

Recording lives: the benefits of an oral history service

Patients at the Sheffield Macmillan Unit for Palliative Care are invited to produce audio recordings of their life histories. **Michelle Winslow, Karen Hitchcock** and **Bill Noble** describe the benefits of this oral history service for patients and professionals alike

At the Sheffield Macmillan Unit for Palliative Care, an 'oral history service' is enabling patients to produce audio recordings of their life histories. The service is supported by charitable funds and run by the Academic Unit of Supportive Care, University of Sheffield (see Box 1).¹

Oral history allows patients to record unique life experiences and offers an opportunity to produce a narrative with greater autonomy than is possible with other methods of qualitative research interviewing. It captures and preserves the voice of the individual. Participants can enjoy recalling personal experience in a whole life context, shaping their identity with a comfortable narrative. At certain moments in their lives, people may feel the need to explore their life story and draw meaning from it. This process of remembering reinforces their sense of identity, at a time when circumstances may have changed their identities out of recognition.² Patients who create a recording to serve as a legacy for their family also enhance their own sense of dignity.³

Key points

- At the Sheffield Macmillan Unit for Palliative Care, an 'oral history service' enables patients to produce audio recordings of their own life histories.
- Hearing a recording of life history enables healthcare professionals to gain a deeper understanding of, and acknowledge, the person beyond their illness.
- Outcomes for patients include raised self-esteem, a sense of worth, attaching meaning to life experiences, the creation of a personal family record, and recognition of their experience.
- There are gains for clinical practice and health research, not least in giving staff a better understanding of the impact of life-threatening disease on patients' identities and lifestyles.

Box 1. The oral history service at the Sheffield Macmillan Unit for Palliative Care: some facts

- The oral history service began in January 2007. It was created by Dr Michelle Winslow, Dr Bill Noble and Alison Reitz (Unit Manager, Sheffield Teaching Hospitals NHS Foundation Trust).
- The oral history team includes a growing number of volunteers, who are trained by Michelle Winslow.
- The service is offered to all patients.
- On average, sessions last an hour. Patients can make a recording in one or in multiple sessions.
- Recordings are not edited, unless a patient specifically requests it.
- So far, 55 oral history recordings have been created.
- Recordings are securely stored on a computer designated solely for oral history. Back-up copies are stored at a separate location.
- With the patient's consent, recordings are available for in-house research.

Consequently, oral history in palliative care is more than an occasional activity or a diversion. Recalling and describing life events brings to light underlying patterns of meaning. The oral history process may assist in concluding 'unfinished business', and patients appreciate interest taken in them as people.⁴ Healthcare professionals who hear recordings can gain a deeper understanding of, and acknowledge, the person beyond their illness.⁵

Cathartic potential

In oral history interviews with palliative care patients, the predominant theme is living rather than dying. People mostly recall identities and events in times prior to illness – before disease irrevocably altered their lives, lifestyles and how they are viewed by others.

There are exceptions, particularly when interviewees have experienced poor healthcare and want to relate stories of its impact. Here, themes might include diagnosis, treatment,



Michael O'Keefe, who recorded his history while at the Sheffield Macmillan Unit for Palliative Care in 2008, with Mavis Broughton and Karl Fieldsend, two volunteers, and Michelle Winslow, Research Fellow (in red)

sufferings and the experience of interacting with the medical world.

Oral history interviews are not a form of therapy, but they are potentially cathartic in offering the patient a non-judgmental environment in which to talk about themselves and their experiences in an unhurried manner, to someone who is genuinely interested.⁶ Developing a life-story narrative can also help to make memories of traumatic life events become more manageable.⁷

Carrying out the interviews

An important part of oral history interviewing is the development of a relationship between the interviewer and the interviewee. An informal rapport creates trust and a more relaxed interview. However, this is problematic in palliative care, as there is often little time to build a relationship before the interview. Patients may be talkative and outgoing when arranging the interview, but they can quickly become tired and withdrawn while they are recording. Thus interviews are mostly arranged and conducted in the space of a few hours.

A CD copy of the oral history recording is given to the interviewee soon after the interview. The recording is their property and

available for research only with their consent. We aim to carry out interviews that follow the narrator's lead, respect their integrity and privacy, and offer them freedom to express thoughts and feelings.⁸ Recordings are created in an informal session during which the interviewee is prompted to recall, and reflect on, life events. Succinct questioning encourages descriptive responses, while reflection on the significance and meaning of events enriches the story.

Issues of meaning, identity, validation of experience and creating a family record become apparent in interviews. In this respect, recordings made with one particular patient stand out. He carved a niche for himself in the 1970s northern music culture as a disc jockey, and his interviews reveal a lifelong endeavour for individuality, discernible as he recalls his unique 'sideline' while working as a construction labourer in the 1960s.

'... the best way to bleach a pair of Levi's, which were the thing to wear, was to soak them in cement dust and water. I used to get big 45-gallon drums, buy my new Levi's and soak them ... not overnight, for weeks, and it used to soak all the colour out. And I would fill it with water and sprinkle various amounts of cement powder in, stir

Holistic care

*it up and just drop in a pair of Levi's, in them days cost about five bob, summat like that. People used to bring me their Levi's to fade 'em ... whenever you pass, jump off the dumper and stir up the old Levi's.*⁹

This reflection from the perspective of another storyteller is apt: 'A small and seemingly unimportant story can, in fact, represent that person's whole life.'¹⁰

The palliative care unit also has an in-house professional photographer, Karen Hitchlock, whose deeply personal images complement the oral histories. She works with patients to create sensitive representations that aim to capture and reinforce their identities.¹¹

Positive outcomes

To date, anecdotal feedback about the oral history service has been positive, as explained here by one patient following an interview:

*'... when I look back, I've had some hard times but I've had some absolutely fantastic times and they will never ever leave me ... Until you do something like this you don't realise just what lovely memories you've got. And it's nice to be able to do this and to share it with my family, if they want to listen to it, and share it with other people as well. You know, it's nice.'*¹²

The oral history service is producing important oral histories with people aware of their incurable medical conditions. The people who relate these life histories have various motivations, but mostly do so with a view to leaving a record for family and friends.

Valuable outcomes for patients include:

- Raised self-esteem
- A sense of worth
- Attaching meaning to life experiences
- The creation of a personal family record
- Recognition and validation of experience.

There are gains for clinical practice and health research, not least in giving staff a better understanding of the impact of life-threatening disease on patients' identities and lifestyles. Volunteers benefit from opportunities to develop skills in oral history collection, including communication and digital recording.

The project team is continually learning and adapting their practice through working in challenging situations. An important benefit of their work is developing an understanding of the potentially broad role of oral history in the palliative care environment – knowledge that is important for the continuation of the service and for future research.

'A small and seemingly unimportant story can, in fact, represent that person's whole life'¹⁰



Sylvia Tagg, who recorded her history during her stay in the palliative care unit in 2008

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