'From My Perspective' - An evaluation of individualized, immersive audio listening experiences for patients within palliative day hospice: a feasibility study

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Introduction

New opportunities for developing diverse creative arts-based interventions in palliative care are emerging, which benefit multiple patient outcomes. Ten people, recruited from day hospice, participated in a creative arts intervention known as "From My Perspective" (FMP). This involved audio-recording life stories with patients, which were then developed into unique and personalised listening experiences (LEs) presented in a physical format known as the "Memory Box" (MB).

Due to COVID-19, one-to-one interviews with participants were conducted remotely, rather than face-to-face during the summer of 2021. For some participants, this intervention helped create a legacy object for family members by combining elements of their voice, narrative, music, and sound design into a tailor-made listening experience. For others, the interview template prompted exploration of key themes and transitions of life, which translated well into the development of the LE and subsequent MB.

Methodology

Upon receipt of ethical and governance approval, 10 participants were recruited from day hospice for this mixed-methods study. Consent and validated measures were completed prior to the initial interview. Equipment was delivered to enhance the quality of the sound / voice recorded during meetings, while the researcher interviewed participants remotely (due to COVID-19 restrictions). A short survey was administered at follow-up, to collect qualitative data, which was analysed using NVIVO.

Each participant's completed LE comprised of their edited audio-recorded interview, combined with music and sound design elements that reflected the participant's story. For example, if a participant shared childhood memories of camping and cooking by the fire, the participant's narration was then combined with night-time / forest ambience, fire crackling sound effects and music.

Recruitment Flow Chart



Outcome Measures

- The primary outcome measure of this feasibility study was to examine if FMP could positively impact on the quality of life and well-being of palliative day hospice patients.
- Validated tools used to measure these results included the McGill Quality of Life Questionnaire (MQoL), an adapted version of the Edmonton Symptom Assessment System (ESAS) and an adapted version of the WHO 5 Well-Being Index.
- The secondary outcome measure was to test the effect that FMP had on family-shared communication / experiences whilst also assessing the effect that the MB delivery method had on the experience of the intervention for participants.



The Memory Box

Listening Experience Extracts

SCAN ME

Results

- All recruited participants were considered palliative with: (1) lung cancer / fibrosis / respiratory disease, (2) stomach cancer, (3) renal cancer, (4) secondary breast cancer or (5) another cancer. Participants were: married (n=3), divorced (n=5), or widowed (n=2). All but one participant had children, and some had grandchildren.
- Based on qualitative data, participants thoroughly enjoyed the intervention which included the interview process and receiving the final product (i.e., both the LE and MB). As a result of this study, it is clear that the interview process was just as important to the intervention as the final product, with most participants indicating their enjoyment of speaking with the researcher, with one highlighting that they found the interview process as therapeutic.
- Each participant felt like the MB added to the project (in comparison to other formats), suggesting the importance that a physical delivery method can have on a project like this.
- 9/10 participants perceived no disadvantages to participating in the project. One participant highlighted that a possible disadvantage could be ''hurting someone unintentionally by leaving them out of a memory''. All participants indicated that they would have liked to receive the questions prior to the interview in order to prepare their answers.
- Initial feedback suggested poor acceptability of the MQoL, ESAS and WHO5. This may have been due to completing them immediately prior to the interview. At this stage we cannot say that this intervention improved the QOL or WB of participants.
- Based on the secondary outcome measures, a common theme throughout the qualitative data was the positive impact that this project had on the communication and shared experiences between the family members of participants. In particular, the ability of participants to physically document aspects of their life for future generations to listen to and to know ''what life was like back then''.

Participant / Family Member Testimonials

Participant #2 *- ''I'm hugely honoured that this experience was given to me. I'd encourage others to consider making their own recording - if that appeals to them''*

Family Member *- ''We are so thankful to have this one last gift from dad, a truly beautiful gesture presented so well and very personal. Thank you Isaac – you nailed it!''*

Participant #3 *- ''The design and workmanship of box are outstanding. Just the right size. The overall idea is brilliant and lovely for me and my family to have and listen to''*

Participant #1 *- ''Can't find words for the project. Isaac has done a fantastic job on the Memory Box. Hopefully my family will have years of enjoyment listening to it''*

Participant #9 *- 'It's just… it's just overwhelming. I just feel so grateful that I can do that. A very worthwhile project. People would pay to get this memory box!''*

Participant #7 *- ''It's a valuable record of aspects of my life which will surely be of great interest to future generations of my family''*

Conclusion

- Evidence suggests acceptability of the FMP intervention within palliative care, in addition to the potential benefits it can have for patients relating to family-shared experiences, legacy and communication whilst also providing patients with the opportunity to capture and share their life-story narratives in a meaningful way.
- Staff recruiting participants saw a positive impact on participants, which needs explored in a randomized controlled trial.
- Having a longer follow-up element to capture the impact of this intervention for family and carers once the participant has died should be included in future iterations of this project.
- We recommend conducting a larger scale, longitudinal study, that captures the family and carer's perspective.

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