LONGITUDINAL QUALITATIVE RESEARCH DESIGN: EXPERIENCE OVER TIME

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ABSTRACT

In this paper I examine time in qualitative research design. I focus on a study design that is almost absent from the literature, in which qualitative data are collected repeatedly and prospectively from a cohort of individuals over a long period. I will refer to this design as longitudinal qualitative research, and argue that it carries risks and benefits. It heightens the need for ethical clarity, particularly in respect to repeated participation. Unless the aim is to examine a trajectory of experience, longitudinal design may diminish a study's explanatory power by making the sampling less purposive: commitments to long engagement must be honoured, and the participants selected may, over time, become less informative than expected about the issue under study. Conversely, longitudinal design benefits from the development of a history between the researchers and participants, offers unique access to the actions of, and interactions with, time in the experience under study, and helps to guard against epistemological naiveté on the part of the researcher. Qualitative research is often blind to time, and I conclude that the greatest contribution of longitudinal qualitative research may be its sensitisation of researchers to the importance of time in social life.

LONGITUDINAL QUALITATIVE RESEARCH DESIGN: EXPERIENCE OVER TIME

In this paper I discuss the significance of time in qualitative research. I examine a qualitative study design rarely seen in the literature (Neale & Flowerdew, 2003; Thomson & Holland, 2003) to which time is intrinsic. This design, which I refer to as longitudinal qualitative research, involves repeated, prospective interviews with a cohort of individuals over several years. I argue that this design has strengths and weaknesses, based on my recent experience in a study of this kind.

Such a design inevitably engages with time. It is interesting how often qualitative research does not explicitly grapple with time, given that time is intrinsic to our social worlds and to the meanings we make about ourselves and others. Our talk is full of time, but it can become assumed, unnoticed, as fundamental as language itself. Even the word is slippery. It refers to many things, so most dictionaries provide long lists of definitions of time (for example, Wiktionary contributors, 2006). The word, time, sometimes represents things you can count. I can, for example, enumerate current clock *time* – it is now 11.06 AM. I can calculate the amount of *time* before the moderator tells me to stop talking. I can count how many *times* this year I have published in a journal with an impact factor higher than two (sadly I can do this on one hand). However the word *time* also represents things you cannot count. *Time* passes (in a linear or a non-linear fashion, depending on discipline and theory). This conference, for example, was once in my future, is now very much in my present and will soon be in my past. *Time* can be a resource – I had plenty of *time* to write this paper but I finished it at the last minute. Or *time* can be a significant moment or occasion – I think it is *time* to move on to the next point.

There is a long tradition of studying time in some disciplines. The philosophy of space and time examines the ontology, epistemology and character of time. These philosophers ask, for example, how and in what direction time moves, and examine the interweavings of time with space (for example Seddon, 1987). Experimental psychology examines perceptions of time duration, variability of judgements about time, and models of human timing (Grondin, 2001). History is implicitly and

sometimes explicitly about time and historiographers are divided about what time means and how time works in history (see for example Zammito, 2004).

Sociologists who write about time usually argue that sociologists do not write enough about time (Baert, 1992), and also that important temporal theories of particular sociologists such as Mead (Flaherty & Fine, 2001), Schütz (Muzzetto, 2006), or Simmel (Scaff, 2005) have been ignored. There are also notable sociologists who constructed their empirical work around temporal concepts: Glaser and especially Strauss' development of the trajectory model of death and illness is a good example (Glaser & Strauss, 1968).

Time and longitudinal qualitative research

I began thinking about time in qualitative research this year, when I joined the Centre for Values, Ethics and the Law in Medicine here at the University of Sydney as a postdoctoral fellow. VELiM has a strong commitment to narrative methodologies, which are based on a belief in the unique epistemic value of stories (Lieblich, Tuval-Mashiach, & Zilber, 1998). Narrative interviews have another, less well-recognised characteristic: they force the analyst to wrestle with time.

Narratives contain all kinds of time because time is inherent in social life and narratives reconstruct social life for an audience. But time is also *structurally* significant in narrative. Moments in time are the pegs on which a narrative hangs. Time is the context for episodes and events. One study I am working in at VELiM focuses on the experience of autologous stem-cell transplantation, a profoundly arduous medical procedure used to treat recurrent haematological cancers. The narrative data in this study are full of time: so much so that "living in time" has become a core analytic category. Participants talk about remembering and forgetting. They make sense of their experiences in relation to their own past experience (their autobiographical narratives), which frequently includes stories of their ancestors. They negotiate between hope and caution about the future. They imagine their future selves and look forward to imagined futures. They talk about time itself: about buying

time and making up for lost time, about the episodic and cyclical nature of time in their illness, about time speeding up and slowing down, about important clinical moments in time, about wanting to turn back time. They also talk about resisting or achieving change, which is inextricable from time. They talk about recovering, about getting their lives back, sometimes about their entire perspective on life being transformed. Related to this they sometimes declare their illness finished, and other times say that it will never end, that self-regulation, vigilance and anxiety, or alternatively enthusiasm, hope and a new sense of what is really important, are lasting legacies.

So this study confronts time by virtue of being based on narrative data. It also confronts time in a less usual way: through long, repeated engagement with individual participants. The study is based on approximately 70 long interviews collected by colleagues at VELiM. The participants are ten people undergoing transplantation, and the carers of nine of those people. Each has met with an interviewer up to six times, many remaining involved throughout two years of diagnoses, treatments, wellnesses, recurrences of illness, and bereavements, telling their stories and answering specific questions in each interview.

Narrative studies commonly collect long, retrospective stories from individuals. In life history or testimonio studies, for example, interviews can go on for hours or days and written stories for hundreds of pages (Beverley, 2000). The narratives themselves may traverse lifetimes. But the act of data *collection* is usually compressed into a short period: one, or perhaps two occasions. Of course the exception is qualitative research based on observation in place - such as the various ethnographies (Carspecken, 1996; Hammersley & Atkinson, 1995; McCall, 2000) - which are characterised by long engagement. However, in ethnography, the focus is generally on culture or structure rather than on individuals, and *time* is usually that invested by the *researcher*, for the purposes of *deeper immersion or understanding* of the culture under study. This is very different from asking specific questions about the actions of time on individual human experience.

Prospective qualitative study designs that return to individual participants repeatedly over years are rare (Neale & Flowerdew, 2003; Thomson & Holland, 2003). A 2003 special edition of the International Journal of Social Research Methodology, for example, focused on this design, calling it "promising" and "new", but noted the lack of a relevant literature to inform its implementation (Thomson, Plumridge, & Holland, 2003). Even its name seems uncertain. I remember a colleague earnestly counselling me not to call such a design *longitudinal*, because I was not measuring the same variables at each data collection as one would in a quantitative longitudinal study. Today, for efficiency's sake, I will use the l word, but I should note that the only book I have found entitled "longitudinal qualitative research" reinforced my colleague's point (Saldana, 2003). Its author advocates an almost quantitative tabulation of presence, absence or change in relevant phenomena based on repeated observation. Such a design is not without value. However, when it is handled this way, time becomes less about *time* and more about the operationalisation of other independent variables - ageing for example, or exposure to risks, experiences or interventions. A certain epistemic position is also inferred: change over time is simply observed by the researcher rather than constructed by the participant in cooperation with the researcher. I think longitudinal qualitative design has more to offer than this.

Strengths and weaknesses of "longitudinal" qualitative study design

Our experience in the VELiM study of autologous stem cell transplantation suggests important advantages and disadvantages of long qualitative engagement with individuals.

I will start with risks and weaknesses. While some participants expressed appreciation for the researcher's presence throughout their illness experience, others withdrew from the study, dissociating themselves from the suffering they had shared with their interviewer. This highlights the most important risk in longitudinal design: the heightened need for ethical clarity, particularly when interviews revisit past ordeals. We need to ensure that long engagement is not damaging, and

that a protracted relationship with an interviewer does not create a sense of obligation to participate.

The primary weakness of this design, I think, is a potential loss of explanatory power. Qualitative sampling should be purposive. As qualitative researchers we are drawn to theorising because explanation and ideas potentially increase the potency and transferability of our work. If the primary object of a study is to examine the trajectory of a particular experience, a longitudinal design can be useful, even vital, allowing a detailed examination of the experience *over time*. However, if the aim is to theorise a particular element of an experience (for example, decision-making in cancer care, or hope in breast cancer) a longitudinal design may greatly *decrease* explanatory power. Commitments to follow participants through for a certain period must be honoured, and the participants selected at the outset may not turn out to be the best people to explicate decision-making or hope, respectively. Of course it is usual for research questions to move into unexpected territory during a qualitative study. However a longitudinal design is likely to move a study towards description and away from the ability to theorise about *anything other than time*.

Now to the strengths of this design. The epistemic significance of the *history* developed between the investigator and the participant is one important contribution of a longitudinal qualitative design. As interviews progressed in the VELiM study, participants were able to digest previously-discussed incidents, as knowledge could be assumed. Past interviews were triggers for memory, and for some participants the shared attention inherent in the interview process seemed to help construct a memory of the experience. The development of trust sometimes enabled greater disclosure.

Long engagement also offers unique access to the actions of time on an experience. This comes partly through observation of changes in talk between interviews. Henry, for example, said in a pre-transplant interview that his wife Grace had wanted to refuse treatment, but after a discussion

with himself and the medical staff "she decided to go ahead." Tragically, after her death, he re-tells this same story, in distress, and concludes "I virtually talked her into it". Henry did not note or evaluate his re-construction of his wife's autonomy, and having both interviews is the only way we could have accessed this transformation. In contrast, repeated interviews enabled some participants to make explicit comparisons and evaluations across time themselves. To give just one example, Abby states, in her third interview:

> I didn't talk so much this time did I? [...] the further you go on, the less, you know, there is to talk about, 'cause you're getting over it you know, and you do, you know, you start to forget it, you know it becomes your past, not your present so, yeah and at the moment I, I feel like, like I said earlier, I feel like it was <u>ages</u> ago and it wasn't <u>really</u>, but it <u>feels</u> that way.

The familiarity and history that evolved between researcher and participant provided greater space for evaluative talk. Participants like Abby openly re-assessed events and responses in relation to previously-held positions and made comparisons between interviews. Longitudinal qualitative research thus clarifies participants' active reconstructions of themselves over time. In fact my colleagues originally designed the study as a way in to the genesis and fluctuations in liminality in constructions of the self in cancer survival. This evident reconstruction also assists me to guard against epistemological naiveté in analysis. In qualitative research based on single "snapshot" interviews, it is dangerously easy for analysts to accidentally slip into the presumption that we are accessing a participant's stable or "true" self. In longitudinal design, constant reconstructions are so evident that this becomes less likely.

Questions to consider in longitudinal qualitative research design

When should a researcher consider or reject a longitudinal qualitative study design? And what special concerns should be reflected in the planning of such a study?

Beginning with logistics, there are certainly resource implications to consider. Long engagement requires continuity of funding. If participants move locality they will need to be traced and travel may be required to interview them. Harnessing the benefit of long engagement between the participant and the interviewer requires a long commitment from and job security for researchers.

Ethical considerations beyond the usual requirements may also be necessary. For example, we have sent out letters, a week or two before contacting for re-interview, that emphasise non-obligation, invite the participant to consider whether they wish to continue, and provide unambiguous permission to decline. This is intended to ensure that participants do not feel pressured to make a decision on-the-spot. Researchers may need additional emotional support to cope with repeated interviews, particularly if the experience under study involves suffering.

There are also epistemological issues to consider. It seems to me that at least some of the data in a longitudinal study should be in narrative form. Narratives, as I have argued, are thick with time. Narrative data better enables us to see participants' active engagement with the complexities of time, and dissuades us from seeing time as the operationalisation of independent variables. In addition, to work in a longitudinal qualitative study you need to be personally able to cope with the built-in epistemological insecurity of repeated interviews, and the reconstruction of the self that goes on in them. Interpretive certainty, and completion of data collection, can be difficult to achieve.

Perhaps the most important consideration is the aim of the study. As I have argued, a longitudinal design illuminates trajectories of experience and human interactions with time, but may diminish the ability to theorise about other elements of experience. Time must be fundamental to the study objectives to justify the use of a longitudinal design. Longitudinal studies can create mountains of data, and we must ensure that the majority of this data serves a focused analytic purpose.

Qualitative research is often blind to time, despite its inescapable presence in social life. Designing qualitative studies longitudinally has advantages and disadvantages, but provides unique access to the meanings of time in experience. The greatest contribution of this design may be its sensitisation of researchers to the importance of time, encouraging us to see time where it exists, which is everywhere.

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