement your family had. How was it resolved?
12) What is the last meal you want to eat and who would you like to join you?
13) Imagine you were lost at sea and your family had to pay to search to find you. Who should make the decision about how long to find you?
14) What music do you want to be listening to on your last day alive?
15) If you were diagnosed with a terminal disease, who would you turn to for advice?
16) If you needed help going to the bathroom today, who is the first person you would ask to help you? Who would you never ask to help you?
17) I want my doctor to be focused on maximizing the length of my life versus quality of my life versus other.
18) If you could pick anyone to sing at your memorial service, who would it be and what would they sing?
19) What do you fear more: experiencing the worst pain of your life or not getting a chance to say goodbye to family?
20) When was the last time you needed help from someone else? What made accepting help easier for you? What made it more difficult?