

This is an Accepted Manuscript of an article published by Taylor & Francis in Disability and Rehabilitation on 23/03/2020, available online:

<https://www.tandfonline.com/doi/abs/10.1080/09638288.2020.1741695?journalCode=idre20>

Ethnographic Research in Healthcare – Patients & Service Users as Participants.

Dr Ruth M Strudwick.

Abstract.

Purpose - This discussion paper provides an introduction and overview of Ethnography as a qualitative research methodology and outlines its usefulness in understanding the experiences of patients and service users during their healthcare journey. Ethnographic research provides an insight into the group being studied. In this paper that author suggests that ethnography can provide an insight into the behaviours, thoughts and feelings of a patient group.

Methods - Research methods used in ethnographic research have been outlined and discussed along with some of the possible methodological and ethical issues that might occur when carrying out an ethnographic study with a group of patients.

Results – This paper discusses some of the potential results of an ethnographic study with patients and how ethnographic research can be used to study the experiences of patients.

Conclusion – the author draws together some lessons that can be learnt and some possible applications of ethnographic research in healthcare settings with patients. Implications for rehabilitation are also proposed.

Introduction.

Ethnography is generally a qualitative research methodology, it studies social interactions, behaviours and perceptions that occur within groups, teams, organisations and communities [1]. Ethnography has roots in British social anthropology where researchers went out to study foreign cultures and in American Sociology (from the Chicago school) which used observation to explore groups on the margins of urban industrial society. The task of these two groups of researchers was the same, to provide a cultural description of the groups that they studied [2]. Since then ethnography as a methodology has grown and developed, moving into other spheres such as education, management studies, health and social care.

Ethnography remains as relevant to contemporary research as it did to historical anthropology [3].

In many respects, ethnography is really the most basic form of social research; it bears a resemblance to the ways in which we make sense of the world around us [4]. The aim of an ethnographic study is to provide a holistic and rich insight into the behaviours, actions and viewpoints of a group, along with the place that they inhabit or are located.

Ethnographic research is slowly gaining traction within healthcare, and there have been several studies carried out by researchers into their own professional group. For example; in their seminal study, Becker et al. [5] studies trainee doctors as they became immersed in the medical profession in the 1960s. Other authors such as Annandale et al. [6] and Batch and Windsor [7] have studied professional nursing cultures. There are also studies from Wolf [8], Goransson [9] and Cudmore and Sondermeyer [10]. All these studies look at the professional culture. Goodson and Vassar [11] argue that the complexity of healthcare lends itself to ethnographic research.

Ethnography studies the culture of a group of people, the group being studied need to have a common enterprise or share a common experience. For example, a social group such as a club, society or sports team, an occupational group who work together, or a group of people who have had the same experience. This could be a group of patients or service users who have the same medical condition or who are using the same services or receiving the same treatment. The study of the group is carried out in its natural setting [12, 13].

This paper focusses on studying groups of particular patients or service users. The term patient refers to people who are unwell and receiving medical treatment. The term service user refers to people using health or social care services. However, a service user may not be unwell, for example pregnant women or people attending a healthcare screening

programme are service users but they are not patients. Both terms will be used in this paper.

The researcher becomes a part of the group being studied and so the primary method of data collection in traditional ethnographic studies is observation. The researcher needs to gain access to the culture in order to gain understanding and insight about what it means to be part of the group. The researcher needs to watch what happens and listen to what is said [14]. The researcher observes the actions and behaviours of the group and its participants. During the observation informal conversations and interviews occur with the participants whilst they are in their natural setting. This allows the researcher to discuss and probe about events that occur whilst they are happening [1]. The nub of ethnographic research is spending a period of time with the group being studied and the participants in order to get to know them better and to understand the way that they behave and think. More recent and emerging ethnographic studies use other methods to engage with the group being studied for example; online and virtual groups [15].

It is generally thought that the period of observation should be carried out over a reasonable period to reduce the impact of the researcher's presence on the culture being studied.

Wolcott [16] states that "people can sustain an act or maintain their best image only so long" [p49]. The researcher's presence may alter behaviour for a short time, but this will only last a short while before 'normal' behaviour re-emerges [17]. Observation of the group enables the researcher to gain a good understanding of the group's norms and behaviours.

Observation should continue until data saturation is reached and no new information is found [18]. This is different from other qualitative research studies where the researcher has a much more transient relationship with the participants. This might be in the form of an interview with the participant and no further engagement. Any study where the relationship between researcher and participant is short and transient allows the participant to 'perform' a role. They are enabled, due to the short interactions to act a part and tell the researcher

only the information that they want to at that time. However, in an ethnographic study, the time spent together is much longer and a relationship is developed. The participant is not able to maintain an 'act' for a long period of time, and so the researcher will start to see the 'real' participant and gain a greater understanding of them. This is due to a prolonged exposure to the participants and the group being studied.

Ethnography employs several research methods, this allows the findings to be linked together and an understanding to be developed [14]. This allows for triangulation or crystallisation [19]. Using different researcher methods allows the researcher to view the different facets of the group being studied. The usual pattern is to begin with a period of observation and to follow this up with either individual interviews or focus groups with groups of participants. Other data collection methods using in ethnography include the study of documents, images and artefacts used within the group. Quantitative methods can also be used in an ethnographic study. These include checklists and numerical data about the subjects [20]. The interviews and focus groups normally follow the observation and explore further any topics or issues identified during the observation. By the time the interviews are undertaken, the researcher and participants will know one another better and it could be argued that there will be greater trust and honesty. At this point in the study, it is much more difficult for the participants to put on an 'act', and the interviews should arise from the observations. The researcher, therefore, has much more of an idea of the key issues and can frame their interview questions accordingly. Ethnography is iterative-inductive research, it is an ongoing simultaneous process of theory building and testing [14]. It is a fluid and flexible way of carrying out research.

Patient and service users can be studied in this way. Ethnography allows the researcher to understand what it is like to be part of the group of patients being studied. In doing so the researcher should be enabled to gain a greater understanding of their experiences, behaviours, norms, beliefs and values and how they see the world. This can be achieved by

spending time with the patient group, and it could be argued that this is much more effective than a survey at a point in time. An ethnographic study of patients can aid our understanding of behaviour surrounding health and illness. This is particularly useful as patients' views on the experience of illness and delivery of services are becoming more important within current healthcare systems. It is important that we do not make assumptions about what service users and patients require, person-centred care and values-based practice are becoming more important in the way that the health and social care services are planned and delivered, so that they are tailored to peoples' needs. Ethnography can show, for example how the effectiveness of a healthcare intervention is felt by patients and influenced by behaviours and cultural practices of those involved [21]. Ethnography can also be useful in understanding the organisation of healthcare and how communication and management effects patient experiences [22].

Previous ethnographic studies of patient groups.

A search of the literature reveals several ethnographic studies of patient groups. It also reveals studies that are badged as ethnographic, but on closer inspection turn out to be systematic reviews of other qualitative studies. Some of these publications are termed 'meta-ethnographies' which are reviews of several qualitative studies and the studies reviewed are not necessarily ethnographic, which can result in confusion regarding use of the word ethnography. Examples include; Strandas and Bondas [23], Scott and Grant [24], Carruthers et al. [25], all of which look at patient perspectives on different aspects of healthcare but none carry out any fieldwork directly with patients.

There were other publications that were labelled as ethnographic but on closer inspection do not include any observation of the participants. It could be argued that these studies do not allow the researcher the time needed to understand the participants and the culture of their group. For example, Kaplan et al. [26] looked at quality improvement for patients with

benign prostatic hyperplasia, they used focus groups, interviews, and process mapping but not direct observation of the patients.

Ethnographic studies found in the literature included a study of the wellbeing of older patients during surgical hospital treatment which involved a period of observation and informal interviews with patients on the ward [27], experiences of diagnosis and management of tuberculosis for Somali patients in which patients were interviewed and observed when they attended clinic appointments [28], experiences and challenges for older people during hospitalisation for cancer treatment which involved observation and interviews [29], and patients and families experiences of patient safety which involved videoing patient interactions with staff members [30]. Pettegrew [31] recommended the inclusion of humour in cancer care after spending 29 months observing cancer care in a private oncology centre. Baim-Lance et al. [32] studied patients in three human immunodeficiency virus (HIV) clinics and explored co-production and improvement of services for these patients.

Each of the studies listed used observation of the participants in the natural setting of the healthcare environment, either on the ward or in a clinic. Time was spent both observing the participants and interviewing them to further explore some of the issues uncovered from the observation. These studies are truly ethnographic with the researcher spending time with the patient group, to better understand their perspectives and to get to know them better in order to represent their voices.

Methodological and Ethical issues.

Ethnographic research within a healthcare setting can be challenging. In order to study a group of patients the researcher needs to become part of the group, so that they can integrate. So, they could take on the role of patient or remain as a researcher. It could be problematic for the researcher to take on the role of a patient in order to become part of the group being studied, particularly if this involves deceiving the participants. In some

ethnographic research it is possible for the researcher to become a legitimate member of the group, or they may also be a member of the group being studied. For example, if the researcher was a patient, or had the same medical condition as the group being studied. In reality this is unlikely, so leaves the option of deceiving the participants by pretending to be a patient or being a known researcher. Deceiving patients comes with ethical issues and dilemmas and it is very unlikely that permission would be given for such a study. In the case of a patient group, anyone playing the role of researcher would retain more of an outsider than insider status due to the nature of the group. However, it is still important that the researcher can represent the voices of the participants, no matter what their status is.

The researcher will need to gain access to the field. This is not easy in a healthcare setting due to ethical constraints and confidentiality requirements. A 'gatekeeper' who can help with access to a patient group is useful and healthcare professionals may be best placed and have a distinct advantage if they want to carry out research in their own practice area [33]. For example, a nurse working on a ward has access to the patients on that ward, or a doctor has access to their own patients. However, it is important to guard against coercion, ensuring that participants are all given a choice about participating and do not feel pressured into doing so because they know the researcher. Covert research is not permissible in most healthcare systems, all studies require ethical approval. A stipulation of ethical approval is that all participants give informed consent to being involved in the study. However, it is difficult for the researcher, particularly when carrying out an observational study to gain consent from everyone they meet as not everyone who is met by the researcher will be a participant [34].

The researcher must 'ensure no harm' to the participants. If the researcher is a healthcare professional, they will need to abide by their own professional code of conduct. They will also need to decide when they might need to intervene, e.g. if they observed malpractice during their observations or if they needed to assist in saving the life of a participant. Dixon-

Woods [35] suggests that the dilemma about when and how to intervene is not uncommon. Other writers discuss this dilemma [12, 13]. Johnson [34, 36] discusses at length why intervention is a difficult concept for healthcare researchers when carrying out research in a clinical environment. He suggests that the researcher should try to plan and consider when they might have this dilemma, so that they are ready should the situation occur. He does however acknowledge that this does not account for the turmoil of the 'messy' world of clinical research. Considering when to intervene would also mean consideration of what you would find to be acceptable behaviour, this would not just be unsafe practice. For example, the researcher might observe poor communication or incorrect information being given to a patient, they would need to decide if intervention in this situation is something that they would need to do. Ensuing no harm also means that the researcher needs to be aware that talking about their healthcare condition or experiences may cause distress for patients, and so they need to be aware of this.

Consent from participants needs to be managed carefully. Consent is a continuous process and therefore a participant can withdraw their consent at any time. This may mean that some data are lost. If a patient from the group does not consent to being observed the researcher will need to manage this to avoid that patient and this could also result in their data being lost from the study. Patient's wishes should always be respected.

The research texts suggest that participants must be anonymous, and their confidentiality needs to be maintained. Researchers will normally either number their participants or given them pseudonyms. This is particularly useful for the reader if they want to follow one participant and their data through the study. It is also useful to provide some demographic information about each of the participants to give context and background to each of the participants. However, it is argued that this needs to be done carefully in order that it does not identify the patient. This could be problematic if the participants have a rare medical condition or they are an outlier in the group, e.g. the only male in the patient group or the

only patient within a certain age group. This is an interesting topic for discussion, particularly when we start to consider patients. Patients involved in research studies may not actually be bothered about being identified. This may not actually cause them any concern. In fact, it may be that they prefer to be identified so that their voice can be heard. Anonymising participants is time consuming and can be difficult to do. One could argue that anonymity should be a decision made by the participant, as they should make the decision about how their information and data are used. It may be in studies of this nature that the participants want to be known so that they can have a voice and make a point.

The way in which observational data are recorded should be considered. Information can be video, or audio recorded, or the researcher can take field notes. Field notes are the most common form of recording observational data. The participants need to be able to trust the researcher for the relationship to work. This can be done by not keeping the data secret. Costley and Gibbs [37] suggest that 'moral trusting' is a good way to care for the participants and promote the researcher's integrity. This should help to reduce the feeling that the research is a 'spy'! The description of events during observation needs to provide the context. If the group interactions and the observation of these occur in one setting, a floor plan of the location is useful to provide context to the reader [14]. This could be a healthcare or a social setting when observing a patient group.

Observation involves all of the senses; this includes sound, movement, touch and smell. Sensate researchers document this information and not just what is seen [38]. Within a healthcare environment the use of the body is key to the culture and experiences of patients and will provide important data.

The researcher needs to be able to consider what it is like to be part of the group being studied [39]. This could be a challenge for someone studying a group of patients who is not a patient themselves and therefore does not have the same experiences. There is an

argument that carrying out research in a familiar environment can be helpful as you know the 'cast of characters' [40]. However, this may mean that familiar information is overlooked [41, 42].

In studies using observation the 'Halo effect' often occurs [43], when participants want to be seen in a favourable light. Other writers describe the 'Hawthorne effect' [44, 45], where participants alter their behaviour due to be observed. However, over a period of time both effects fade and the participants settle back into 'normal' behaviour [45, 46]. It can therefore be a challenge to balance the need to be open and honest with the need to fit in and become unobtrusive. The researcher does not want to keep reminding the participants about the reason they are there, as this will reduce the chances of 'normal' behaviour.

The researcher needs to find a 'place to be' when observing the group. This could be a physical place to sit or stand and observe or it could be with one person or people from the group where they feel comfortable. They also need to decide what to wear; should it be a healthcare professional's uniform, normal clothes or the attire the patients are wearing, e.g. hospital gowns. There are no right or wrong answers here, although this may be dictated by the gatekeeper or ethics committee. Coffey [47] says that the researcher should have an acceptable appearance which includes dress, demeanour and speech. Hammersley and Atkinson [4] suggest that the personal appearance and impression created by the researcher have an influence on data collection.

The researcher will need to decide how much time they will spend with the group, for how long and in what situations. This will largely depend upon the nature of the group. Social occasions may also be included.

With regards to interviews and focus groups, there are some additional considerations. Sampling is a consideration. Generally ethnographic research utilises a purposive sample

where 'key informants' are selected from the group [48]. How the interviews and focus groups are recorded should be considered, e.g. audio or video. The location and time at which interviews, and focus groups are conducted should be considered, along with transport and payment of participants for their expenses and time. Payment could pose a problem if the patients are receiving benefits. It is also important to be aware that talking about their experiences could cause distress for patients and so support or counselling needs to be arranged just in case.

Conclusions.

Ethnography is a simple and effective qualitative research methodology for studying groups of people with a common enterprise or experience. Ethnography studies the culture, behaviours and norms of the group traditionally using observation, interviews, focus groups and the study of documents and artefacts relevant to the group in order to understand what it means to be part of the group being studied.

Ethnography is therefore a useful research methodology to understand the experiences of patients and service users during their healthcare journey. It can provide information about what it is like to have a particular medical condition or diagnosis and the norms and behaviours of patients with this condition. An ethnographic study of a patient group can also provide insight into the healthcare system from the perspective of the service user.

Ethnographic research can aid understanding of the patients' perspective on different aspects of their healthcare journey and allow for their voices to be heard.

References

1. Reeves P (2008) Research in Medical imaging and the role of the consultant radiographer: a discussion. *Radiography* (2008) 14, e61-e64.
2. Brewer J D (2000) *Ethnography*. Open University Press, Buckingham.
3. Vine T, Clark J, Richards S and Weir D (2018) *Ethnographic Research and Analysis – Anxiety, Identity and Self*. Palgrave Macmillan, London.

4. Hammersley M and Atkinson P (1991) *Ethnographic Principles in Practice*. Routledge, London.
5. Becker H S, Geer B, Hughes E C and Strauss A L (1961) *Boys in White – Student Culture in Medical School*. New Brunswick: Transaction Publishers.
6. Annandale E, Clark J and Allen E (1999) *Interprofessional Working: An Ethnographic Case Study of Emergency Health Care*. *Journal of Interprofessional Care*, 13 (2), 1999.
7. Batch M and Windsor C (2015) *Nursing Casualization and Communication: A Critical Ethnography*. *Journal of Advanced Nursing*, 71 (4), 870-880.
8. Wolf Z R (1988) *Nurses' Work, the Sacred and the Profane*. Philadelphia: University of Pennsylvania Press.
9. Goransson K (2006) *Registered Nurse-Led Emergency Department Triage: Organisation, Allocation of Acuity Ratings and Triage Decision-Making*. PhD Thesis, unpublished. Orebro, University, Sweden.
10. Cudmore H and Sondermeyer J (2007) *Through the Looking Glass: Being a Critical Ethnographer in a Familiar Nursing Context*. *Nurse Researcher*. 14(3), 25-35.
11. Goodson L and Vassar M (2011) *An Overview of Ethnography in Healthcare and Medical Education Research*. *Journal of Education Evaluation for Health Professions*, 8(4) 1-5.
12. Hobbs D and May T (Eds) (1993) *Interpreting the Field – Accounts of Ethnography*. Oxford University Press, Oxford.
13. McGarry J (2007) *Nursing relationships in ethnographic research: what of rapport?* *Nurse Researcher*, 2007. 14, 3, p7-14.
14. O'Reilly K (2005) *Ethnographic Methods*. Routledge, London.
15. Reynolds J, Milton S and Garnett E (2018) *Introduction: Entangling Ethnography and Health*. In: Garnett E, Reynolds J and Milton S (Eds.) *Ethnographies and Health*. Palgrave Macmillan, London.
16. Wolcott H F (1999) *Ethnography – A Way of Seeing*. Altamira Press, Oxford.
17. Nieswiadomy R (2002) *Foundations of Nursing Research*. 4th Ed. Prentice Hall, Upper Saddle River, USA.
18. Creswell J W (2007) *Qualitative Inquiry and Research Design – Choosing among five approaches*. (2nd Ed.) Sage, London.
19. Richardson L and St Pierre E A (2005) *Writing – A method of enquiry*. In Denzin N K and Lincoln Y S (2005) *The Sage Handbook of Qualitative Research*. (3rd Ed.) Sage, Thousand Oaks.
20. Hammersley M (1992) *What's wrong with Ethnography?* Routledge, London.

21. Prout A (1996) Actor-network theory, technology and medical sociology: an illustrative analysis of the metered dose inhaler. *Social Health Illness* 1996, 18, p198-219.
22. Savage J (2000) Ethnography and Health Care. *BMJ* 2000, Vol. 321, 1400-1402.
23. Strandas M and Bondas T (2017) The nurse-patient relationship as a story of health enhancement in community care: A meta-ethnography. *Journal of Advanced Nursing*, 2018; 74: 11-22.
24. Scott D A H and Grant S M (2017) A meta-ethnography of the facilitators and barriers to successful implementation of patient complaints processes in health-care settings. *Health Expectations*, 2018; 21 p508-517.
25. Carruthers H, Gomersall T and Astin F (2018) The work undertaken by mechanically ventilated patients in Intensive Care: A qualitative met-ethnography of survivors' experiences. *International Journal of Nursing Studies* 86 (2018) p60-73.
26. Kalpan A L, Klein M P, Tan H J, Setlur N P, Agarwal N, Steinberg K and Saigal C S (2014) Use of patient ethnography to support quality improvement in benign prostatic hyperplasia. *Healthcare* 2 (2014) p263-267.
27. Uhrenfeldt L and Hoybye M T (2015) Care interaction adding challenges to old patients' well-being during surgical hospital treatment. *International Journal of Qualitative Studies on Health and Well-Being*. 2015, 10 p1-8.
28. Gerrish K, Naisby A and Ismail M (2013) Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK. *Journal of Advanced Nursing* 2013, 2285-2294
29. Uhrenfeldt L and Hoybye M T (2014) Lived experiences and challenges of older surgical patients during hospitalization for cancer: An ethnographic fieldwork. *International Journal of Qualitative Studies on Health and Well-Being*. 2014, 9 p1-10.
30. Collier A and Wyer M (2016) Researching Reflexivity with Patients and Families: Two Studies Using Video-Reflexive Ethnography to Collaborate with Patient and Families in Patient Safety Research. *Qualitative Health Research* 2016, Vol. 26(7) 979-993.
31. Pettegrew L S (2017) An ethnography of humour, ritual and defiance in cancer care settings. *Journal of Organisational Ethnography*, Vol 6, No 2, 2017 p159-176
32. Baim-Lance A, Tietz D, Lever H, Swart M and Agins B (2019) Everyday and unavoidable coproduction: exploring patient participation in the delivery of healthcare services. *Sociology of Health and Illness*, vol 4, no 1, 2019 p128-142.
33. Allott M and Robb M (Eds) (1998) *Understanding Health and Social Care – An Introductory Reader*. Sage, London.
34. Johnson M (2004) Real world ethics and nursing research. *Nursing Times Research*. 2004: 9: 251-261.
35. Dixon-Woods M (2003) What can ethnography do for quality and safety in health care? *Quality and Safety in Health Care*, Oct.2003, 12, 15, p326-327.

36. Johnson M (1997) Observations on the neglected concept of intervention in nursing research. *Journal of Advanced Nursing*, 1997, 25 p23-29.
37. Costley C and Gibbs P (2006) Researching others: care as an ethic for practitioner researchers. *Studies in Higher Education*. 31 (1) p89-98.
38. Edvardsson D and Street A (2007) Sense or no-sense: The nurse as embodied ethnographer". *International Journal of Nursing Practice* 2007; 13; 24-32.
39. Allen D (2004) Ethnomethodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings. *Nursing Inquiry* 2004, 11(1), p14-24.
40. Roberts D (2007) Ethnography and staying in your own nest. *Nurse Researcher* 2007, 14:3, pp15-24.
41. Styles J (1979) Outside/insider: Researching Gay Baths. *Urban Life* Vol. 8, No.2, p135-152.
42. Holland C K (1993) An ethnographic study of nursing culture as an explanation for determining the existence of a system of ritual. *Journal of Advanced Nursing*, 1993, 18, p1461-1470.
43. Asch S E (1946) Forming impressions of personality. *Journal of Abnormal and Social Psychology*. 41, 258-290.
44. Vehmas T (1997) Hawthorne effect: shortening of fluoroscopy times during radiation measurement studies. *British Journal of Radiology*, 70: 838, p1053-1055.
45. Bowling A (2nd Ed) (2004) *Research methods in health – investigating health and health services*. Open University Press, Maidenhead.
46. Ellen R F (Ed.) (1984) *Ethnographic research – A Guide to General Conduct*. Academic Press, London.
47. Coffey A (1999) *The Ethnographic Self*. Sage, London
48. Geertz (1973) *The Interpretation of Cultures*. Basic Books, New York.