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From ethical approval to an ethics of care: Considerations for the inclusion of older adults in ethnographic research from the perspective of a ‘humanisation of care framework’

Jayme Tauzer[a,*], Fiona Cowdell[a], Kristina Nässén[b]

[a] Birmingham City University, United Kingdom
[b] University of Borås, Sweden

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ABSTRACT

A deeper understanding of care demands the methodological finesse of qualitative research: we must observe, listen, and witness to expose what matters to care recipients. In this paper, we – a team of three: one early-career researcher and two supervisors – reflect on our experiences of designing and then seeking ethics approval for ethnographic research on care for older adults, many of whom demonstrate a lack of capacity to consent to research. Viewing experiences of well-being and dignity as embedded within interpersonal negotiations, this study privileges care home residents’ daily life, looking to stories and observations of daily life to reveal the complexities of well-being in the care home setting. This paper emphasizes the importance of using qualitative research methods to gain a deeper understanding of care practices, particularly in the context of care for older adults with varying cognitive capacities. By privileging the daily life experiences of care home residents and employing the logic of process consent, we aim to include the voices of all participants, not just those who can provide written informed consent. However, obtaining ethics approval for this type of research presents several challenges, requiring careful negotiation and the inclusion of consultee advice. This paper highlights the tensions between procedural ethics and the need for better inclusion of vulnerable populations in ethnographic research on care. By addressing these challenges, we can move towards a more context-sensitive and humanised approach to research ethics that values the lived experiences of care recipients.

Introduction

It was a particularly warm July afternoon, and after having some afternoon tea, I asked Theresa,[1] *a 75-year-older resident of the care home where I conducted research for my PhD thesis, if she’d like to join me out on the balcony to get some fresh air. Theresa declined, explaining, “I just want to sit in silence–sometimes you think I’m dull but I am not, I like peace. They want me to be busy though. It is like in school. Sit straight, don’t speak! Sit and look busy and they don’t bother.”*

Overhearing this from the kitchen, a care worker, Mary, explained, “Oh, she must be talking about her school days. She was quite a stern school teacher, weren’t you, [Theresa]?”

Theresa shrugged and gave a half-smile, and I[2] wondered if this *is* what she really meant. It seemed an adequate, in fact quite eloquent, response to my invitation to socialise outside at that moment, rather than a musing about her past.

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* Corresponding author.
E-mail address: jayme.tauzer@mail.bcu.ac.uk (J. Tauzer).

[1] All names given in this paper are pseudonyms.

[2] Though the paper considers the team’s experience with this project design and implementation, the first author, Jayme Tauzer, is the singular researcher who collected data and thus the paper is written from her account.

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Theresa is one of many participants of this study whom, when I assessed, I considered not having sufficient capacity to provide informed consent.[3] Theresa was enrolled on the advice of her daughter, who felt that she would likely enjoy participation. Theresa is often social and philosophical, and she offers up her understanding of daily life in the care home. Other times, she is private and declines invitations to socialise. An important component of a qualitative event is that it is connected to other meanings, contexts, and events. This means that any singular moment or experience has an embeddedness which, even when not consciously recognized, exists implicitly (Merleau-Ponty, 2002/1945). Thinking with this embeddedness, we can understand the small interaction with Theresa, where she communicated momentary dissent to participation. Consent, which occurs in moments and is shaped by context, occurs through interacting. And each interaction is a new assessment of consent, or, just as importantly, an opportunity for participants to communicate dissent.

As was often the case, especially during my early days of research, Mary offered a narrative as well. In providing Theresa's backstory, Mary was giving some context which might enable further conversation between Theresa and I. Perhaps she was even apologising for Theresa's refusal to join me, which may be viewed as rude–this already speaking to the limited rights care home residents may possess. Dissent, even to daily interactions outside of formal consent required for study participation, is viewed as poor manners or a lapse in judgement, rather than as a clear and justified communication of one's unwillingness to participate at a given moment.

These interactions were opportunities to strengthen rapport with staff, who often did not quite understand my role as an ethnographer while they tirelessly provided care work. The moments where staff or family members shared their knowledge were helpful: they are the experts in this space and they are sharing their expertise, helping me to become more of an insider over time (Clifford and Marcus, 1986). They are also expressing attitudes: one should not reject the invitation of another, the idea that residents' preferences are best understood in relation to their previous role as productive members of the workforce (*"she was quite a stern school teacher"*). Yet these instances, when staff would speak "for" residents, risk convoluting the dynamic, sometimes confusing residents, and detracting from a more intimate, present exchange where they are given the chance to decide if they want to participate, or not (Yeom, Ahn, & Kim, 2017)

The formal ethics requirements to involve adults who lack capacity to consent as legally required by the Mental Capacity Act (including assessing capacity of consent), can, in practice, contradict these moments of consent which emerge in real life situations. As I assimilated to the care home, I experienced many challenging moments which called the consent procedure into question, where my interpretation was required to understand how to most ethically proceed with my inquiry, and where my positionality served as a starting point to make these decisions.

The implications that these complex interactions have on including diverse voices in research is the focus of this paper. An ethnographic approach helps highlight the interpersonal dimension of care events and the qualitative, existential nature of well-being, but studies of this design often face significant gatekeeping at the ethics approval phase, far before ever setting foot in the care home space. Barriers to consent exist at the structural and institutional levels, through ageist attitudes towards all older adults, and especially those who lack capacity, as well as at the interpersonal level, through power dynamics between care workers and care recipients (Pratt, 2002)(Hellström, Nolan, Nordenfelt and Lundh, 2007).

In the following paper, I explore the way that a person-focused ethics of care–the humanisation of care framework–may help to think through the consent process and to highlight that consent is momentary and occurs in relationships. Furthermore, I explore potential barriers to conducting qualitative research with older adults who may lack the cognitive capacity to provide informed consent, arguing that these barriers can exemplify the tension of procedural ethics with the subtler ethics which lie within interpersonal navigations both in care relationships and within the ethnographic approach to research. I will illustrate my use of process consent through some vignettes.

Background

This study contributes to the collective aim of the Marie Curie Skłodowska Action (MSCA) INNOVATEDIGNITY Fellowship, which is an international early career training program for care science scholars who engage with experiential aspects of well-being and care for older persons through qualitative research. Drawing upon the *Humanisation of Care Framework (HCF)*, a theory based model used to explore experiential aspects of well-being, this study sets out to problematise the complex and context-based understandings of what it means to experience well-being in care[4] (Galvin & Todres, 2013). Applying a humanisation of care framework helps us to understand how one's experiences of care may be either humanising or dehumanising in the context of care provision. The framework has some similarities with the person-centred approach theorised by Tom Kitwood (1997), extending from the person-centred approach in taking a focus on the phenomenological aspects of the caring experience to highlight the dimensions of well-being from potentially humanising experiences, to potentially de-humanising experiences. Thus, this is a value framework which can guide qualitative research on care and well-being (Todres, Galvin, & Holloway, 2009).

In the HCF, dimensions of well-being run along several inextricably interwoven and connected dimensions of human experience, such as uniqueness/homogenisation, sense of place/dislocation, agency/passivity. The framework allows us to look at these dimensions of well-being, as a spectrum, ranging from, for example, a humanised experience (agency), to the often less desirable (passivity) experience. The humanised characteristics are treated as "ideal" types, which may not always be achievable or desirable depending on the type of care being provided. For example, when looking at uniqueness/homogenisation, "uniqueness" may not be the most desired characteristic when one needs to adapt to best practice safety protocols, such as adhering to hygiene measures during the recent COVID-19 outbreaks. In other words, the HCF helps us to explore the possible dimensions of care to better understand one's experience of well-being in context, and to consider the actions which may facilitate or obscure one's experience of well-being.

The HCF helps us to view well-being as more than just the absence of

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[3] In the England and Wales, assessing mental capacity follows a careful process required when working with a population which includes, or may include, adults who demonstrate a lack of capacity to provide informed consent to participate in research. According to the Mental Capacity Act (MCA), all individuals must be assumed to possess capacity unless established otherwise. Establishing capacity was done by sharing the Participant Information Sheet with potential participants and then asking some questions about the study to gauge whether the information was retained, understood, and could be repeated back to me. Because I had yet to establish rapport with most residents, I triangulated with staff and family members when assessing capacity. All participants should be assessed in the same way, and no assumptions about capacity or lack thereof should be made prior to assessment. The Health Research Authority (HRA) outlines that in order to demonstrate capacity, one must be able to understand information relevant to make a decision, retain said information, use or weigh the information given, and finally, be able to communicate (by any means) a decision based on the provided information (for further reading on the assessment procedures, see Fletcher 2023 in this issue).

[4] Through the INNOVATE Dignity fellowship, this project is one of 15 qualitative research projects designed to support the use of qualitative research to explore and nuance our understandings of care for older persons. This particular project is meant to employ ethnographic research to look at issues of gender and well-being in the residential care home context.

illness, and care as a process which is reflexive and occurs in relationships, rather than as a mere transaction. Furthermore, this approach enables us to view the older adult care recipient as an agential person, rather than as a passive subject. Research *on* older adults often promotes homogenising stereotypes and can fail to consider the multiple and intertwining identities that follow us throughout the life course (Calasanti, Slevin, & King, 2006; Minkler, 1996). A humanisation of care perspective helps to engage with the complex, nuanced aspects of the individual, and centres older adults' experiences and perceptions (Todres et al., 2009).

Situated ethics, or the ethics of the humanisation of care, presents an alternative approach to procedural ethics, one that acknowledges the complex and context-sensitive nature of caring practices. While this approach may be "messy," it is crucial to recognise that research can be a component of the care matrix. Understanding the context in which care is delivered is essential to providing humanised care that respects the individual's needs and preferences. By highlighting the contextual dimensions of care, we can demonstrate how our ethnography engages with an ethics of care and humanisation of care framework. This framework provides a useful alternative to the more fixed ethical procedures, emphasizing the importance of understanding the unique circumstances of each individual.

Thus, there is an ontological thread that runs through the acts of humanisation of care practices, and consent to participate in qualitative research: it occurs in relationships, a reflexive event between individuals. The value of context in shaping one's lived experience is central to understanding well-being as it pertains to care across varied contexts. This is foregrounded by an ethnographic methodology, which helps us to understand and describe the relationship between people's subjective experiences and social structures.

Negotiated process consent

Care and caring are wrapped into consent: residents and staff navigated my presence as I became more of an insider in their daily lives, deciding where and how I fit. Not all participating residents lacked capacity to provide written, informed consent, but a majority did. It was important to identify a consent procedure that would include all willing participants, regardless of their capacity to provide informed written consent. Approaching this study with the perspectives of the HCF and the imperative to be as inclusive as possible, the preliminary protocol asserted that process consent is the most suitable way to fairly engage a population in which many participants lack capacity to provide informed, written consent. Negotiated process consent is not uncommon in the world of qualitative health research, and the value of this consent process has been written about by dementia researchers specifically, as it supports the inclusion of participants who may lack the capacity to provide informed, written consent (Dewing, 2008).

Obtaining informed consent is a crucial aspect of ensuring that potential participants' rights and autonomy are respected. However, in situations where a person's capacity to consent is impaired, such as in some cases of dementia, obtaining informed consent becomes more complex. The traditional model of informed consent may not be applicable to individuals with cognitive impairments, and it is essential to find alternative ways to include them in decision-making processes. In this context, the model of process consent developed by Dewing becomes particularly relevant. This model acknowledges that individuals with dementia may not be able to provide traditional forms of consent, but it aims to use all remaining capacities of the person to obtain their consent. This approach emphasizes the importance of getting to know the person and understanding their preferences to ensure that their wishes and rights are respected. Process consent highlights the relational aspect of consent: it is not a one-off occurrence, but a process, which is regularly negotiated and communicated interpersonally (Grout, 2004).

In this consent process, the participant is repeatedly, through relations, either providing or declining consent to participate in the research. Negotiating consent requires moving beyond the signed document, even beyond the verbal "yes", to reading for non-verbal signs of consent as expressed by the body. Consent as negotiated occurs within every interpersonal interaction (Dewing, 2008). Process consent is a methodological tool of obtaining consent when the person with dementia has very limited capacity for informed consent, on the one hand, whereas informed consent using proxy (e.g., consultee, see below for explanation of this term) as the primary way of obtaining consent, followed by assent of the person with dementia as secondary to informed consent rather than the primary source for consent.

This process highlights that consent is not merely a one-off event, but that it is regularly negotiated through various forms of communication, whether this is verbally, through mood, or body language[5] (Nolan, Ryan, Enderby, & Reid, 2002). Perhaps even more importantly, especially as this project takes place in the private living spaces of participants, negotiated process consent gives the opportunity to say *no*. Consent to participate in the project does not, and should not, mean that I have full, unlimited access to the lives of participants during the study. Negotiated process consent aligns with the ethos of the ethnographic approach, where consent occurs as the researcher and participant build a relationship (McKeown, Ingleton, & Repper, 2010).

Moving process consent through the formal ethics application

In the first application for ethical approval, I argued that I should employ process consent with every resident, regardless of their capacity, so that every potential participant could engage with the study in the same fashion. The goal here was inclusion, and the argument hinged on the strength of the ethnographic process in establishing the level of rapport required for process consent (Draper, 2015). I explained that the recruitment process would begin the moment I arrive at the community, data would only be collected once I could introduce myself, begin to embed myself into the community, and obtain consent. Furthermore, in a fluid and changing environment, signed consent forms may act as a barrier to participation (Boulton & Parker, 2007), and may bureaucratise the relationship between researcher and participant (Mapedzahama & Dune, 2017), thus harming rapport and stunting the natural flow of data (Wynn & Israel, 2018).

This being my first experience applying for ethical approval both in a healthcare setting, and in the UK, I relied on the expertise of my main supervisor, who is experienced in UK-specific ethical requirements for qualitative research in healthcare settings, to navigate the culture of the formalised ethics process. However, the ethics application justifying the use of process consent was not approved by a UK National Health Service Research Ethics Committee (REC), which is responsible for studies taking place in care settings.[6] We were asked to include a version of signed consent or written advice for each enrolled participant, and to only interview participants who demonstrate, through careful application of the MCA[7] indicators, capacity to provide written, informed consent for themselves. Taking this feedback seriously, I re-designed the consent process to include consultee advice for those residents who do not possess capacity to consent to participate, and to require written informed consent for interviews, and from staff for observation. The strength of the participant observation design is not only that it enables one, but it *requires* one to move through the layers of familiarity slowly

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[5] 'Consent as process' is typical of ethnographic works operating outside of medical contexts which may have more strict requirements to 'protect' potential interlocutors.

[6] NHS RECs are required to follow the legal framework of the Mental Capacity Act, it is not the REC with which I take issue, but the frictions that can result when applying an ethnographic logic to health-care research in the UK, especially when working with a population which may include those who demonstrate a lack of capacity to provide informed, written consent.

[7] Mental Capacity Act - Health Research Authority https://www.legislation.gov.uk/ukpga/2005/9/contents

and with time (Roper and Shapera, 2000). In seeking ethical approval for an ethnographic study in residential care during the pandemic, I gained useful insight on issues of gatekeeping and paternalism of older adults, issues which persist outside of this context (Minkler, 1996).

Especially while issues of isolation and stigma facing older adults in residential care have been so recently highlighted by the COVID-19 pandemic, conversations on barriers to participation and inclusivity in research matter (Cascio and Racine, 2019). There are issues with using consultee advice at a time where family and friends are not allowed to visit or spend time in the homes of residents. In my experience with recruitment, friends and family were glad to have a “fresh young face” to interact with their family members–highlighting the collective understanding of socialisation as an important component of well-being. However, I was gaining permission to access the care home at a time when many were not allowed or able to visit with their loved ones. Even with equal access to residents, there are tensions with consultee advice, e.g., the assumption that friends or family members may truly know what the person wants; or that some legal consultees may not have lived or been in close relations with their parents for a long time, therefore not knowing what they would like or want. This demonstrates that consultee advice does not accommodate for the fact that preferences change.

Awareness of these tensions helps to further understand the impacts that protected care settings during the pandemic (and beyond) may have on the agency and rights of older adult residents, who are often viewed as static in identity(Calasanti, 2008). However, this process is constricted by the MCA’s legal restrictions on involving only those who have written consultee’s advice–especially when used with ‘vulnerable populations’. Though an integral aspect of safeguarding, the ethics review process risks reinforcing cultural stereotypes of older adults, as not able to take decision and lacking agency, which contributes to the governance of this population. This is arguably as much a political act as one grounded in ethical concern (Stevenson, Gibson, Pelletier, Chrysikou, & Park, 2015). Consequently, the ethics review process can reinforce paternalistic attitudes towards older adults and can silence populations and individuals who do not demonstrate a specific ability to provide informed, written consent, and threatens to stymie research endeavours, preventing new research from ever taking place (Murphy, Jordan, Hunter, Cooney and Casey, 2015).

The process consent approach differs from the informed consent required by committees with the assessment of capacity on one occasion rather than as an ongoing process, which often ends up in excluding the person with dementia rather than using any form of remaining capacity to include them in research. Process consent is contingent on rapport, which was flagged by the committee as a potential area of concern for the study design, as rapport is not a quantifiable thing that I can present prior to my fieldwork period(Corrigan, 2003). You cannot ensure that rapport will build between myself and each resident and member of staff (and it did not), but the notion that rapport is a subtle art which will guide me through my research to engage with those who desire interaction was not well recognized by the REC at the time, and the focus was instead on the issue that rapport is not a one-off event (Bell, 2014).

Consultee advice

In order to include residents who demonstrate lack of capacity to provide informed written consent in participant observation, we included consultee advice, which relies on the opinion of a close relative or friend to determine whether their friend or family member would likely participate in the study. The Mental Capacity Act defines consultees as those who would be most fit to give an opinion about the potential participant’s willingness to participate in the study(Department of Health, 2005). Consultees do not provide consent on behalf of potential participants, but they provide advice, helping to include the potential participants wishes and preferences in the decision making process. The concept of negligible harm is important here, as consultees need to gauge, basically, whether their friends or family would want to sit and talk with me, or sit with me, in the care home, which is their home.

However, prioritising the opinions of close relatives or friends over those who interacted with residents more regularly was complicated during this pandemic period when many residents had not been able to have visitors for months. Staff helped me reach out to those who they understood to be the best likely consultee. Communication between residents and family was often facilitated by staff, not by me or by residents directly. Had family and friends been allowed to enter the separate sections of the care home housing groups of residents, I would have met with them, discussed my plan with the resident and their family member(s), the process of seeking advice on the behalf of resident participants would have been more relational, including people from many parts of the participants’ lives.

The Ethnography

Taking place in a private residential care home located in the United Kingdom, this ethnographic study took place throughout the spring and summer of 2021. I resided in a private on-site apartment in the care home for weeks at a time over the course of three months, making a few return visits thereafter. During these periods, I was in the care home 24 h a day. The fact that I was residing in a care home during the COVID-19 pandemic, during an event which placed disproportionate pressure on this population through prolonged periods of isolation, increased (and often changing) regulations, and experiences of loss and illness, shaped this project from design to dissemination of findings. The design for this ethnographic study evolved with health and safety protocols as the care home adapted to public health concerns during the pandemic.

I was required to obtain informed, written consent for interviews with residents of the care home. Thus, this limited the number of interviewees to just three participating residents of the care home. Interviews are valuable – it is a different type of data source, and there is a sense of vulnerability and earnestness during these events (Hellström, Nolan, Nordenfelt and Lundh, 2007). One interview gave a man a chance to speak about the challenges of caring for his wife who has dementia, and who was also a participant in this study. In another interview, I spoke with a retired nurse resident about her expert perspective on care, and how she felt her care was handled during the 2020 lockdowns, when, in a few months’ span, her section of the care home lost seven residents to COVID-19. The third interview was with a man who was a temporary resident when his daughter, his primary care giver at home, would travel for work.

At first I was disappointed that I would not be able to conduct interviews with more residents. However, though the interview privileges a type of storytelling, it is not the only, or even best way to tell one’s story. So much is said in observation and interaction as well, and this form of communication enabled those who were not ethically, legally, or perhaps cognitively capable of holding an interview to share their experiences and what mattered to them. Ethnographic data is observational, documenting body language, how participants move through space, how they react to other people and non-human agents. This form of data collection is easily blurred into daily life: participants over time began to see me as a confidant as my role in the community grew more natural. It became more difficult to understand when a conversation was data or when it was a moment between friends. This poses ethical challenges, which were complex, but rewarding to navigate, fusing the relationship between care and research, as will be detailed later on in three case studies.

The complexity of the research process meant that attention to body language, verbal cues, and having a sense for norms of each section of the care home (for they varied greatly) was important to ensure that my presence was not intrusive or stressful for staff or residents. I participated in the daily life of the care home through care acts: making tea, helping residents making phone calls, reading mail, washing dishes and disinfecting surfaces, having a chat, listening to stressed staff talk about their shift, and much more. Care sat firmly at the centre of all these interactions, and care occurred between residents, staff, and me. In the following, I will share three short case studies to demonstrate the way that care and consent were bound up in the ethnographic logic of this research project.

Julia

The day after interviewing George, the man whose wife has dementia, I sat with his wife, Julia, and we knitted together for a few hours, speaking about her experiences moving into the care home with her husband. Julia had been enrolled after consultation with her husband, who in addition to providing informed consent for himself, was enthusiastic about Julia's inclusion in the study. The day prior, I had complimented Julia on her cardigan. She said that she made it and then, "I make everything that I wear". I asked her if she'd like to show me how to knit, and we agreed to try it together the following evening.

"Well, I haven't done this in ages", she began slowly, clumsily looping the polyester pink yarn around two large knitting needles. She patiently explained to me how one would "cast on", but before too long, Julia was knitting expertly, and her instructions stopped, she focused on her job and began to speak openly about her life, telling me about her childhood and her training to become a teacher. Her chipped pink nail polish glittered as her knobby, stiff fingers moved quickly, wearing the memory of a lifetime of knitting. I paid close attention to what Julia was telling me, but I also knew that perhaps Julia was not fully aware of me, of my intention for being there. Eventually, a man yelled from his room and Julia's awareness came back into the room. I assured her that he is fine, and she shuddered, saying, "I wish they could do something about that racket. He is always yelling and I am worried nobody is there to help him". Then she looked around, and not seeing George, she asked after him. We started talking about how it feels to live in different rooms from her husband, and the conversation, becoming more related to my topic of inquiry, gave me an opportunity to reacquaint myself and my role to Julia.

The experience of sitting and having a chat over time, allowed for interruptions, shifts in topic, reacquainting to the topic, and continuing to discuss matters outside of my inquiry in a way that felt less rigid, more natural. During this time, Julia told me some things that I did not feel were appropriate to directly quote, so I did not capture Julia's verbal account exactly, as I would in an interview. Instead, I captured a feeling of the interaction, a sense for what Julia was expressing. Rather than gleaning the interaction for a singular perspective, I tried to capture the mood and feeling from the entire interaction, making my role clear where appropriate while also allowing for the spontaneity of our dynamic to play out (Pols, 2005).

Like my experience talking with Julia, many of the interactions in the care home were ambiguous, but by reading body language, tone, and by carefully observing the 'natural' flow of care workers and residents, I etched myself into the daily life of this care home and gently and as transparently as possible. Though the process is complex, it upholds the values underpinning the HCF: that consent is an interpersonal process which occurs temporarily and can change across moments. In the following section, we will share some experiences of seeking consent throughout this research project to further explore the complexity of these interactions.

Eva

"It's warm out there!" I greeted the room, which was buzzing with the sound of electric fans. It was a hot afternoon, and the windows were open to create a cross-breeze in the room. Eva was sitting in a chair in the dining room, dressed in her nightgown (someone explained that this was the only clothing item most residents owned thin enough to be appropriate for this weather). Positioned under a fan, Eva's face was glistening and pale, and her soft white hair was wet on the edges, causing small curls to cling to her temples like wet leaves on a windshield. Mary, one of the caregivers, continued to gently dampen Eva's face with a cloth. "It certainly is, and this poor thing", she said, turning to Eva, "we are simply not accustomed to this kind of heat, are we dear?" Eva sighed and raised her eyebrows in agreement. "Yes, it's far too warm" I chimed in, hoping to join in the small talk. Eva looked away from me, frowning, and then to Mary. Since Eva appeared uncomfortable with my presence, I chose to sit in a chair a bit further away.

In this situation, I quickly understood my participation to be an imposition, as there were clear signs that Eva had felt a sense of discomfort with my voice and presence. Of course, a sweltering afternoon might be a particularly difficult time to engage with someone unfamiliar. I also wondered how it would feel to be sat in a thin nightgown, a logical response to staying cool in the heat, but not with much consideration for Eva's feelings of privacy or dignity. Though Eva was in a common area used by all residents, staff, and anyone who entered the community, her clothing, and the activity of being given a washcloth, were private activities.

Following this event, it is important to explain that I did not observe Eva from a distance without her knowing. As I grew more used to each 'community' within the care home (a separate living quarter with its own common areas made up of about 10 residents and 3–4 staff at any given time), I grew better at focusing my observational eyes on those residents and staff who were willing to participate, and not observing the others, such as Eva in this instance. The households are open to any visitors and the common areas would often contain many different people, coming and going, and when I wasn't on "data collection mode" I would still be around, interacting with people, from whom I did not have consent (or consultee advice), or, as in Eva's case, were part of the study, but from whom I did not have present consent to observe for the purposes of data collection.

I had previously spent time with Eva and grew to understand that she often preferred my presence along with the company of other staff. Eva, who is non-verbal, and who has been living at this care home for four years, is a favourite resident among care workers, and they often explain things to me as they are helping her with mealtimes. Staff will explain how they read Eva's face for signs of being hungry, or not interested in a certain dish. They explain how they might adapt the daily menu to a soft diet.

Whether or not these explanations bother Eva, I cannot readily discern. Staff do not speak about Eva in front of her, rather opting to speak in "we" ("we eat lots of tomato soup, don't we?"). In this way, it did not feel voyeuristic when I participated and observed in her care. But there was a line drawn: I wouldn't accompany Eva to her room or to other areas alone, which I might occasionally do with other residents, with whom I'd established a stronger rapport. I also wouldn't often address her directly, sit too close to her, or even sit at the same table, depending on her mood. During my time in this section of the care home, Eva and I have exchanged the occasional smile, kind glance, or nod. But most of the time, we kept our distance. Through my time in her private living space, I placed myself gently at the periphery, mostly through observation, but also through participation, as Eva and her care workers navigated the presence of an outsider in Eva's home. Importantly, though a stronger rapport did not build during the study, Eva did not always dislike my presence, and in fact, she seemed quite calm and understanding when I would accompany her along with a member of staff. Had Eva consistently demonstrated discomfort with my presence, I would not have included her in the study, as was the case with some other residents. This is a very sensitive distinction which is subjective in nature. Here, I relied not only on my ability to 'read' Eva, but on the comfort and naturalness of staff with whom Eva had a more consistent rapport.

Over time, I became more familiar with residents' daily schedules, and would know when certain residents may be willing to spend time with me. Discerning consent was slightly more difficult with residents who preferred to stay in their room, as I would have to impose in order to gauge consent. I often did this by offering care staff to bring residents' their tea or coffee. This way, I would have a reason to knock and say hello but would also allow for residents to inform me that they would rather be alone, either verbally or through body language (or if they were sleeping, with a physical therapist, on the phone, or in the bathroom, et cetera).

Rebecca

Because she was comfortable with telling me when she did not want to participate, I felt confident that Rebecca's participation was consensual and I visited her whenever she said she was up for it. Through staff, I learned that she did not marry, had no children, and her niece signed the consultee advice sheet, but this was about all that could be gleaned about her life before the care home. When she was in the mood for my visits, she would often tell me about the series she was watching at the time, an antique shopping competition. We would sometimes sit in silence for periods of time as she grew more engaged with her show.

My experiences with Rebecca help illustrate care work through ethnographic presence and sensibilities. She was not always an eager participant, but consent was there, subtly, in the interactions that we did have. This calls into question what a "good participant" may look like (Garand, Lingler, Conner and Dew, 2009). Participation, and what defines "good" participation, could be seen as similar to well-being, which is outlined by the HCF as operating along several connected, but separate values, such as insiderness, uniqueness, and embodiment, running along a spectrum of humanisation-to-dehumanisation. The dimensional understanding may help us to complicate what it looks like to participate "well": remaining solitary, prioritising privacy, and dissenting to participation can be equally valuable to understanding the shape of experience in the care home. There was a slowness, a subtlety to the time I spent with Rebecca. Unlike some residents, who had a seemingly endless supply of opinions and stories to share about their experiences in the care home, Rebecca required patience, slowness. Then, *sometimes,* she would tell me about how it feels to be in her bed, hearing people out in the room but not knowing any of them, about not wanting to know them. Sometimes she would share her feelings of not wanting to be a part of the care home, that her bed-ridden state was physical, but her rejection of the care home was more than that, it was a choice. Her insiderness, keeping a sense of separation from the community in the care home, is where Rebecca seemed to find a sense of safety. "It will be good for her, having those chats, I'm glad that you go in", one care worker told me, and another: "everyone enjoys a nice chat". True, I reflected, but for Rebecca it seems somehow equally valuable to reject the invitation for a chat, to establish her right to a private life in a living situation as public as the care home. Through the slowness of our relationship, Rebecca showed me how she protects her sense of agency by having a boundaried relationship with care workers and with myself (Bartlett and Martin, 2002).

Rebecca's case reminds us that advice given by staff members may not necessarily align with the desires of the resident. Although staff may have a closer relationship with Rebecca, this does not necessarily mean that they know all of Rebecca's preferences or wishes. This raises the question of who is best suited to provide guidance in such situations, which is an issue with the viability of consultee advice (and the importance of this being *advice*, and not consent on the behalf of an individual). Rebecca's case also highlights the empowering effect of active participation, particularly in situations where individuals feel trapped or powerless. By actively participating and expressing her thoughts and feelings, Rebecca can importantly enact her sense of agency and also contribute a valuable voice on how it feels to navigate a limited sense of agency in the care home.

A reflective note

The cross-disciplinarity of care work and research further structured the ways in which participants and myself engaged in this study. These *collaborative moments* expose a multiplicity of interpretive lenses at play–carers offer their interpretations, first, as a supportive insiders' knowledge to help with my introduction to the field (Hastrup, 2018). Later, my interpretive lens, shaped by not only the fact that I was new to the care home, but that I was using my time differently–instead of providing a set of care services for residents over an eight-hour-shift, I could come and go more flexibly, spending longer amounts of time simply 'being' with residents. This eventually meant that I held information that could only present itself slowly, information about mood, preferences, and subtler needs (like making a call or getting a new pillow) which sometimes would fall through the cracks in a busy day of care work.

My role, as a PhD student studying the care home, also meant that these collaborative moments could sometimes feel awkward, and my inquiry could be interpreted by some as criticism. Sometimes I would come into a community of the care home to see carers quickly get off their phones, or stop chatting casually with one another. Though caregivers were given a participant information sheet detailing that their identities would be kept confidential, I worried that they felt they had to participate in the study to please management who had been a part of the recruitment process. There is no way to prevent the possibility of subtle coercion in this case, but I assured care staff that I was interested in the daily life of the residents and my role was not to hawk over carers as they did their jobs, but that I hope to be "part of the furniture" (Draper, 2015, 39). My own working class background, and the fact that my mother had worked as a "lunch lady" in public schools, strengthened rapport between carers and myself, as a "trusted outsider" (Bucerius, 2013).

My 'outsiderness' shaped and guided many interactions around consent and intention. Throughout the study, my foreign identity was often brought to the forefront of interaction between residents, staff, and myself, and was instrumental in establishing consent. First, I am American in the United Kingdom during a time where so few outsiders made their way into the isolated care spaces. My clumsy, untrained hands would often give me away as someone who is not a regular member of staff. Even the way I prepared tea exposed me as an outsider; I steeped tea too long, added too little milk ("is this builder's tea?" one resident joked). I re-introduced myself to residents, accepting "close-enough" titles, such as 'nursing student', 'American girl who wants to talk to us about care', 'who wants to know how we like it here', or sometimes just 'the girl' (which required some more information on my part). When necessary and appropriate, I would remind everyone of my role, my goals in talking to them, and I used my role to help remind residents of why I'd want to ask them questions or sit with them while they lived out the details of their daily lives. Furthermore, my role as an outsider to the care home culture impacts not only possible rapport between residents, staff, and myself, but it also means that I may not always correctly read body language or cultural and social cues in the way they are intended by participants.

Throughout the study, I experienced a shift in my initial hierarchical positionality - a common feature of any research context - through a process of mutual accommodation (England, 1994). As we became accustomed to one another, the hierarchical and procedural form of seeking ethics became more nuanced and entrenched, as I became a "guest of the guests" (Boccagni & Bonfanti, 2023). Additionally, vulnerability occurs and is experienced by everyone involved in the study–not only those lacking capacity to consent–such as the vulnerability experienced by staff workers in relation to more privileged residents (Reed-Danahay, 2001). These observations highlight the significance of an ethnographic approach in healthcare research, which requires sensitivity to power dynamics and the complex dynamics of vulnerability in healthcare settings. This experience underscores the importance of process consent not only for individuals lacking capacity, but also in any setting where a power dynamic exists between the researcher and participants.

Discussion

Doing ethics is a messy process. It took time to build a sense for what consent, and just as importantly, *dissent*, looked like from each potential participant in this project. It took time to understand the general flow of the communities within this care home, each being quite different, and to gently find a space where I could fit. Importantly, it took time to build trust. Relational ethnographic work requires a 'caring for insiderness' (Desmond, 2014; Todres, Galvin, & Dahlberg, 2014). My own positionality was both an asset to gaining information about this community, and a barrier to understanding certain complex cultural cues. The interaction required to repeatedly assess consent, (an initial concern for the HRA ethics committee as being "overburdensome"), varies greatly from individual to individual and that this sense for being a burden is developed over time and through rapport (Kontos, 2006). Informing Julia that I am interested in her experiences for my study throughout our conversations looked different than my long afternoons spent with Rebecca, for instance.

The need for not just more, but deeper, explorations of the world of residential care for older adults is pointed to over and over (Westwood, 2016; Simpson, Wilson, Brown, Dickinson, & Horne, 2018; Cowdell, 2013). Yet, the struggle to represent the experiences and voices of participants who do not demonstrate capacity began the moment this project came into existence. This begs the question not only of representation, but the power structures which generate said representations (Marcus & Fischer, 1986). It is by describing the care home from *within*, experiencing along with, which will help us to move beyond paternalistic views and treatment of older adult care recipients (Connor, 1989), and to engage with the lived experiences of residents. The phenomenological approach underlying the HCF is useful when engaging in such research. Even with consultee advice, I was still tuned into looking for signs that each participant wants to take part in the study (e.g. through body language, verbal expression). This relational approach to consent, bound up in the ethnographic design, is good practice and is informed by such a phenomenological approach to well-being and care.

Describing the way one might tread carefully through intersubjective events to best respect one's wishes to consent or dissent to study participation is difficult to describe in an itemised formal ethics application, or to make sense of in a procedural fashion (Fluehr-Lobban, 2003; Simpson, 2011). The case studies presented in this paper show that there is scope for a different approach which is much more ethical and inclusive than can be fully accounted for in the procedural ethics. There is no possibility that I could have described my experiences with Julia, Eva, or Rebecca before going into the care home and meeting them, or even to explain which percentage of residents would likely want to sit and have a chat with me on which days, or which times of the day the care home would be most active. Instead, ethically engaging with, including, or excluding potential participants was bound up in the care logic of the care home and relied on all actors to carefully negotiate our positions (Cascio and Racine, 2019).

In a project which aims to highlight the stories of those living in this care home, how are these stories witnessed, gathered, and represented? The justification for this project existing at all is that older adults' experiences of care, and in this particular case, residential care, is underexplored, and tends to focus on the institutional failures over the lived experiences of older adult residents (Malta-Müller, Kirkevold, & Martinsen, 2020). It is not too bold to call this project one of anti-oppression, one which would do well engaging with ongoing debates in postcolonialism and disability studies–grappling with subjectivities and directly engaging with a 'politics of position' to highlight which voices are enabled to represent whose experiences.

Conclusion

Consent, like care, is not an immutable *thing*, but it is a messy, nuanced process. Conducting research with the ethos of *process consent*, wherein one reads each situation for consent between individuals, allows for the inclusion of participants regardless of their capacity to provide informed consent. The methodological issues of engaging adults with varying capacity to participate in ethnographic research are supported by the philosophies of care and caring (Donnelly, 2004). Well-being, an existential, multi-faceted experience which occurs along varied, and sometimes even contradicting, characteristics, is supported in this process, a way to "care for insiderness" (Todres et al., 2014). The balance, for instance of privacy or solitude, for the chance to share one's experience and engage in research is a choice which is taken away by overly paternalistic ethics barriers. In fact, research can be a component of the care matrix. The ways in that engaging in research can improve mood and well-being among older adults has been explored (Butterworth, 2005; Grout, 2004). With process consent, consent is negotiated through the relationships built between researcher and participant, be it staff or care home resident. The strength of the ethnographic design parallels the humanisation of care framework: to de-centre the verbal interview as a story-source, to listen and observe for the embodied ways participants may communicate what matters to them (Kontos, Miller and Kontos, 2017). Developing a consent process which adequately values and understands the complexities of ethnographic research in care home settings with older adults is a necessary next step in addressing our need for more inclusive research, and ultimately better care.

Declaration of Competing Interest

None.

Data availability

Data will be made available on request.

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