Collecting Illness Narrative

Interviews, ethnographies, visual methodologies and autoethnographies have been widely used in social and clinical sciences to collect illness narratives from patients, care givers, and healthcare professionals. This entry provides an overview of theories and methods relevant to collecting illness narratives with a particular focus on chronic conditions. It also discusses sensitivities and controversies associated with narrative enquiry.

What Is an Illness Narrative?

An illness narrative consists of oral or written accounts of an illness experience that are elicited and collected during fieldwork, an interview, a workshop, or a naturally occurring conversation. In any of these situations, a narrative may be (a) a short story about a therapeutic event and specific characters such as an encounter between a patients, doctors, nurses or care givers; (b) an extended story about a significant aspect of one's life such as an illness, a trauma, recovery, or bereavement; or (c) a narrative of one's entire life from birth to present, – whichat is often referred to as a life history. Illness narratives are rarely simple or linear, they are polysemic and multivocal— – that is, they consist of (and conceal) many different stories and interpretations of events (Kleinman, 1988). It is a form of qualitative enquiry that encompasses a very broad range of data collection methods and analysis that have been employed very differently in different research traditions.

Historically, illness narratives were collected and recounted by traditional medical practitioners, folklorists, historians, and novelists. They were considered to be 'unscientific' accounts. In their contemporary form, patient stories, have been increasingly being viewed as relevant and complementary to the biomedical model of understanding illness. 'Narrative medicine' advocates urged doctors to pay more attention to the patients' narratives during the therapeutic encounter (Charon, 2006). This movement established the experiential corpus of patient knowledge as an entity deserving of attention and study. Illness narratives within this tradition provided a bridge between the uniqueness of the individual experience and the physicality of the body.

Collecting and analysing narratives of illness has been a core research activity in medical sociology and anthropology, and more recently in healthcare organisational research. Social scientists are interested in illness narratives for different reasons. They are not interested in the therapeutic event per se but on personal experiences of events and the social context which that shapes their experience. This is a complex task because there rarely is a direct correlation between an illness event and an illness experience. Narratives help us untangle this complexity as they provide deep insights into the way that different individuals experience and interpret illness. However, despite their subjectiveness, these narratives are socially constructed. Narratives exist in the intersection of biography, healthcare, and society. One story tells us as much about the healthcare system and the society as it does about the individual (Riessman, 1993).

The term 'patient stories' is often used interchangeably with 'narratives'. This reduces the narrative to a descriptive entity. The narrative is found within and extracted from the story through the process of analysis. The narratives—: the meaning and structure of the story—, are linked to the identities, biographies, and aspirations of the research participants and the societies in which they live in. These narratives are often in juxtaposition to illness experiences measured using a biomedical framework. The 'lived experience' with all its complexities offers an alternative voice to that of the biomedical account. Narratives have the potential to complement the biomedical enquiry by contributing to a

patient-centred agenda, challenging received wisdom, and generating new hypotheses (Hurwitz, Greenhalgh, & Skultans, 2004).

The Particularities of Chronic Condition Narratives

Narratives of chronic conditions started gaining prominence in sociological research as they addressed complex processes of identity disruption, recovery, and self-management. The sociological analysis of illness narratives recognises subjectivity in adaptation to chronic illness, the way disease is perceived, enacted, and responded to by self and others (Riessman, 1993). Chronic conditions feature heavily in narrative enquiry due to the profound biographical disruption that they cause because of the length of their duration. Chronic conditions are those conditions persisting over three months and those which that, in most cases, cannot be cured, only controlled, and are often life-long and limiting in terms of quality of life. They include: diabetes, chronic obstructive pulmonary disease (COPD), asthma, arthritis, epilepsy, coronary heart disease, and stroke. Cancer and dementia are also considered chronic conditions. Chronic conditions can potentially change the individual irreversibly. Chronic illness challenges the view of life being ordinary and controllable.

Methods

Collecting illness narratives involves the documentation of the personal meanings patients, care givers, family members, and healthcare professionals attribute to illness episodes and their often irreversible impact on their lives. This requires skill and judgement across the entire data collection process: initiating engagement, starting data collection, dealing with unpleasant news, ending engagement, and following -up if necessary. Illness narratives can be collected using a wide range of qualitative research methods. The following subsections provides a 'how-to' guide and some methodological considerations in narrative enquiry.

Prior to Data Collection

The informal nature by which illness narratives can be elicited, particularly in a naturalistic enquiry such as an ethnography or participatory action research, may blur the boundaries between formally informing participants that they are taking part in research and 'having a chat'. Illness narratives should always be collected by adhering to the research protocol as approved by the relevant ethics research committee. This involves providing all engaged participants with a participant information sheet and a consent form. The researcher should provide the participants with ample time to read through the participant information sheet and answer any questions. Attitudes towards the compensation of research participants vary from no compensation to shopping vouchers or financial renumeration. Participants often refuse payment, as they view research participation as key to making sense of their illness experience and giving something back.

Interviews

Interviewing is the most salient method in narrative enquiry. Narrative interviews are based on the premise that humans organise experiences as stories and their function is to elicit this story. They can take place as a one-onto-one interview, joint interview with other participants, or as a focus group where group experiences are elicited. The interviewer guides the conversation with the aim to develop a coherent story line. The narrative approach uses attentive listening and provides space for key events, counter-narratives, and contradictions to emerge. It is important to also keep contextual data

for each interview such as silences, sighs, body language, and changes in or lack of eye contact. Notes on informal communication before and after the formal data collection process can provide useful cues in framing the data during the analysis.

Narrative researchers need to create an atmosphere that creates positive reciprocal interaction. Also,It is key important is to that researchers participants engage with their researcher's positionality and arebe able to be reflective about the way that their own personal and professional experiences influenceing the research process. Tom Wengraf has highlighted the need to maintain the principles of conceptual openness (there are no prior hypotheses to be 'tested') and communication (some of the rules of every day communication are followed, but moderated by a concept of 'active listening') when interviewing. He advises against paraphrasing, consoling, giving advice, interpreting, and intruding by sharing personal experiences. Instead he encourages interviewers to ask more open-ended questions to generate more insights and to be prepared to mirror emotions instead of trying to rescue someone who might be distressed. The interviewer can support and encourage the interviewee by paying attention to their his or her listening posture, eye contact, non-verbal sounds, and by allowing lengthy pauses. Wengraf He advises spending one hour after the interview writing debriefing notes, as this will provide the account of the narrative with valuable information on the interaction and the first impressions (Wengraf, 2001).

Historically, interviewing was used as a method on its own with a small number of interviewees. Michael Bury's seminal paper on biographical disruption is based on semi-structured one-onto-one interviews with 30 patients with rheumatoid arthritis in an outpatient clinic in the north-west of England. Participants were purposively selected to concentrate on those with an emerging illness at the earliest possible point in order to explore the problems of recognition and changes in life situation as well as new relationships occasioned by the development of the illness (Bury, 1982).

Later on, larger interview projects emergeding harnessing digital tools for online curation and dissemination. Since 2001, the Health Experiences Research group at the University of Oxford and the DiPex charity have been collecting and video-recording illness experiences. By 2018, the healthtalk.org website contained 25,000 clips of illness narratives on 85 conditions. The narratives are collected and analysed using a rigorous and standardised process of thematic analysis and the website has received the Department of Health's information standard, which means that the website can be recommended to healthcare professionals and patients as a credible source of information (Herxheimer & Ziebland, 2004).

Interviews can be conducted face-to-face, over the phone, or via teleconferencing software such as Skype. Filmed interviews can be posted online after participants have signed an informed consent form agreeing to their public release.

Ethnographic Data in Hospital-Based Research

Interviewing is also present in ethnographic data coupled with fieldnotes of observations and informal discussions. Illness narratives are collected often in situ and are embedded within a process of prolonged immersion. Katie Featherstone and colleagues (2018) recorded narratives of hospitalisation experiences by people living with dementia and their care givers. They conducted 436 in-situ interviews within 684 hours of observations in 10 wards within 5 sites. They used excerpts from interviews and observations to illustrate key points within the themes of resistance to care and organisation (Featherstone, Northcott, & Bridges, 2018). Illness narratives may also feature be used in evaluative studies of quality improvement initiatives. The collection of illness narratives there has a direct applied value in informing the redesign of healthcare service provision. Sofia Vougioukalou and

colleagues collected narratives of hospitalisation experiences by lung cancer and intensive care unit patients in order to understand how do clinical pathways make use of illness narratives to redesign services. They used 29 one-onto-one interviews, 2 group interviews, and 155 hours of observations in four clinical pathways within two sites. They found that using ethnographic approaches within an evaluative framework poses some tension regarding time spent 'in the field' and proposed different ways that illness narratives can be elicited within restricted timeframes (Vougioukalou, Boaz, Gager, & Locock, 20198). In these two studies, illness narratives were collected within hospital environments and about hospital environments. In this type of hospital ethnographyies, illness narratives consist of meaning- –making processes about hospital experiences.

Arts Workshops and Visual Methodologies

Visual methodologies have been also widely used in community-based health research to collect illness narratives around health and illness, embodiment, and difficult experiences. Arts-based qualitative health research is often focused on enabling aspects of health experience to be heard which that might otherwise be silenced. Engagement with music, visual arts, movement-based creative expression, and creative writing can help people express experiences that are too difficult to put into words. This new take on narrative research frees the informant from word-based disclosure and creates new avenues for expression.

Jen Tarr and colleagues used arts workshops to elicit narratives of chronic pain and explore alternative ways of communicating about pain. They held four workshops over a period of two months which that were attended by 22 participants. Professional artists were hired to run the workshops. Stories of pain conditions were elicited, but in relation to the workshop activities and in dialogue around the production of drawings rather than as individual narratives. The term spontaneous element in the disclosure of narratives is referred to as 'imprography', a combination of improvisation and ethnography (Tarr, Gonzalez-Polledo, & Cornish, 2018).

Not all creative enquiries need to be conducted in a group. Dawn Mannay and colleagues have used 'sand-boxing' to provide an opportunity for participants to create three-dimensional scenes in sand-trays, employing miniature figures and everyday objects. They have used this technique on a one-onto-one basis with 9 mature students in higher education and 39 children in state care. Data production was followed by elicitation interviews to acknowledge the polysemic nature of the sandscenes—the arrangement of the props within the sandbox. All the visual data were polysemic because of the ambiguous and multiple meanings that could be generated. They found that this method engaged participants in an affective level and in-depth discussions took place around the multiple meanings that participants attributed to the features of their creative outputs (Mannay et al., 2017). These two examples highlight the different ways that visual methodologies can be used in narrative enquiry on a one-onto-one basis or as a group.

Autoethnography

The role of the researcher in the research process has been previously discussed. An increasingly popular method in narrative enquiry is that of autoethnography, where in which the researcher's own experiences become the focus of attention. More specifically, autoethnography is an approach to research and writing that seeks to describe and systematically analyse personal experience in order to understand cultural experience. This approach challenges canonical ways of doing research and representing others, as the focus is turned to oneself (Ellis, Adams, & Bochner, 2011). The narrative in an autoethnography is a personal one that is informed by the research training that the author has undertaken. In this context, narratives, become a tool for emancipation and social justice. Havi Carel,

a philosopher, uses her own experiences of lung cancer to address shortcomings in the communication skills of the medical profession, the epistemic injustice experiences by patients when their lived experience is disregarded, and bi-directional orientation processes that patients face towards a changing world and a changing self (Carel, 201608) .

After Data Collection

Once the collection of the illness narratives is over, a wide range of data has been assembled from the researcher participant and the researcher. It is considered good practice for the researcher to inform the research participants on about the next steps of the research engagement process. Examples include discussing establishing contact at a later date, sharing with participants interview summaries or whole transcripts, consulting participants on emerging themes, inviting participants to an end-of-project celebration event, and informing them of publications. Follow-up strategies vary and researchers have different strategies and preferred methods of communication.

Power Dynamics

The process of collecting illness narratives is not free from bias and power imbalances. Gender, age, class, educational and professional attainment of participants, and researchers shapes the data collection process. Mike Oliver, an academic and disability activist, challenged the social relations of research production whereby the employed, knowledge-enfranchised, healthy individuals conduct research on the poor, the diseased, and the disabled 'others' without offering any assurances of how the research will positively impact on their lives and when (Oliver, 1992).

At the same time, engaging with other people's illness narratives is emotionally involving and taxing work that, when coupled with precarity and higher education funding cuts, can have unprecedented effects on the researchers' mental health. The emotional disclosure that has taken place during a narrative interview might be consequently distressing for the participant. Social scientists are not always trained in providing psychosocial support to distressed research participants. In mental health nursing, communication skills training provides a range of verbal (listening, paraphrasing, summarising, questioning) and non-verbal skills (seating position, attentiveness to body language, silence, touch) to aid communication with patients, improve rapport, and mitigate distress. Even though social scientists are not expected to provide a therapeutic encounter, and should indeed avoid to doing so, they need to have identified useful tools to deal with distressed interview participants.

There are also additional sensitivities in cross-cultural communication, age differentials, and norms. Establishing rapport and managing the emotional labour involved in enquiry requires skill and experience. Appropriate debriefing and supervision sessions could be organised, to provide the researcher with the support mechanisms required to cope with the emotion work required in narrative enquiry.

Critiques of Narrative Inquiry

Arthur Kleinman, a psychiatrist, proposed a more nuanced engagement with narratives to bridge the gap between the patient and doctor during the therapeutic encounter. He argued that patients use narratives to make sense of their illness and want to share those with significant others in their lives, therefore the sharing becomes an inherent part of the meaning-making (Kleinman, 1988). Bearing witness to the suffering of others builds community and this contract between the interviewer and

the interviewee is considered by some to be unique to this form of research enquiry (Frank, 2010). However, Paul Atkinson and Sara Delamont argue that the meaning people ascribe to suffering and how it is communicated is culturally constructed and limited by the research process. They argue that narrative analyses should be systematic and that assumptions about meaning should be examined. They consider uncritical acceptance a problem in narrative enquiry because narrative research requires scholarly analysis and evaluation. They offer a word of caution in treating an open-ended interview as the pathway to someone's soul, as it an interview is a situationally constrained interaction that should lead to the production of ideas through the appraisal of evidence. (Atkinson & Delamont, 2006). In response, Arthur Frank has defended the position that illness narratives are distinctive and enjoy an exceptional place in human lives. He considers narratives as unique stories that need to be told and not just data to be analysed. He argues that the analysis of narratives should be grounded in their appreciation and finding commonalities between narratives (Frank, 2010).

Conclusion and Areas of Future Research

Narratives are subjective accounts of embodied knowledge, an experience not often shared between the researcher and the interviewee. Collecting illness narratives in a professional research capacity requires knowledge, skill, compassion, and attentiveness. Illness narratives are predominantly collected through interviews. They can also be collected through focus groups, ethnographies, participatory action research, visual methods, and autoethnographies. The relationship between the storyteller and the listener is key in collecting illness narratives. During the process of collecting illness narratives a transformation takes place from the lived experience into the interpreted. The process of 'narrativisation' therefore acts as a reflexive, therapeutic, and transformative mechanism for people who have experienced illness. Not all aspects of impeded quality of life or psychosocial adaptation will be revealed to the researcher. Researchers need to be mindful of variation in language use, values, and patterns of socialisation between the generations. Preparation for interviewing should include dealing with bad news, handling distressing topics, and signposting for psychosocial support for all interview participants, including the researcher. The emotional labour required to undertake the enquiry may adversely affect the mental health of the researcher. Whether collecting illness narratives is a special kind of enquiry or qualitative health research as usual is the subject of an ongoing debate.

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