

Case Examples



Rather than the often blank response to the question,

"What is most important to you?"

the Conversation Game cards

provide important vocabulary

to give voice to patients' needs and concerns,

and give opportunities to explain and personalize those ideas.

UK

"Whenever we use the Conversation Game within a session on ACP the trainees give positive feedback, often stating that it puts it into context and offers an opportunity for excellent interactive learning."-GP Commissioner

"Years on, I'm still using the tools with patients and families."-Admiral Nurse

"I attended a workshop for Chaplains and had terrific feedback from the use of the cards. Well done."-PHINE Network

It helped our patient who couldn't speak have the conversation... -Acute Trust RN

The following are examples of cases where the card game has been useful, sometimes as expected, sometimes in unexpected ways. In addition to advance care planning for families in the community setting, the card exercise in the acute care setting can impact care planning, expose quality of life issues, and identify activities that are amenable to intervention.

As we gather more case examples from the UK, the following (US) cases were presented in an article in the April 2007 Journal of Palliative Medicine. The content may be of help in considering how you might use the cards as well. With thanks to Coda Alliance for sharing these examples with us.

A surviving family member writes:

"Mike's passing was so peaceful and was, thanks to you, just exactly the way he wanted. I say thanks to you because if you hadn't loaned me the Cards, I would not have known that Mike wanted to be at home, with everyone around him, that he could understand that we cared about him and that he lived a

worthwhile life and that we were touching him. These are all things he picked from the cards. What a lucky man to have the end the way he wished for. People must have thought I was nuts because I kept saying "This is exactly what Mike wanted!"

The ICU intubated patient

The palliative care physician was asked by the ICU attending physician whether she might begin some discussions of end-of-life issues with a 46-year-old man in the unit who had been on a ventilator for six weeks following multiple traumas in an automobile accident. He had a T6 spinal cord injury, multiple fractures, bilateral chest tubes, bullous emphysema, and recurrent pneumonias. The ICU attending doubted that the patient could ever survive off the ventilator, and doubted that he would leave the hospital alive. Nonetheless the patient was usually alert enough to communicate by nods or mouthing words, although he could not write.

The palliative care physician met with the patient and his wife, explaining that in the last couple of months there had been a lot of attention paid to his lungs, bones, kidneys, digestion, infections, and skin, but that she was hoping to help them take inventory on "the rest of what makes him who he is". She showed them the pack of Cards and asked the wife to show him each card and help him do the 3-category sort.

The palliative care physician came back the next day and found that in the "not important" pile were all the cards that had any mention of death. But there were plenty of cards in the very important pile, and the couple was asked to sort through the "very important" cards again for him to pick out the top ten. Later that day they worked on ranking the top ten.

Both the patient and his wife commented that the exercise had brought forth conversations that they had needed to have, but not gotten around to before that. His "wild-card" was to help his teen-age son to cope; the patient noted that his son had been left out of a lot of the prior discussions about what had been going on.

The results of his card-sort were used to identify issues that were amenable to physician/other health care provider intervention and other issues that were important to quality of life more generally. Within the top five were "to be free of pain", "not being short of breath", and "to be free from anxiety." The patient's priority for improved symptom control was communicated back to the ICU attending. The social worker was asked to arrange a family meeting that would include the son. Since preparing for death was clearly not the patient's chosen agenda, that topic was dropped, and in fact he was later successfully weaned from the ventilator and sent to an inpatient rehabilitation program.

Sorting the family's issues

Mrs. K had lung cancer with t-spine metastases, cord compression treated with radiation therapy, and profound hyponatremia due to SIADH. She was delirious, with suspected meningeal carcinomatosis. The series of attending hospitalists had convened multiple family meetings, trying to address the family's innumerable questions on details of her medical care, complications, explanations of her symptoms, medications, test results, etc. The three adult sons and husband all had different approaches to information and different emphases on issues.

Using four packs of cards, the palliative care physician asked the husband and each son to pick out from his deck the cards that he thought would be the patient's top ten if she were doing the sorting herself. The physician then went through each of the four groups of ten cards with the family as a group, laying out the cards and stacking the ones that got more than one "vote". This exercise allowed the group both to

acknowledge the range of their interpretations of her concerns and to direct the focus toward those goals and values that a majority of the family members agreed on as being most important to the patient.

Preserving Hope

Mrs. M was a 69-year-old first generation Hispanic married woman with treatment-resistant acute myelogenous leukemia. Her experience with her illness so far was that each time she had been ill and hospitalized she had recovered and returned home. A devoutly religious Catholic, she stated, "God will heal me." The admitting physician had indicated "full code" on her admission orders.

At the request of the attending physician, the palliative care team suggested convening a family meeting with the couple and their sons, but the sons declined the meeting. The sons explained that the dynamics of the family were such that their father's role was a gender-based traditional cultural role. Their father was reluctant to bring up end-of-life issues for fear of their mother losing hope. The sons felt that their mother had been keeping a strong front as a means of protecting her family. She had a reputation with both friends and family of being a strong, capable woman. At work and in her community, others frequently turned to her for support and advice.

The palliative care social worker introduced the Cards to the patient and spouse with the suggestion that they choose some that were most important to Mrs. M, and to think about whether other important things were missing from the deck. The pack of cards was left in room for the family to use when the patient was feeling like talking. The sons later commented that they were grateful and appreciative that the cards were available to review and discuss as the patient's condition declined. The simple but direct statements on the cards made it possible for them to talk with their mother about her hopes and wishes. She still felt strongly about wanting to have family around and wanting to help others, so they arranged for many extended-family members and friends to visit. Mrs. M gave each visitor blessings and asked them to look after her husband and sons. As the family saw her condition worsening, they felt there was no "unfinished business" and requested that no resuscitation attempts be made at the time of her death.

A different side of Mom

The patient was a 60 year old female physician suffering from breast cancer with metastases to the lungs who had two children, a son age 29 and a daughter 27. The hospice chaplain had convened a family meeting to discuss the patient's wishes since both of the children had been away from home and had now moved back to care for their mother. The chaplain suggested they use the Cards as a segue into the discussion.

When the patient identified the things that were most important to her, her children were amazed. Since she was a doctor and also a scientist, the children said that they thought she would be more clinical about her selections and would pick the cards having to do with the nurse and/or doctor, being mentally aware or not being in pain. They were surprised that she chose cards having to do with emotions like human touch, helping others, keeping a sense of humor, having family near and not being a burden. They said this gave them a look at the emotional side to their mother, and they then felt more comfortable being able to express their own emotions about her dying. They had been afraid to hold her hand or tell her funny stories until the meeting with the cards. It opened up a whole new discussion for them about death and dying and life in general, and at the end of the discussion they all hugged.

Comparing in pairs

One of the physicians who had piloted use of the Cards discovered at a Thanksgiving family reunion that he had been named as alternate agent for his step-mother-in-law in her durable power-of-attorney for

healthcare document, with her own daughter being named as the primary agent. He gave a pack of cards each to the mother and daughter. He asked the mother to pick out what would be her top ten concerns if she were near the end of life, and asked the daughter to pick from her pack the ten concerns she thought her mother might be choosing as the most important. When both of them were finished picking the top ten, they compared cards. The daughter had picked eight out of ten of her mother's top ten. As he watched the mother and daughter in an animated discussion about the mismatching two cards, he felt confident that the daughter was going to be a knowledgeable surrogate for her mother.

The unbefriended: Introducing hospice

A 75 year old man was admitted to custodial care in a skilled nursing facility with a history of malnutrition and failure of self-care, weight loss and anemia. Fifteen months prior he had Stage 2C transmural colonic adenocarcinoma with regional lymph node involvement, and now had multiple hepatic metastases. He had a 4 year history of urinary retention, reportedly attributed to prostatic hypertrophy, but now also had a markedly elevated PSA. He had a history of medical noncompliance with multiple failed outpatient appointments, failure to take medications on an outpatient basis, involvement of adult protective services, and a diagnosis of mild dementia following a CVA 18 months ago. Despite his history, psychiatric evaluation had deemed him to have intact decision-making capacity - at least sufficient to sign himself in for the SNF admission - and determined that he did not need court-appointed conservatorship. "Wants full code" said the prior physician's report, "Code status discussed with patient: full life-sustaining interventions for now. He says "life is precious." "

In answer to the 'tell me what you understand about your illness' question, the patient was able to acknowledge that his life expectancy was in months rather than years. So the nursing facility attending physician introduced the card-sorting exercise, saying, "These are things that other people whose time might be short have said are important to them. I was wondering if any of them are really important to you, or if there are other things not on these cards that are very important to you." The patient had difficulty reading the cards for himself, but listened to each one being read aloud and indicated whether he thought it was important, so-so, or not important. For one who had distinguished himself as a loner, it came as a bit of a surprise that it was very important to him to have medical care givers who know him as a person and whom he could trust. He wanted to have an advocate who would know his wishes and who would help him sort out some financial issues.

Review of the preferences he had expressed in the card exercise revealed opportunities where hospice could help meet several of his expressed needs: He could develop a relationship with a hospice nurse that he could trust, the hospice social worker could help him with getting his financial affairs in order and also help with his funeral planning, and hospice staff would pay attention to his physical comfort. Hospice was introduced as a program that could help him meet these goals, he agreed to the referral, and his goals were incorporated into the hospice plan of care.