Cards as Prompts in Adaptive Serious Illness Conversations

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1 Introduction

Serious illness conversations (SICs) are structured caregiver-patient conversations focusing on the wishes and hopes of the patient. The aim is to support shared decision-making, especially in the area of palliative care and advanced care directives. A major challenge in SICs is to avoid caregiver presumptions in influencing the preferences of the patient, since they may not have thought about the subject prior to the conversation and may need some guidance to reflect. This is especially true in patient groups where symptoms, life expectancy and outcome vary significantly, and which often receive aggressive end-of-life treatments, such as in the case of haematological malignancies.

In this pilot study of SICs we used cards representing things that are potentially important for quality of life as props for patients to visualise and reason about priorities, hopes and fears in the context of their illness and treatment. We report some preliminary results and outline an experimental study to evaluate and develop card assisted SICs.

2 Background

The original Serious Illness Conversation Program (SICP) focused on patients with incurable cancer (life expectancy less than 12 months), and the approach has never been evaluated for patients treated with curative intent. However, haematological malignancies (hm) include chronic but treatable conditions (e.g. myeloma) as well as curable but serious ones (e.g. acute leukemia). Patients are also more likely to receive aggressive end-of-life treatment than patients with solid tumours (Egan et al., 2020). A Swedish study on the palliative care registry showed that patients with hms are more likely to die in emergency hospitals and less likely to receive specialised palliative care (Skåreby et al., 2025). Interventions targeted at facilitating communication regarding patient preferences and improving shared decision-making in this patient population are therefore important.

Myrhøj et al. (2025) show that patients receiving a SIC are less likely to receive aggressive end-of-life treatment, and more likely to be referred to specialized palliative care. Despite this only a minority of patients identified as being eligible for SIC actually receive a documented conversation. Reasons for this might be difficulties in adequately predicting life expectancy and chance of survival in hms as well as a hesitance among physicians to raise the subject of SIC, as it is strongly associated with end-of-life (Baxter et al., 2024). These difficulties are expected to increase with the expansion of new treatments. In palliative care, cards as props in caregiver-patient conversations facilitate end-of-life conversations and help patients to better express their hopes and wishes (Paiva et al., 2024).

Communication in health care is crucial (e.g. Ratna, 2019; Morreale et al., 2023). For example, patients are more likely to take medication effectively if they have been involved in discussions about treatment options, and understand and support the decision about what is prescribed (Drew et al., 2001). In linguistics, care-related interactions have been studied repeatedly. For example, Conversation Analysis (CA) has been used for qualitative analysis in different areas of health care such as shared decision making in doctor-patient interaction (Hartvigsson et al., 2018; Herlitz et al., 2016) and for analysing communication in patients with conditions that affect language such as aphasia (Goodwin et al., 2020) and schizophrenia (Breitholtz et al., 2021). Quantitative studies, also based on transcribed authentic material, have provided important insights for conversations in health-care. For example, Howes et al. (2012) show that the level of *repair* (how interlocutors attempt to address potential misunderstandings in the conversation as they arise) in patient-doctor interaction can predict subsequent adherence to treatment.

3 Pilot study

The conversation model with cards as props has been developed in collaboration with palliative (Paiva et al., 2024) and haematological care givers, with input from patient representatives. The aim is to provide a semi-structured guide for conversation which could be easily adapted to the individual patient – it should be applicable in early phases of the disease as well as in patients undergoing curative treatments. The goal is to get patients to reflect on and communicate their wishes and priorities in care and treatment in different potential phases of illness. The conversation should be applied when the patient has already received all relevant information regarding their diagnosis, treatment and prognosis from the treating physician. For this purpose we developed a deck of 14 cards containing statements representative of possible wishes/priorities of patients, including two empty cards for the patients to be able to express any wishes not present in the deck.

In a pilot study of two patient groups, one consisting of patients with acute lymphatic leukaemia[1] and one in patients with multiple myeloma,[2] 5 patients in each group were invited to participate in a card-prompted conversation, after which they were interviewed regarding their experience of the conversation. The conversations and follow-up interviews were analysed using methods from Grounded Theory (Birks and Mills, 2022). Patients were encouraged to use the cards to reflect and choose the 3-4 cards most relevant to them, and also naming the single most important, if any. The patient was then asked to reflect on two hypothetical scenarios; one where they were certain that they would improve in their disease and, if that were a medical possibility, be cured, and one where they did not respond to treatment and would be facing palliative care. They then went back to the cards to decide whether either scenario would prompt them to change their cards. The conversation ended with a discussion between the patient and caregiver on what had been said and how knowing about prognosis could impact one's priorities.

The pilot study shows that patients appreciated the conversations and felt that they added significant value to the regular conversations they had with health care professionals at the haematology clinic. They expressed that the conversations supported them in identifying, articulating and communicating their needs and wishes. The cards offered both structure and flexibility, facilitating a personalised dialogue. The patients felt that these conversations would be of most value if offered early in the disease trajectory.

Figure 1: Some of the cards used in the card-prompted SICs

4 Future work

We will develop the card assisted SICs by carrying out a series of role-play experiments involving non-patient subjects to investigate the robustness of the terms used on the cards, to be able to pinpoint possible causes of misunderstanding and different interpretations that may affect the SICs. Not involving patients enables us to test how radically different set ups with regard to the number and type of cards used affect the conversations.

We hypothesise that optimising the number of cards and the degree of abstraction of the terms used is important, and will carry out one experiment (a) testing the impact of card specificity on the conversation and one (b) testing the impact of the number of cards. Each of these will include 2x12 conversations, 48 in total. We will compare key dialogue measures between the subject groups within (a) and (b) respectively. We can thus draw conclusions about the effect of the targeted feature on the dialogue. We will also qualitatively analyse the data, especially verbal and non-verbal references to the cards. Based on the pilot study, we also believe that this study will provide further insights regarding statements that are not included in the card deck patients are presented with, as patients in the pilot study tended to point out themes they were missing. This information will feed into the design of patient conversations in the second phase of the proposed project.

[1] Curable with intense chemotherapy, but immediately life-threatening in case of treatment failure

[2] Incurable, chronic malignancy with many available treatment options

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