

End of Study Report

Planning for Future Care with Patients with Advanced Cancer: Examining the feasibility of using the Trajectory Touchpoint Technique for Advance Care Planning.

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Executive Summary

Advance Care Planning can be a hard topic to talk about. The patients, relatives and clinicians that agreed to be part of this study all liked the way the Trajectory Touchpoint Technique helped in the ACP.

- The pictures helped the patients to lead their ACP and to make decisions.
- The pictures easily showed what topics can be spoken about without limiting the discussion in any way.
- The pictures helped the patients to talk about their motivations behind their decisions.
- Clinicians felt that the ACP talks were more focused and deeper with the pictures than without.

It is suggested that the TTT approach should be tried in other healthcare settings. These could be earlier in a patient's diagnosis where talking about and making decisions about the future would help the patient.

Background to the study

Advance Care Planning (ACP) is a process where patients talk with their healthcare team about what may happen as their illness progresses. Close relatives often participate in the talk which can include the support and care the family needs. The decisions made are written in the patient notes and used to guide and inform future care. ACP has shown to help patients and their families to make decisions for the future and to prepare for end of life. ACP helps healthcare teams to understand what a patient wants for themselves.

However, few people with a life limiting illness (such as cancer) have an ACP. Patients and families often find future and end of life care a difficult subject to talk about. Doctors and nurses may not mention ACP because they don't want to upset the patient or their family. Training on how to start difficult conversations may also be part of the reason healthcare teams don't always start ACP conversations.

This study used a new way to try to start ACP conversations. The Trajectory Touchpoint Technique (TTT) uses cartoon pictures printed on paper. The images are simple representations of important topics that many people find it helpful to talk about at end of life or if they have a life limiting illness. The TTT helps people to talk about what they feel comfortable with, and in their own time. These are often the topics they are most worried about or things that may be hard to talk about. Rather than responding to a long list of questions, patients talk about the pictures that have meaning for them. The TTT was first used to understand experiences of Hospice Care. So far the TTT has been used in over 240 detailed interviews.

Research question

Is the Trajectory Touchpoint Technique a feasible intervention to support Advance Care Planning in patients/families with advanced cancer?

Study methods

- **Develop the TTT** - In this study the TTT was tested to find out if it could be used for ACP conversations. A literature review was completed to find out what topics

patients at end of life found it important to talk about. Cartoon pictures were then found that represented those topics.

- **Train the healthcare team** - Once the pictures were chosen, the clinicians were trained on how to use the TTT.
- **Have ACP conversations** - Patients that agreed to participate in the study used the TTT pictures to lead their own ACP conversation with their doctor or nurse.
- **Interviews** - After the ACP talk, the patient and their relative were interviewed to find out how helpful the cartoon pictures were for them. The doctors and nurses were also interviewed 1:1 so they could share what they thought about using the TTT pictures in ACP talks. All interviews were recorded with the consent of the patients, relatives and healthcare team.
- **Analysis** – the interview recordings were transcribed. Thematic analysis was done on the transcriptions to understand the opinions of the patients, the relatives, and the clinicians.

Analysis

Data was collected over 4 weeks in a single acute in-patient palliative care unit. Patients (n=4), relatives (n=2), and clinicians (n=3) took part in the study.

Every participant felt that the pictures were easy to talk about and that the approach helped them in their ACP conversation. Patients and relatives commented that it is a good way to start a conversation: *“Yeah, I think it’s a good starter if they’re not doing it or they don’t know where to start” (Relative)*. *“This is for kids. But I can apply it to myself which is fascinating. Simplicity!” (Patient)*. The clinicians also found the approach a helpful way to start a conversation: *“positive introduction to the conversation. And I think that’s how it should be. It’s sort of what’s important to you and then you move from that into other areas” (Clinician)*.

The pictures were chosen to represent important topics for patients at end of life or with life limiting illnesses. Participants understood the images and chose to talk about the ones they felt were important for them: *“[That image] still strike me... Well, it’s me husband and meself” (Patient)*. The cartoons also helped to soften the conversation without taking away

any importance, as can be seen in the cheery way that participants responded to some of the pictures: “... And I thought, ‘Well that’s me and you’ [Laughs]” (Relative). Other pictures have shown patients that it is okay to talk about what they want, when they are ready to talk about it: “People have also looked at that [image] and said immediately where they want to be when they die... which sometimes is a difficult thing to raise. Particularly when someone’s earlier in their journey or trajectory in terms of cancer” (Clinician).

Clinicians said that the TTT pictures also help staff to understand and to become more comfortable with ACP, as is shown by this comment: “She [junior colleague] actually did say, ‘Oh, it’s not as scary as I thought it was.’ So, yeah, I think it would help these people into ACP conversations really” Clinician.

Findings

- The TTT approach helped patients to start talking about the things they felt comfortable with and that were most important to them.
- The TTT pictures helped relatives to know what was okay to talk about.
- Clinicians found the visual aid helped focus the talk.
- People reacted to the pictures that had meaning for them in an open and honest way.
- Clinicians felt that the ACP with the TTT approach helped to make the talk deeper than those they had done in the past.

Recommendations & Next Steps

We suggest that the findings from this study show that the TTT is a useful way to start difficult conversations, like ACP. New studies in primary and secondary care should be planned for patients in end of life or with life limiting illnesses. These new studies should focus on difficult conversations in different settings.

Deliverables	Status
Submission of a minimum of one scientific study paper to peer reviewed journal (Social Science and Medicine)	One paper is being edited.
Submission of abstracts to national and international academic conferences	Done.
Summary Report (4 Pages) with recommendations for commissioners and future research studies to develop the evidence base for the TTT in ACP.	Done.
Summary articles (1 page) will be submitted to the RLBUTH Newsletter, University of Liverpool News Website; the LCCG Website and popular media.	
Post on Social Media (Twitter/Facebook) will briefly detail study progress and findings, and link to published outputs outlined here.	
A videocast will be hosted on the Palliative Care Institute Website.	