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Methodological considerations of ethnographic research to explore home care

Abstract

Background

Ethnographic methodology and methods have been widely and successfully utilised in nursing and healthcare research, in particular to explore culture within clinical settings. However, ethnographic studies are less often used to explore the impact of home medical technologies, despite the ongoing drive for patients to assume self-care responsibility and receive healthcare in the home.

Aim

The aim of this article is to discuss methodological considerations of undertaking ethnographic research within patients' homes. This article will draw on an ethnographic study that aimed to explore the culture of patients and their families living with peritoneal dialysis at home.

Discussion

The article discusses the in-depth insights generated through observing participants in the home, recording fieldnotes in the home environment through text and diagrams, minimising intrusion and promoting privacy of participants through adapted periods of participant observation, and the researcher's role in caring for ill participants in the home.

Conclusion

The article concludes that ethnographic methodology can be utilised to generate holistic, rich data, but the methods used require adaption when used in the home environment.

Implications for practice

It is vital that healthcare professionals and policy-makers understand the impact of living with home medical technologies. Ethnographic methodology can be used to understand how patients and their families live with these technologies.

Keywords

Ethnography, Participant observation, Nursing, Home Medical Technologies, Home, Community

Methodological considerations of ethnographic research to explore home care

Introduction

Despite the increasing emphasis on and drive for more patients to be cared for at home (Allen, 2012; National Health Service, 2014; Schildmeijer et al., 2018; The Kings Fund, 2017), few ethnographic studies explore patients' experiences of home medical treatments. The few ethnographies that have explored home medical treatments have not critiqued the methodological considerations of this approach. This article will discuss the methodological considerations of using ethnographic methodology to explore the impact of home medical treatment, drawing on an ethnographic study undertaken with patients and families using peritoneal dialysis [PD] (a home-based treatment for kidney disease).

Ethnography is an holistic approach (Liehr & Marcus, 2002) involving the researcher participating in the everyday lives of the people they are studying, watching, listening and asking questions (Hammersley & Atkinson, 2007). Ethnography aims to portray a culture and "understand another way of life from the native point of view" (Spradley, 1980, p.3). Participant observation characterises ethnographic research (Hammersley & Atkinson, 2007), whereby the researcher, for example, participates in activities, asks questions, observes events and interviews participants (Spradley, 1980). Ethnographic methodology is not prescriptive and can be adopted to explore various issues in different settings (Savage, 2000). In classic ethnographies of the 1920s, the researcher lived as part of the cultural group and participated in their daily activities, including Anderson's (1967) work with homeless men and Thrasher's (1963) study of Chicago gangs. However, this approach diversified and evolved, with later ethnographers learning through observation, interviews and analysis of documents (Heyl, 1979).

Ethnography enables the researcher to work with participants in their natural environment, exploring their culture. Culture is defined as "the shared knowledge and schemes created and used by a set of people for perceiving, interpreting, expressing, and responding to the social realities around them" (Lederach, 1995, p.9). Within nursing, ethnographic approaches have explored the culture of clinical environments, such as a medical assessment unit (Griffiths, 2010), fertility unit (Allan & Barber, 2005), haemodialysis unit (Tranter et al., 2009) and satellite haemodialysis care (Bennett, 2011). While this is the natural environment for nurses, it is often unfamiliar for patients. Therefore, when considering the culture of patients and their families living with home medical treatments, observing participants

in their homes appears essential. While it is possible to observe patients in hospital engaging with technologies they manage at home, this does not reveal the reality of living with a home medical treatment. Ethnographic approaches have examined how healthcare treatments/interventions are administered in the home environment, including hospice nursing (Wright, 2001), intravenous therapy (Gardner et al., 2003), and personal care technology (Lilja et al., 2003). However, there is little discussion amongst authors about the usefulness and appropriateness of ethnographic methods to understand the culture of living with home medical treatments.

Overview of the study

An ethnographic study explored the culture of patients and families living with PD in their homes. Following ethical and governance approvals, patients (n=16) and relatives (n=9) were purposively (Patton, 2002) recruited from a single, tertiary National Health Service Health Board in Wales. Patient participants included 12 men and four women, aged 54-85, who had used PD for between six months and seven years. The relative participants were all women, including six wives, two daughters and one niece. All patients and relatives were interviewed and observed using PD in their homes, up to three times (Baillie et al. 2012)). Data were coded using NVivo 8 (QSR International Pty Ltd. Doncaster, Australia) and analysed thematically using Wolcott's (1994) approach. Overall, the culture of patients and their families living with PD was highlighted, including introducing medical equipment at home, learning and practising complex clinical skills, managing crises, and, for some, recognising the limited options for the future (Baillie and Lankshear 2015a, Baillie and Lankshear 2015b).

The aim of this article is to discuss the methodological considerations of undertaking ethnographic research in participants' homes, which presents several valuable methodological advantages, but also requires adaptation from a traditional ethnographic approach to ensure the study is conducted ethically. The following considerations, identified through reflection on the study and reading of the wider literature, are discussed: in-depth insights, recording fieldnotes, intrusion and privacy, and caring for unwell participants in the home. Pseudonyms are used throughout.

In-depth Insights

Participant observation afforded a unique perspective of life with PD, which could not have been generated through interviews alone, demonstrating the advantage of undertaking ethnographic research in participants' homes. Triangulating interview and observation data provided a valuable insight into how people live with home medical treatments. The following fieldnote example shows

the integration of medical, dialysis and domestic objects within the home, which could not have been demonstrated through interview data alone:

“James was lying on his bed, which was at the front of the living room, with the sofas either side of him. Behind one of the sofas was a stand with hooks on it, with the PD weighing scale hanging off, and the coffee table was covered with a wipe-able table cloth with a bottle of alcohol gel on it. Therefore, while the living room had the usual furniture and family photos, there were clear signs that James was unwell.” (Fieldnotes James, Janice and Julie)

Interestingly, participant observation also uncovered where patients diverged from the strict taught techniques, which no participants discussed during the interviews. One participant explained how he connected his dialysis treatment using a different procedure to the one he was taught:

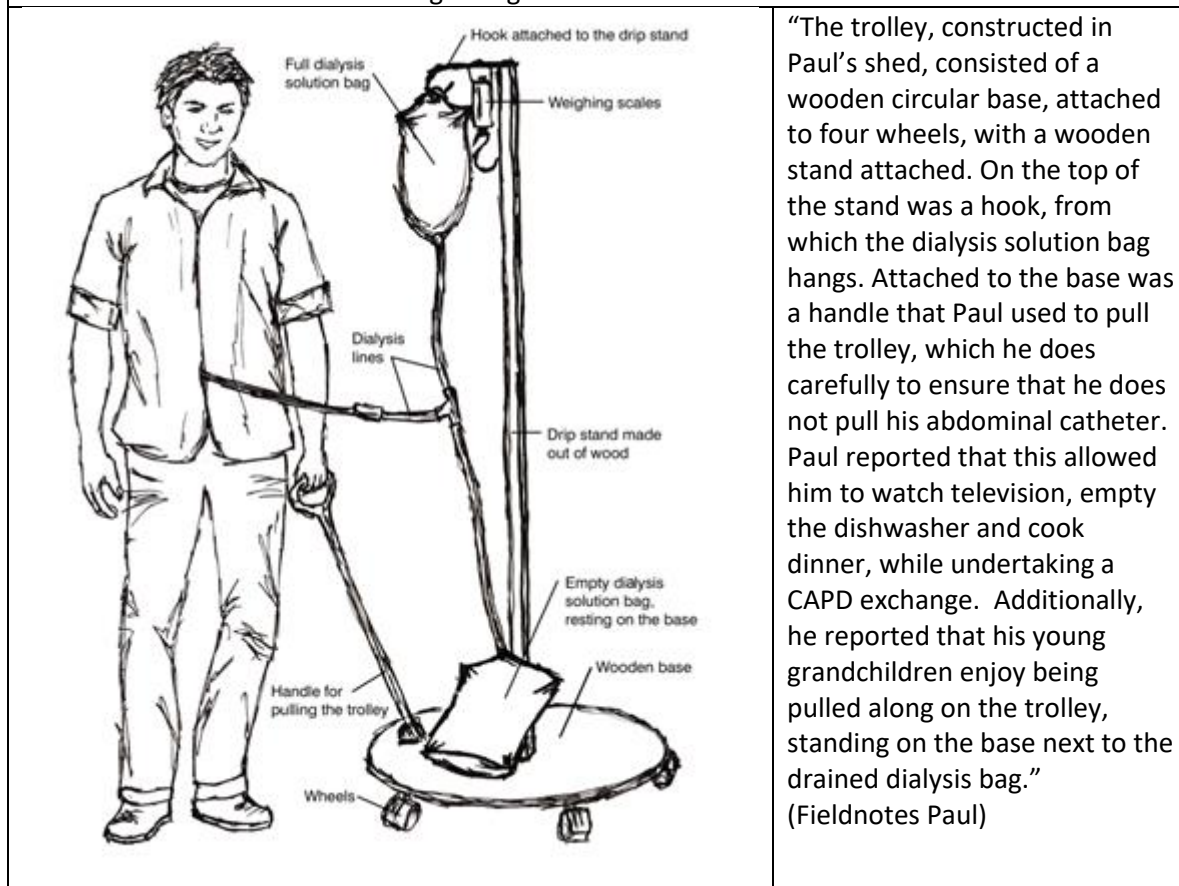
“Rhodri opened the iodine shield packaging, hibi-scrubbed his hands again and picked up the shield to place it around the end of the dialysis bag lines. Rhodri explained that he is not supposed to do this (you are supposed to do this on the table) but that he cannot see to place the dialysis bag lines into the shield when it is on the table.” (Fieldnotes Rhodri)

Participating during an observation reinforced the experiences described by participants in interviews and enabled better understanding of the challenges patients face in managing PD at home:

“Julie [daughter] had reported that her son carries the dialysis bags upstairs weekly, but that James [patient] and Janice [wife] struggle to. I tried to lift one of the boxes with 4x2000ml bags and could barely lift it. I have no idea how patients are expected to carry these boxes.” (Fieldnotes James, Janice and Julie)

While participants in the study described their inventions for integrating PD, observing the equipment designed by participants and how they used them reinforced the interview descriptions. Additionally, drawings of the equipment represented how participants used equipment to ease the burdens of PD (Box One).

Box One: Fieldnotes demonstrating a diagram and text



Therefore, participant observation provided rich data, reiterating information gleaned from the interviews and demonstrating a wealth of data not identified elsewhere in this study or in the published renal literature (Baillie and Lankshear 2015a, Baillie and Lankshear 2015b).

Recording observations

Fieldnotes were documented in a notebook as text and diagrams, which were written as expanded accounts in a word processing document immediately after the observation. Participant observations were informal and formal, with fieldnotes written about the home environment, interactions between patients and their families, and reflections on the interview. Conversations with participants before and after the audio-device was recording were documented as fieldnotes, with participants’ permission, ensuring vital data were not wasted:

“Paul said that he gets on well with CAPD because he has to, he cannot have a kidney transplant due to having three strokes since starting dialysis, and therefore he has to “get on with it.” (Fieldnotes Paul)

During the interviews participants showed the equipment they used during their dialysis exchanges, which were then discussed and documented as fieldnotes while the audio-recorder continued to record. One participant Carl undertook a dialysis exchange during the interview, which was documented as fieldnotes and described alongside the interview transcript. This enabled the interview and observation data to be analysed together:

“[Carl opens up the packing of the dialysis bag, removing the dialysis bag and removing the packaging – which covers up the recorder. I gently remove the packaging off the recorder]

Carl: Cover it up you’d have to come back again (laughs)

JB: (laughs) So you said [names nurse] came to the house and trained you to do dialysis?

Carl: Yeah

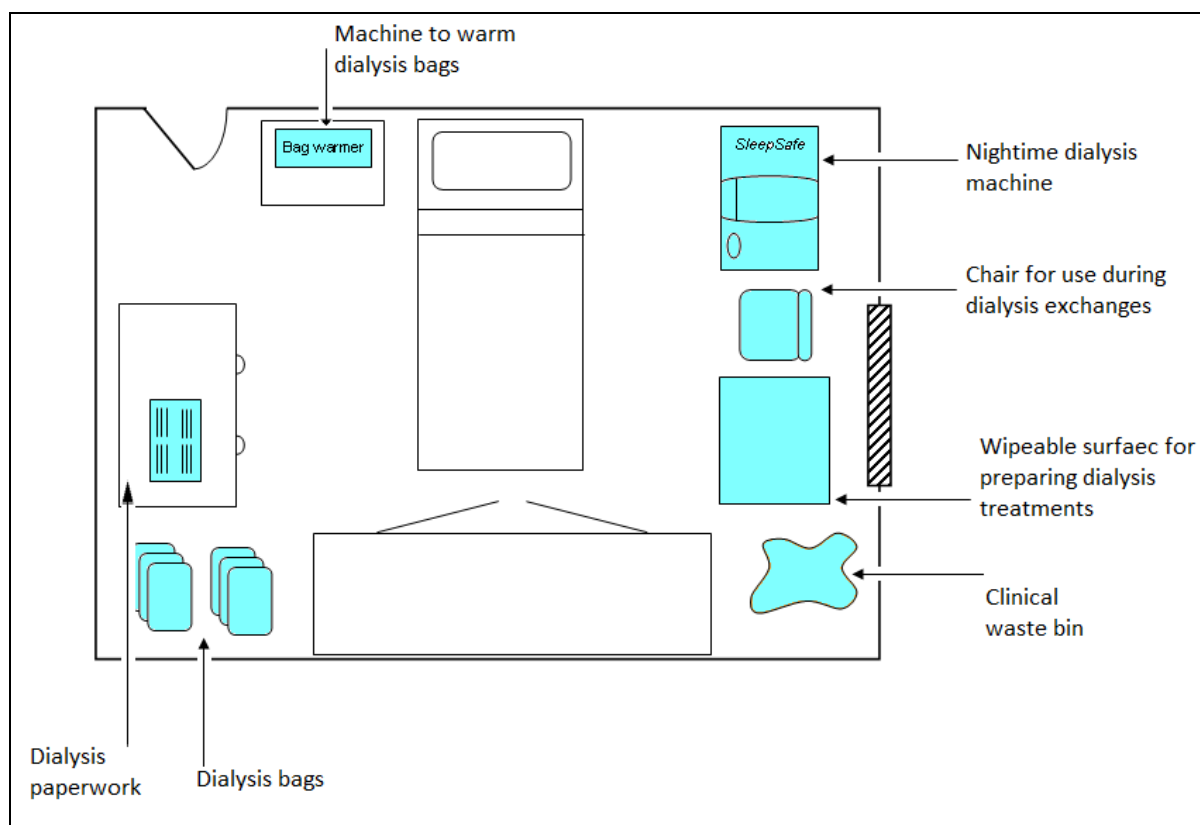
JB: OK and what did you think about peritoneal dialysis at first?

Carl: Well I thought it’d be complicated, but it’s like everything else, you know, if you start a new job it’s always complicated, but then you sort of get into it

[Carl opens up a packet of sterile gloves] (*Interview Carl*)

To further capture the impact of PD and explore how patients and their families live with medical equipment, diagrams were drawn of participants’ dialysis spaces, which were reproduced in word processing documents. Observing participants’ home environments and documenting them through annotated diagrams provided insight into the impact of PD, variation between individuals and how PD was incorporated into their homes. The diagrams also demonstrated the dominance of dialysis within the home, which was emphasised by highlighting medical equipment in blue (Figure One).

Figure One: Drawing of a participant’s bedroom



Fieldnotes were thus recorded as text during conversations, during the interview and during observations, and diagrams were drawn as a visual aid. Ethnographic fieldnotes can capture this valuable data for analysis, which would not have been analysed in other methodological approaches where data consists of interview transcripts alone.

Intrusion and privacy

Undertaking ethnographic research within participants' homes requires an adapted approach to minimise feelings of intrusion and promote participants' privacy. One potential limitation of home ethnography is the inability to observe patients over the 24-hour period or for extended periods of time.

Ethnographies in settings such as hospitals can include fieldwork during the night, at weekends and for prolonged periods, providing insight into the culture of the area over 24-hours. However, observations in this study were undertaken during the day (08.30-18:00) and working week only (Monday–Friday, participants' preferences). It would have been inappropriate and obtrusive to observe participants during the night in their homes. Therefore, rather than observing an individual

undertaking dialysis overnight, other aspects of dialysis care were observed, as demonstrated in the following fieldnote extract:

“Kaye [wife] had stressed the importance of her routine in coping with Kris’s dialysis care. In the morning Kaye disconnects Kris from his dialysis treatment and cleans the machine. At 17.00 she “lines” the machine ready for the evening, which involves connecting the dialysis bags to the machine with plastic tubing. At 20.30 she puts the machine on to “prime”, whereby the dialysis fluid is circulated through the plastic tubing, while she helps Kris get ready for bed. Kaye then connects Kris onto the machine for nine hours. I therefore asked whether I could visit the couple at 17.00 to observe Kaye lining the machine, which they agreed.” (Fieldnotes Kris and Kaye)

However, participants in this study continued to dialyse overnight and it is acknowledged that this aspect of their routine was missed.

Due to the demands of managing a complex treatment, it would have been insensitive to observe participants for longer periods. Observations lasted up to three hours, including taking consent and the interview. Some participants were visited multiple times, to undertake a second interview (for example if the first interview was stopped due to the participant becoming fatigued) or further observation of a dialysis procedure, other participants preferred a single visit. This approach was acceptable to participants and it is argued generated in-depth insight, despite not capturing 24-hour data.

Unwell participants in the home

When undertaking ethnographic research in the hospital setting, the nurse researcher can easily report concerns about a patient to the clinical team. However, a nurse researcher visiting patients in their homes, without an accompanying healthcare professional, may identify concerns about a participant. To protect participants, while maintaining a researcher-participant relationship, ensuring clear routes of communication with the clinical team is essential for reporting concerns promptly and appropriately. Therefore, a reporting process was arranged with a senior PD nurse, and several concerns were reported to her, explaining to participants why it was important to do so.

On one occasion a participant was nauseous, in pain and awaiting a visit from her General Practitioner. The extract in Box Two, from the reflective diary, demonstrates the series of events. Overall, I worked outside of my research role and instead adopted a caring approach, influenced by my familiarity with dialysis equipment and ability to contact the senior nurse directly for guidance. In this situation, it was important to balance maintaining confidentiality, with the tenet of beneficence (Beauchamp and Childress 2013).

Box Two: Reflective diary extract

“Because Aileen felt unwell I said I could stay if she wanted and she said please. I therefore fetched Aileen a glass of water and we chatted, waiting for the GP or Aileen’s niece. Aileen began to feel nauseous and eventually she went to the bathroom where she vomited. I fetched Aileen’s water and helped her back to the living room. Aileen had not yet done her morning dialysis bag, and it was nearly one o’clock, so she decided to perform the exchange. I therefore laid out the plastic bag on the floor next to Aileen’s dialysis station (which she then places the used caps and packaging on) and lifted the bag off the heater and onto the dialysis station. Aileen then connected herself up, and I brought over the sofa footstool to enable Aileen to raise her leg, which was still painful. I also put the next bag on the warmer, and placed the night-time bag within reach to enable Aileen to easily put it on to warm. Aileen was not sure whether she should aim to get the four bags done but leave each bag in for a shorter amount of time, or whether she should do just three bags that day and leave the bag in for the normal amount of time. I therefore telephoned the Home Dialysis Manager and explained the situation. She recommended that Aileen do three bags that day and leave the fluid in for the correct amount of time, and said that the PD team would call the next day. As Aileen finished the bag exchange, which required me to lift the bag onto the hook on the wall, her niece arrived with her brother and daughter. I therefore said I would telephone Aileen the following week to see how she is, and Aileen thanked me for staying with her. The GP had also phoned to say that she would be visiting shortly. I felt slightly uneasy about whether I had acted appropriately, but I decided that I had not done anything clinical and that it was the most ethical thing to do.”

On another occasion first aid advice was given from a nursing perspective without involving the individual’s clinical team, working within my scope of practice (Nursing and Midwifery Council, 2015). This event took place prior to taking consent and was therefore documented in the reflective diary; data were subsequently generated with the couple following consent:

“Kaye welcomed me in to the flat and explained that Kris had been having a nosebleed for one hour, and she had telephoned the GP. When I went into the living room Kris was holding a tissue to his nose. Kaye told Kris to tilt his head backwards, but I explained that forwards was safer as it reduced the risk of blood going into the lungs.” (Researcher Reflective Diary)

Therefore, when undertaking research with people who use home medical technologies, it is vital to develop mechanisms for reporting and managing concerns about participants.

Discussion

There are important methodological implications of this study in terms of the usefulness of ethnographic methodology to explore how patients and families live with home medical treatments.

Patients are often interviewed in their homes in qualitative studies, with researchers reasoning that this promotes participants’ comfort (Sivell et al., 2015), convenience (Gill et al., 2008) and control

(Jokinen et al., 2002). Furthermore, researchers commonly write fieldnotes afterwards of their interactions with participants, providing context to the interview (Fink, 2000). Ethnographers have published about how to write fieldnotes (for example, Emerson et al. (1995)), and debate exists around how and when fieldnotes should be recorded (Mulhall, 2003). Unlike ethnographic observations in a clinical area where the researcher can excuse themselves to write notes away from participants (Mulhall, 2003), this is not permissible in a person's house. The way in which fieldnotes are written during observations impacts on the relationship between the researcher and participants (Emerson et al., 1995). It is thus imperative for the researcher to explain during the consent process that notes will be written and the reasons for this, reiterate this during the observation, and write notes quickly and succinctly.

In addition to written fieldnotes, ethnographers may also draw diagrams of the environment under study (Griffiths, 2007), or take photographs of the phenomena (Hurdley, 2006). This study utilised diagram drawings, which were analysed as part of the fieldnotes. These diagrams proved extremely useful for demonstrating the impact of dialysis on the home and participants' dialysis innovations. Diagrams of this type have not been identified in the ethnographic health literature and it is thus suggested that their use is novel within the health field. Participants were comfortable with these diagrams, but frequently offered that photographs could be taken. Ethnographers increasingly use photographs (Hammersley & Atkinson, 2007), but these could threaten participants' anonymity. For future research, if participants' anonymity is a concern, photographs could be taken but not reproduced in outputs, with their content described in fieldnotes.

The participant observations described in this article lasted up to three hours, with up to three visits per participant. Observation periods vary between studies: Blogg and Hyde (2008) observed each participant once for up to three hours, while Björnsdóttir (2014) observed home nursing care lasting 20-60 minutes, over three weeks. Observation periods may be extended in hospital ethnographies, for example Griffiths (2010) observed a medical assessment unit over three years. However, Hammersley and Atkinson (2007) warn against prolonged observation, commenting that the resultant data becomes "unmanageable" (p.36). The participant observations described in this article were undertaken during the daytime, Monday-Friday. Therefore despite observing participants at different times of day, ultimately data were not generated overnight. Hammersley and Atkinson (2007) suggest that in some settings it is impossible to conduct fieldwork at all times of day and therefore recommend a selective approach, which can result in better quality data. Overall, Watts (2008) considers the

balance of discovering information in qualitative research and not intruding in participants' lives. Therefore, negotiation is needed between generating rich holistic data and being unobtrusive in participants' homes.

Researchers collecting data in the home environment, regardless of the methodological approach, may encounter a participant who is unwell. Nurse researchers face ethical challenges when undertaking research and managing the nurse-researcher role (Griffiths, 2008; Orb et al., 2001), but must promote the wellbeing of patients and act in their best interests (Nursing and Midwifery Council 2015). Participants may require medical attention and the researcher may therefore need to adapt their role, practising in line with codes of ethics and professional standards (International Council of Nurses, 2012; Nursing and Midwifery Council, 2015). In her ethnographic work with individuals claiming incapacity benefit, Grant (2011) discussed giving participants information about benefits after the interview, recognising that researchers are not neutral during the research process. This further demonstrates the role of the researcher in offering support to participants in non-healthcare research settings.

Conclusions

This is the first article to reflect on the methodological considerations and advantages of using ethnographic research to explore the culture of living with home medical treatments. Researchers are required to write fieldnotes in front of participants when observing in the home, and thus seeking permission from participants and writing succinct notes as text and diagrams is necessary. An adapted approach to participant observation may be required in the home, including shorter observation periods during the daytime. Healthcare professionals generating data in the home need to ensure clear referral pathways to the relevant clinical team are established. Ultimately, ethnography within the home can provide detailed insight into how patients and their families live with home medical treatments.

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