



Aalborg Universitet

AALBORG UNIVERSITY
DENMARK

Ethics and the impossibility of the consent form: Ethnography in a Danish nursing home

Balkin, Emma Jelstrup; Kollerup, Mette Geil; Kymre, Ingjerd Gåre; Martinsen, Bente; Grønkjær, Mette

Published in:
Journal of Aging Studies

DOI (link to publication from Publisher):
[10.1016/j.jaging.2023.101110](https://doi.org/10.1016/j.jaging.2023.101110)

Creative Commons License
CC BY 4.0

Publication date:
2023

Document Version
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):
Balkin, E. J., Kollerup, M. G., Kymre, I. G., Martinsen, B., & Grønkjær, M. (2023). Ethics and the impossibility of the consent form: Ethnography in a Danish nursing home. *Journal of Aging Studies*, 64, [101110].
<https://doi.org/10.1016/j.jaging.2023.101110>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal -

Take down policy

If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.



Ethics and the impossibility of the consent form: Ethnography in a Danish nursing home

Emma Jelstrup Balkin^{a,*}, Mette Geil Kollerup^{b,f}, Ingjerd Gåre Kymre^c, Bente Martinsen^d,
Mette Grønkjær^e

^a Department of Clinical Medicine, Aalborg University, Sdr Skovvej 15, 9000 Aalborg, Denmark

^b School of Nursing, University College of Northern Denmark, Aalborg, Denmark

^c Faculty of Nursing and Health Sciences, Nord University, Postbox 1490, 8049 Bodø, Norway

^d Department of Public Health – Department of Science in Nursing, Århus University, Tuborgvej 164, 2400 Copenhagen, NV, Denmark

^e Clinical Nursing Research Unit, Aalborg University Hospital & Department of Clinical Medicine, Aalborg University, Sdr. Skovvej 15, 9000 Aalborg, Denmark

^f Clinical Nursing Research Unit, Aalborg University Hospital, Aalborg, Denmark

ARTICLE INFO

Keywords:

Informed consent
Ethnography
Older adults
Nursing homes
Cognitive impairment
Documents as active agents

ABSTRACT

Based on ethnographic fieldwork in a nursing home in northern Denmark, this article addresses challenges experienced in putting formal ethics requirements into practice. We consider how to unite procedural ethics with actual, lived ethics, when researching with vulnerable participants who live with a cognitively impairing condition. The article centers on the story of one resident, who wanted to share her experiences with what she had perceived as inadequate care, but who balked once the wordy consent form was produced. The resident panicked that her words could now be used against her, that talking with the researcher would (further) compromise her care. She was caught in a bind, on the one hand she had a deep desire to tell her story, on the other the piece of paper in her hand threatened to trigger her anxiety and depression. In this article we therefore approach the consent form as an agent. By mapping out these unintended consequences of the consent form, we wish to draw attention to the complexities of ethical research conduct in practice, ultimately arguing that the concept of appropriate informed consent should be broadened so that it is sensitive to the lifeworld of participants.

Introduction

Ensuring that research participants give informed consent is a cornerstone of ethical research conduct. However, ascertaining what counts as informed consent can be challenging when working with cognitively impaired persons. The standard approach is to ask the participant to sign a consent form, which simultaneously informs them of their legal rights. While the formal consent form seems like a benign and simple tool for ensuring informed consent is given, in this article we will problematize this taken-for-grantedness. Because to very old, cognitively impaired persons this form may not appear benign at all. For some - otherwise willing - participants it can be experienced as both bamboozling and threatening.

The empirical basis for this article is an ethnographic project that examines well-being in very old age (85+ years) in two nursing homes in

Denmark. We take as our starting point the case of the recruitment process of one resident, we will call her Helen, who wanted to participate in the research project, but for whom the consent form became not only a significant barrier, but a source of actual distress. Helen initially demonstrated both enthusiasm for participating in the research, as well as an understanding of what it entails to participate. However, once she that she was required to sign the consent form, she panicked. Helen suffered from anxiety and depression and had a vexed history with bureaucratic documentation and the ways in which it could affect her lifeworld. By mapping out these unintended consequences of the consent form, we wish to draw attention to the complexities of ethical research conduct in practice, ultimately arguing that the concept of appropriate informed consent should be broadened. While Helen did eventually give her consent to participate in the study, the mechanics of the process caused her undue distress.

* Corresponding author.

E-mail addresses: emmaesjb@dcm.aau.dk (E.J. Balkin), ingjerd.g.kymre@nord.no (I.G. Kymre), bm@ph.au.dk (B. Martinsen), mette.groenkjaer@rn.dk (M. Grønkjær).

<https://doi.org/10.1016/j.jaging.2023.101110>

Received 31 May 2022; Received in revised form 20 January 2023; Accepted 24 January 2023

Available online 7 February 2023

0890-4065/© 2023 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Drawing from both anthropological theory and new materialism (Appadurai, 1986; Birk, 2016; Knappett, 2002; Latour, 2005; Law & Mol, 1995; Prior, 2008) we view the consent form as agentic. For Helen, the consent form was representative of the bureaucratic documentation that entangles with formal institutional processes of care delivery, with the ability to enact changes in the immediate lifeworld. To her, the consent form appeared as a proxy for a system that had failed her. From this vignette, we delve into some of the complexities involved in putting formal ethics requirements into practice. In doing so, we draw attention to the epistemological and methodological tensions that arise when trying to marry the legally required consent form with *in situ* ethics. Helen's example also highlights some of the practical challenges in discerning whether capacity for consent is present.

The fieldwork was conducted by Emma Jelstrup Balkin, and when talking about the experiences in the field, we use the first person to convey the ways in which ethics unfold intersubjectively in particular situations (Lambek, 2015) and in this article we will argue also *inter-objectively* (Latour, 1996). First proposed by Latour interobjectivity refers to the ways in which the human and non-human interact and entangle to produce particular subjectivities, or "ways of being a person" (Birk, 2016: 193). Applying this lens to our analysis allows us to consider the role the consent form may play in the ethnographic encounter and beyond.

Ethnography and ethics

Ethnography attempts to understand the lived experiences of persons in their social and cultural contexts (Madden, 2017). This is usually achieved through long-term, in-depth involvement in the day-to-day lives of the people studied. Ethnography, particularly within the anthropological tradition, has tended to concern itself with marginalized groups of people and has a unique ability to gain an understanding of the experiences of marginalized people (Banks, 2018). Nursing home residents arguably form a marginalized group in society. Existing outside the bounds of "ordinary society", they are "almost invisible" (Denning & Milne, 2011: 2). In addition to being unseen in society, they are also largely unheard, especially those who live with cognitive impairment (O'Connor, Mann, & Wiersma, 2018; Wiersma et al., 2016). Ethnography is therefore uniquely positioned to bring the experiences of this marginalized population to the fore.

While ethnography as a method employs certain research techniques, namely participant observation and interviews, its real strength lies in the way it is grounded in the interpersonal relationship between researcher and interlocutor. The ethnographer is the instrument for knowing (Ortner, 2006). Because the ethnographer uses their whole self to build relationships with their interlocutors in the field, the ethnographer cannot simply be interchanged with someone else (Pels et al., 2018). Ethnography then, is above all, a relational enterprise between human subjects (Bell, 2019). Based on trust and reciprocity, these interpersonal relations are the basis for ethnographic knowledge production (McGranahan, 2018). It is through this relational approach that we are able to grasp at the granularities of the lived experiences of our interlocutors (Atkinson, 2017).

This, very personal, approach can be challenging to reconcile with formal ethics requirements. Ethnographers are, on the whole, acutely aware of their ethical obligations (Pels in Pels et al., 2018), chief among them to do no harm, to be transparent, to obtain informed consent, to be respectful and to be aware of the power differentials that may exist between ethnographer and participant (AAA, 2012). These are the principles guiding fieldworkers as they navigate relations in, and beyond, the field. Increasingly, ethnographic projects are subject to formal ethics review processes in the form of Institutional Review Boards (IRBs) or Ethics Review Boards (ERBs). The purpose of such boards is to "provide objective and independent assessment of the harms and benefits to those who participate in research as its subjects" (Simpson, 2011: 378). In and of itself a perfectly noble goal. However,

these boards take a different approach to ethics, one that originates in the biomedical field in the 1950s and 1960s (Murphy & Dingwall, 2007). This approach is modelled on experimental research in which the potential risks to the participants should be accounted for before research can go ahead. It therefore is framed within a positivist approach, which demands that the research trajectory be mapped from the outset, including who the participants are, what questions they will be asked, the exact locations of the research and what the results are expected to be (Murphy & Dingwall, 2007; Wynn, 2018). These expectations are antithetical to the way ethnography works. Ethnography is explorative, inductive, iterative and emergent in nature, making procedural ethics ill-equipped for handling the kinds of ethical dilemmas that arise over the course of ethnographic fieldwork (Hastrup, 2009).

One fundamental aspect of ethical research to which most, though not all (Bell, 2014), researchers across disciplinary divides can agree is that of informed consent (Fluehr-Lobban, 2013). Researchers must ensure that their participants understand the purpose of the research and enter into it voluntarily. The standard way of obtaining informed consent is through the use of a consent form. A sheet of paper to be signed by the participant, granting the researcher the right to use the information provided by the participant. Institutions claim that the consent form grants protection to research participants (Wynn & Israel, 2018). Its use in ethnographic research has been criticized by other scholars, who point to consent as something that is continuously negotiated over the course of the research engagement, rather than a one-off event (Bell, 2014; Felzman, 2020; Lederman, 2007; Murphy & Dingwall, 2007; Plankey-Videla, 2012; Wynn & Israel, 2018). In a study conducted by Lisa Wynn in 2010, surveyed ethnographers reported that the requirement to use a written consent form was often insensitive to local contexts and proved inimical to their research (Wynn, 2011). In many research settings, the written consent form "symbolized colonial histories, capitalist landgrab or state surveillance bureaucracies" (Wynn, 2018) making potential participants understandably suspicious and reluctant. At the heart of ethnography is the trust that the fieldworker builds with their interlocutors (Pels in Pels et al., 2018). Introducing the consent form into this relationship is often perceived as a breach of that trust (Wynn, 2011).

The issue of how to obtain informed consent when working with cognitively impaired older adults is another matter of concern. How do we assess a person's capacity for consent? Cognitively impaired older adults are often considered to be a vulnerable population in need of protection, which has long resulted in their exclusion from research (Beattie et al., 2019; Dewing, 2007). This is reflective of an attitude that sees research as intrusive, rather than empowering (Felzman, 2020; Russell & Barley, 2020). As cognitively impaired older adults are now increasingly being included in research, those working in this field point to the value of "process consent" (Dewing, 2002; McKeown, Clarke, Ingleton, & Repper, 2010). Based on a feminist ethics of care, process consent hinges on the interpersonal relationship between researcher and participant; and is built around the following principles: "informed flexibility, sympathetic presence, negotiation, mutuality and transparency" (Dewing, 2007: 13). These have also been the guiding ethical principles of the ethnographic project on which this article draws.

Entering the field: ethical preparations

Unlike in many other countries, conducting qualitative research in Denmark generally comes with fewer of the formalized ethics restrictions described above (Murphy & Dingwall, 2007, Pels in Pels et al., 2018). Universities uphold their responsibility for the ethical conduct of research through education and guidance (see Forskerportalen, 2022). There is no requirement for formal approval from an Institutional Review Board. However, if the researcher wishes to collect "sensitive information", it is a requirement that all research participants sign the standard EU General Data Protection Regulation (GDPR, 2016) consent form. Such sensitive information is described on the form as: "health

information, race and political conviction etc.” This is a rather vague description that means that in reality most qualitative researchers – not knowing exactly where a semi-structured interview might take them – need to secure a signature on this form, lest they run the risk of not being able to use their data. In addition, this being an EU funded project, I was also required to obtain approval from an external ethics scrutiny board. This process was much less extensive than those of the IRBs mentioned above. However, it did ensure that potential ethical concerns were appropriately taken into consideration, to the extent that that is possible before entering the field.

For this study, I had been given consent from both the authorities and the director of the nursing home to conduct ethnographic research. However, I of course still needed to obtain informed consent from individual interlocutors whom I wished to interview. To accompany the consent form, I wrote a simply worded information letter about what the project entailed and what it would mean to participate, taking care to not make any grand promises about what the outcome might be, knowing that it is possible for research participants to have certain expectations around the outcomes of a study (Atkinson & Delamont, 2018; Birch & Miller, 2012; Murphy & Dingwall, 2007).

Entering into a field, where potential interlocutors are already deemed vulnerable by the system, caused many reflections on the ethics of doing so. As a starting point, we wanted this project to be as inclusive as possible. After all, the aim was to reflect the reality of lived experiences in nursing home care. However, we also anticipated some ethical quandaries. We initially tried to circumvent these in the research proposal by suggesting that Emma would only work with residents without dementia, so that we could ensure informed consent was possible. On the ground, this soon proved to be somewhat naive. None of my interlocutors have dementia diagnoses, but at this advanced age most have some cognitive impairment in the form of memory loss, executive dysfunction or mild confusion. To mitigate ethical challenges, I used process consent (Dewing, 2007): telling them often who I was and why I was there. When they mistook me for a staff member, I made sure to explain that I was an independent researcher. I tried to keep keenly attuned to their signals, so that I could back off if my presence became too taxing. There were also many other residents who did have dementia, with whom I interacted because the nature of ethnographic work meant that I was often present in a space that is their home, and they *wanted* to engage. Selecting only those without any obvious cognitive impairment felt unethical, and, as Helen’s case proves, also very difficult practically. Therefore, remaining alert to how I was received and how my presence was perceived was important at all times – as it is in all ethnographic research.

Thus, while I was prepared for issues relating to dementia, I was less prepared for other kinds of cognitive impairment. While depression and anxiety can be symptoms of dementia, geriatric depression can also cause non-neurodegenerative cognitive impairment (Invernizzi, Simoes Loureiro, Kandana Arachchige and Lefebvre, 2022, Lockwood, Alexopoulos, Kakuma, & Van Gorp, 2000), for example in the form of executive dysfunction, which includes “deficits in planning, strategy development, spatial working memory and verbal fluency” (Lockwood, Alexopoulos, & van Gorp, 2002: 1119, see also Morimoto, Kanellopoulos, Manning, & Alexopoulos, 2015). In this article it is this kind of cognitive impairment we consider, and its implications for obtaining informed consent, as well as the ways in which existing consent procedures complicate the ethnographer’s ability to conduct research ethically.

Meeting Helen

“When are you coming to talk to me?” Helen said across the lunch table in the nursing home dining room. We had not yet been introduced, but she had heard of me and was eager for her story to be included in my research. I introduced myself and told her a bit about my project, that I was there mainly to learn about the older persons’ perspectives, I

wanted to know what it feels like to be a nursing home resident. She said that I could come and visit her any afternoon, “in the mornings I’m no good” she said. I thought to myself that maybe she was not a morning person. Later it became clear that mornings were tormenting for Helen, as this was when her anxiety peaked. But, speaking confidently and clearly now, Helen came across as intelligent and lucid and I thought to myself that informed consent would not be a problem with this resident. She knew who I was and what I was doing, and she was *asking* to be included. This would soon prove to be much more complicated.

The next day I visited Helen in her cosy room to discuss her participation. It was neat and tidy, the paintings on the walls bearing witness to her former life. We sat in her comfortable armchairs; she offered me some walnuts and I told her once more about my project. She was lucid and keenly interested. I handed her my information letter and consent form and explained that the interview would be on her terms, we could stop at any time, she did not have to answer my questions if she did not want to and that what she told me would be anonymized. I would use pseudonyms and I would not recount any of what she told me to the staff. But I would use her story to gain more knowledge about older people’s experiences and lifeworlds. “Yes” she said, “I would like that, if I can help others to not go through what I had to, then I would like that.” Helen was keen to get started with the interview straight away, and in my desire to acquiesce to her needs as much as possible, I initially took her oral consent as the green light to go ahead, thinking that the signature was a formality we would get to soon. She glanced at the forms, then put them aside and immediately started telling me her story. Helen had a pressing need to talk *now*, and I decided in a split second that the most appropriate thing to do was to let her and to worry about the form later. Should she not want to participate formally, I would simply delete any record of this conversation and chalk it up to “unusable data” (Hamilton, 2017), I decided.

I asked if I could record our conversation and she said yes. As luck would have it, my dictaphone had died and so I scribbled notes instead. She did not mind. When she started talking, she did not stop. She had a lot to say. Helen never thought she would end up in a nursing home. She and her husband of 60-odd years were very independent, until he became seriously ill and could no longer be cared for at home. After lengthy hospital stays, he was placed here in the nursing home, and after some months Helen also got a room here. Shortly after Helen moved in her husband died and her whole world fell apart. She plunged into a deep depression, exacerbated by what she experienced as very poor care. Helen’s grief was initially met with understanding, but soon it was also expected to abate. I recalled that a staff member once told me that in the nursing home death is always present. In other words, the staff experience dying as an everyday occurrence, attached with a list of practical tasks to manage. But for Helen, understandably, the death of her husband was not an everyday occurrence. She felt pressure to “get over it,” which only served to deepen her grief. She now thinks of the period of her husband’s demise as a traumatic event that triggered a severe anxiety in her.

Helen talked candidly about her anxiety and depression, a condition she was struggling to come to terms with. “I wish I didn’t have these dark thoughts. I wish I could just be happy and carefree like... like other people” she said, gesturing towards the door and the other residents outside it. This speaks to her loneliness and alienation in the nursing home. She told me that the staff do not understand what it is like for her. They try to force her to do things in the mornings, when she is at her worst. They demand that her day should follow the same institutional routines as everyone else. They say that is what is best for her. But Helen simply cannot comply. She spends most mornings in bed, crying. Around lunch time the cloud starts to lift, and she can somewhat get on with her day. Talking helps, she said, but the staff do not have time to talk. The nursing home does not make provisions for talk therapy either. When I later asked staff whether the nursing home ever employs the services of a psychologist, they looked at me as though I was speaking a foreign language.

After we had talked for more than two hours, a carer entered and said it was soon time for dinner. “I think she’s snooping a little,” said Helen. But it was indeed time for dinner. We started to wrap up our conversation. I thanked her for her time and trust, and she said it had been wonderful to have someone really listen to her. She pulled out the consent form again and her mood visibly changed. “What exactly is this?” She asked nervously. I explained that it just (upon reflection this “just” seems anything but) meant that I am allowed to use the information she has given me but that she will remain anonymous. But she was not really hearing me now. The anxiety started to wash over her, and she began to panic. The consent form in her hand stared back at her with malice. “No,” she said haltingly, “no, I don’t think I want to sign this.”

Initially, this reaction took me aback a little. She had already consented to the interview, in fact *asked* to be interviewed. We had had a great conversation. Helen had been visibly relieved by relaying her burden. I had explained to her the terms that I was there under and that had been fine. She had enquired whether I would share our conversation with the staff and I had assured her that I would not. Signing the form now was merely a formality. But it is perhaps not surprising that the form elicited this reaction. It is a densely worded document, in small font, with a legal vocabulary that refers to various sections of the GDPR legislation (See Fig. 1). Written in Danish, the form provides the potential participant with information about their legal rights in accordance with GDPR legislation. Following a brief description of the

project, it then informs them that the university may collect the following data: “regular personal data (name, address, email, age, self-published data), “confidential personal data“ (social security number, grades, significant social problems etc.) and “sensitive personal data“ (health information, race, political conviction etc.). The “etc” is not explained further. The form then includes contact information for the primary researcher, as well as the university legal department, and advice on how to lodge a complaint. It details who the information will be shared with and when it will be deleted. It then asks the potential participant to sign in order to allow the university to collect their data for research purposes. This is the official university consent form that all research participants must sign. I had asked the university to allow me to make a simplified version of this form, containing all the relevant information in an easy-to-understand language and with large font. At 85+ years vision is a problem for most of my interlocutors. But the university legal office had rejected my suggestion, insisting I use the standard form. Universities, too, have an obligation to ensure the GDPR regulations are followed and therefore are reluctant to grant flexibility, even in situations, where it is so clearly warranted.

Understanding the context of hesitation

To understand Helen’s hesitation, it is necessary to recognize that aged care is steeped in bureaucratic documentation. Every time a staff member enters Helen’s room, they note down why they are there, what

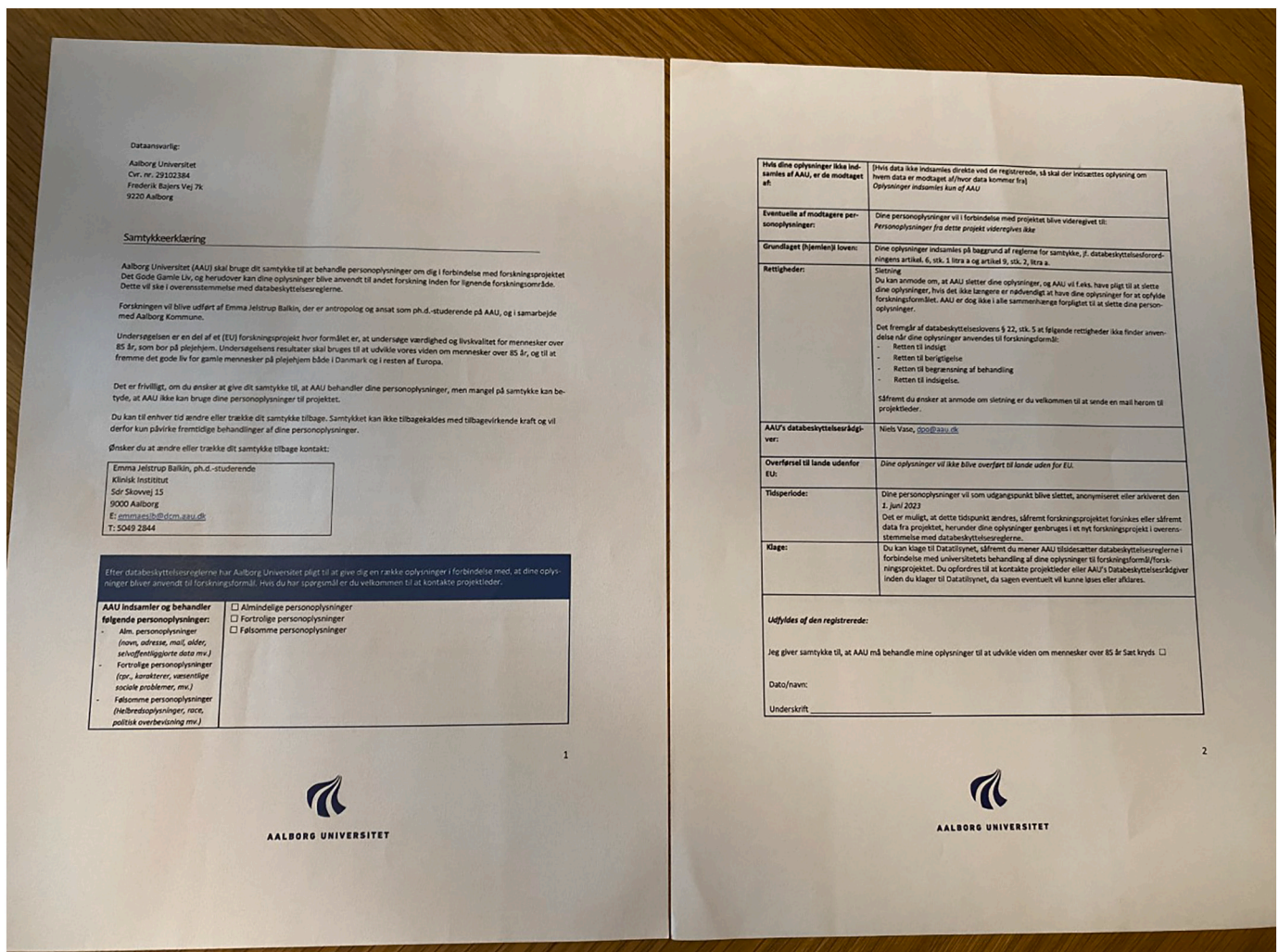


Fig 1. The consent form.

they have done there, what the resident said or did or needed. Every aspect of institutionalized life is documented. The intention behind this is to ensure a high standard of care. But that is not always how this is experienced by the resident. The notetaking, whether on the clipboard or iPad mediates the resident-carer relation and interrupts its direct intersubjectivity. Instead of remaining an immaterial and immediate relation between two persons, the interaction materializes in the form of a document that will go and live a life elsewhere, outside this room, outside this moment.

Helen has had bad experiences with these kinds of documents. When she first moved here, her anxiety spiralled, and she sank into a deep depression. The staff could not handle her in a way that felt comforting and reassuring to her. Instead, she felt humiliated and violated by their attempts to help her “get on with things.” During those first harrowing months in the nursing home Helen had complained about her treatment. “I had to go all the way to the top,” she says. “Have I no rights here?” she had asked. The nursing home director had responded by saying that if Helen was unhappy, she could just move out. Eventually Helen’s complaints, with the help of her daughter, reached the authorities, who sent a representative to review what her needs were. The representative took down a lot of notes, filled in forms. The representative left, the forms were filed.

Helen had expected this to be the start of things improving. Instead, things got worse. The information she thought she had given to the authorities in confidence, was instead relayed to the staff, who subsequently confronted her about it. Why was she not happy with her care, they wanted to know? They started showing up her in room to observe – and note down - what she could and could not do, including watching her take a shower. To Helen this was deeply humiliating and exacerbated her anxiety.

It now becomes clearer why Helen was so suspicious of documents. For Helen, the consent form was representative of a bureaucratic system that had failed her. That had systematized her distress in order to flatten it. Instead of empowering her, it had stripped away her dignity. With her own signature to rubberstamp it. The consent form was acting on Helen, making her anxious. It also had the potential to act elsewhere, once it moved from her hands to my folder to an unknown place in the system. In reality, it would sit in a locked cupboard in my office for the duration of my PhD, then to be destroyed. But to Helen, it carried the potential to appropriate her story, to turn her words against her. She worried that signing the document would turn her story into an immutable fact, one over which she no longer had ownership. Helen knew that the documentation filled out in her room had the ability to collapse time and space and connect her to disparate parts of the system, and not to her advantage either. That these documents could take on other meanings than she had intended and have unforeseen consequences in her immediate lifeworld. I left Helen’s room feeling upset that the form had caused her such distress, and angry that the structures in place to safeguard an ethical approach to research had instead had the opposite effect.

I met Helen again a few days later and she pulled me aside to say that she had decided she would not give her consent. It had started causing her stomach pains, a symptom of her anxiety. And she was concerned it would trigger her depression. I of course accepted her decision, any request to reconsider would have bordered on coercion. She was very apologetic and worried that she had wasted my time. I assured her that she had not and that her health and well-being were much more important. It was like she was trying to talk herself into signing and I was trying to talk her out of it. The formal consent form gives no guidance on how to handle the kinds of negotiations it spurs. This legally required form was starting to appear to me, not as a simple piece of paper, but rather as an active agent in my relationship with Helen. We now turn to an analysis of documents as active agents.

Documents as active agents: the imagined life of the consent form

In anthropology, the distinction between people and things has long been acknowledged as ambiguous (Appadurai, 1986; Knappett, 2002; Latour, 2005; Law & Mol, 1995). From a new materialism stance, Law and Mol argue that humans and objects are mutually constitutive (Law & Mol, 1995). Subjectivity, from this perspective, is not an interior property, it is rather something that emerges at the intersection of “affecting (the world) and being affected (by the world) [...] between mastering (the object) and being mastered (by the object)” (Birk, 2016: 193). Material objects are implicated in webs of social action, or networks, where agency is distributed between human actors and material objects – an *interobjectivity* (Latour, 1996). Drawing on actor-network theory, Prior considers documents to be “vital objects” that can “drive and shape political, economic, medical and scientific activities as much as humans do” (Prior, 2008: 833). As such, documents are not merely “inert carriers of content,” rather they *do* things, they act in the world (Prior, 2008). Nursing home documents act as vital objects organizing knowledge about each resident, charting her needs, her (dis)abilities, her diagnoses and medication, and fragments of her history and sometimes her preferences. The idea is that these files will aid staff, so that any staff member will be able to access what is deemed to be the essential knowledge about each resident. These files render certain things knowable, while obscuring others. All of Helen’s important details were there in her files, but she did not feel known.

The documents enter into a complex network, linking Helen with other actors. Helen experienced first-hand how a document could “drive forward patterns of activity” (Prior, 2008: 830), positioning her differently in her care relationships. Rather than mastering the object, the object – the document – was mastering Helen. Helen’s life and its vicissitudes were through documents transformed into a “case” that travelled up the rungs of the system and back down again. The case document played an active role in directing staff attention and producing particular subjectivities (Whitaker, 2021). Rather than listening to what Helen was saying she needed, the staff listened to what the case document was telling them she needed. Helen wanted to stay in bed until lunch time, to be left alone to cry in peace. The file, however, said that Helen needed to get out of bed and on with the day. If she was feeling down, the morning routine would do her good. In the debate between Helen and the file, Helen’s voice was often drowned out. The file carried more authority. Helen’s reluctance to sign the consent form thus cannot be separated from her experiences with the power of documents in the nursing home. The care staff may well have a different experience, but for reasons of confidentiality and trust I have not discussed Helen’s story with staff. Nor did I read her file. This analysis therefore is based on what Helen herself told me, and her lived experience of the way documentation is used in the aged care system. Accordingly, this article should not be read as a critique of individual care staff, but rather of the parameters set by a system which relies heavily on documentation to direct care praxis.

Consenting to what?

In the vignette we have presented above, we have fleshed out one person’s relationship to documents in the nursing home context. We have done so for several reasons. One is to exemplify how ethical quandaries can play out in the field, with implications that go well beyond what can be anticipated by formal procedures; another is to demonstrate the importance of understanding context. The nuances in Helen’s story are only made graspable through the in-depth engagement with both Helen and her immediate lifeworld that ethnography makes possible. But the requirement to use a written consent form *imposed* ethical dilemmas instead of mitigating them.

The extent to which informed consent can ever be given for ethnographic research is a matter of debate. The ethnographic researcher can

never fully inform the participant about the research (Atkinson & Delamont, 2018). This is not through a desire for duplicity (Pels, 1999). It is simply the nature of the ethnographic method that it is emergent and unfolding. Ethnography often uncovers unanticipated findings. This is in fact one of its strengths. But it leaves open the question of how far the participant's consent stretches. Helen had already experienced losing control over her own story and the consequences it had on her everyday life. We are very mindful not to reproduce this effect in the process of turning her story into data - or perhaps more aptly "creata," a concept deployed by Brinkmann to underline how qualitative data are not independently existing facts, but rather something created actively and collaboratively between the researcher and participants (Brinkmann, 2014) - and eventually into published scholarship.

Even though the consent form would have no actual implications on Helen's care, it is also too simplified to say that it would only sit in a locked cupboard. For while no one in the care system was going to look at it and draw conclusions from it, it was nonetheless giving us, the research team, the green light to take Helen's story and transform it in ways beyond the immediate scope of the initial consent. By signing the consent form, the research participant hands over control of their story to the researcher. While they have the right to withdraw at any time, they have no say over how the data is analysed or employed. The ethical ethnographer, then, needs to consider what it is they are asking for consent for (Felzman, 2020; Murphy & Dingwall, 2007).

In an ethical research encounter the participant should not be exposed to harm, nor should they feel taken advantage of, either during or after the event. In reality, however, a signature on the consent form can in no way guarantee this. Anthropology has unfortunate historical entanglements with colonialism, during which riches were extracted from indigenous populations for the gain and prosperity of the colonial powers (Aull Davies, 2007; Pels, 1999). Ethnographers today must be mindful to not metaphorically continue this legacy of exploitative extractivism, by mining their participants for "rich data" as a means to their own scholarly ends, without regard for the implications for the participant and their communities. An ethnographer's ethical responsibility extends to how they handle the "raw data" of an interlocutor's story in the process of turning it into anthropological knowledge.

When I interviewed Helen, she talked for a long time. She had a lot to get off her chest, or "off her heart" as we say in Danish. I know that Helen wants her story to contribute to improving nursing home life for other people. But when it comes to telling that story there are decisions to be made about how much detail to provide in order to make this point. The ethnographic interview can at times prove to have a therapeutic effect, because it creates a space in which the participant is able to narrativize painful experiences (Birch & Miller, 2000). While this can be beneficial to the participant, it also means that sometimes information is revealed unintentionally. The signature on the consent form, however, allows me to use it all - from its point of view, it is all data. But because I was there in the room, played a part in birthing the story in this particular form, I am aware that there are parts I should exclude. What emerges from the ethnographic encounter is not just commodified data (Pels in Pels et al., 2018, Russell & Barley, 2020). This vulnerable person placed her story in my hands and my ethical obligation to her extends very much to what I do with this story. The consent form gives no guidance on how to parse this. The form just wants to be signed or rejected. Use it or lose it, so to speak. Here the researcher is left to puzzle this out for themselves. Process consent, on the other hand, gives the participant the flexibility to modulate their participation.

Consent as an on-going process

The consent form gives the impression that consent is a one-off static event (Plankey-Videla, 2012), and in doing so collapses the temporal aspect of consent into a blanket "yes or no" answer to participation (Felzman, 2020). But the reality of ethnographic research is that it takes

place over an extended period of time; during which consent may at various times be present or absent. Reorienting to a process concept of consent recognizes that consent is something that is embedded in social relationships and should be continuously negotiated along the way. As Wynn and Israel argue consent can only be established through human interaction (Wynn & Israel, 2018). This is in line with Dewing's process-consent approach to research with cognitively impaired older adults, where the research participant's non-verbal cues are taken into account and given equal value to the opinions of carers (Dewing, 2007). Continuously monitoring whether consent is present helps to minimize the risk of coercion. This requires much more of the researcher than simply securing a signature on the consent form, but it is also more likely to achieve real ethical engagement in the field. As Hammersley reminds us, it should not be assumed that compliance with procedural ethics requirements is indeed ethical (Hammersley, 2009).

In this article we highlight some of the complexities that can eventuate when conducting ethnographic research with cognitively impaired older adults. In this case it proved difficult to even ascertain whether cognitive impairment was present, at least at the outset. It is worth noting that staff were very hands-off and did not impose any restrictions on who I was allowed to approach. Therefore, I did not initially know that Helen suffered from mental illness when she first approached me. It was Helen herself who later told me about her struggles with anxiety and depression, and it was only when she reacted with such fear of the consent form that I realised her participation might be problematic, though by no means impossible. What this also highlights, however, is that there is room for more nuance in our understanding of cognitive impairment in older adults. Because in this age bracket cognitive impairment is often synonymous with dementia.

But dementia is not the only cause of cognitive impairment in old age. The link between depression and cognitive impairment is well-known, yet not well-understood (Halahakoon, Lewis, & Roiser, 2018). While Helen did not suffer from dementia, her mental illness did cause, at least transient, cognitive impairment. Indeed, depression in later life is associated with more severe cognitive impairment than in younger years (Invernizzi et al., 2022). For Helen, this is particularly bad in the mornings, when her anxiety peaks and she feels unable to think or reason. She copes by staying in bed, waiting for the beast to leave her alone. Around lunchtime she starts to feel better. The symptoms ease and she starts to feel a little more like herself.

What this points to, is the difficulty researchers can encounter in discerning whether there is capacity for informed consent. When I first met Helen, she appeared lucid as we engaged in a mutual conversation. She asked intelligent questions about my study and specifically asked to be included in it. But by Helen's own account, when she is in the cloud of depression and anxiety, she loses her ability to rationalize and is frightened of everything. For me then, as a researcher, it was not only an issue of ascertaining her capacity for consent, but also a matter of whether my presence and engagement with her would trigger those symptoms. As it turned out, it was not my personal presence, but the presence of the consent form that threatened to throw out the delicate balance she strives so hard to maintain. I had no way of knowing this before I engaged with Helen. But once in that situation I had to handle it as responsibly as possible. I did so, guided by the principles of feminist research ethics, which go well beyond the harm/risk-reduction principles of the consent form to actively *care* for the participant and their well-being (Felzman, 2020). Care ethics is a deeply relational approach to research, and I responded to Helen as I would have to anyone sharing something so painful and personal with me - I listened empathetically and acknowledged her suffering.

Ethics thus must be seen as a set of values guiding the researcher through the entire process, from initial concept and research design through fieldwork engagement and the way we represent our participants in our publications (Felzman, 2020; Fluehr-Lobban, 2013; Hammersley, 2018). Some ethnographers seek sustained consent by returning to the field to verify their interpretations with their

participants (Birch & Miller, 2012). While this can be an excellent way to include and show respect for one's participants, in the case of working with cognitively impaired older adults, it may be asking too much. During my conversations with Helen, I would stop and ask to clarify certain things as we talked, in line with the aforementioned principles of process consent. But, as a research team, we did not find it appropriate, for example, to run this article by her. We feared that it would overwhelm her. Checking and doublechecking initial interpretations as they occur during the interview or informal conversation may be a better way to ensure that consent around interpretation is present.

For Helen, the consent form was a threatening presence. Initially, it sat on her coffee table, while she mulled it over. Its presence was uncomfortable, and she moved it onto her bookshelf, hidden among other pieces of paper. Here the form was pacified, silenced for a while. Helen's stomach pains subsided. She had successfully mollified the form and went about enjoying her summer with long sunny days and visits from her children. I had a summer holiday too, and when I returned to the nursing home, Helen came to find me. She had found the form the other day, while looking for something else. It made her realise that it was not going to hurt her. She wanted her story to be included in my research and if signing the form was required, she would do it. I wanted to be able to tell Helen that her oral consent was enough. I told her again that I had really enjoyed my time getting to know her, that her signature was not worth any amount of distress, that even without I had still learned a lot from her. This situation serves to illustrate that so much of what we learn in the field cannot fit neatly within the boundaries of a consent form. I am not sure exactly what made Helen change her mind, but I think there is a temporal dimension to it. The fact that she could forget about its presence in her room made it somehow less threatening. During its dormancy the object had lost its mastery over her (Birk, 2016). Somehow, Helen had realised that by signing this document she could affect the world, because doing so allowed her story to be told, which was what she had wanted. She made an active decision not to be afraid of the form.

Concluding remarks

In this article we have given an ethnographic account of how the consent form can be unsuited to ethnographic research. The consent form can lead us to think of ethics as a formality external to the research process, instead of a relational issue embedded within it. As we have demonstrated in this article it can ultimately do more harm than good. While Helen did eventually sign the form, it put her through entirely unnecessary anguish. Though she was the only participant to so vehemently voice her discomfort with the consent form, I noticed an uneasiness in most of my other participants when it came to signing the form. Putting a signature on an official-looking form like that clearly carried some weight. Many could not read the small font, and most had no idea what GDPR was all about. Though I explained what it meant, many soon forgot. One woman chased me down the hall after our interview, suddenly worried that her signature meant it was going to cost her money to participate. This gets to the heart of the problem with the standard consent form: its normative stance on who a participant is. Produced for use by a particular kind of person, it makes assumptions as to the abilities of a "standard person," potentially excluding those who fall outside its normative assumptions of literacy, sightedness, cognitive reasoning, and the fine motor skills required to sign one's name. It also fails to recognize the power documents can hold over people. Turning a new materialist lens on this issue has been useful to render visible the ways in which objects, such as the consent form, are implicated in shaping social reality and in mediating interpersonal relations, producing particular subjectivities in the process.

The problem we have unfolded here is not with informed consent. The problem is rather the one-size-fits-all approach that in this case caused a lot of undue distress. While the intentions of the GDPR regulations is to protect all citizens from potential abuse of their data, there is a clear risk of legal requirements being conflated with research ethics.

This evidences a tension between, on one side, the legal obligations to protect personal data, and ethnographic commitments to conducting research ethically on the other. It raises important epistemological questions around what constitutes ethnographic data. The GDPR consent form makes an assumption that data can simply be "alienated from its relations of production" (Pels et al., 2018: 395). To suggest that ethnographic data can be commodified in this way is to misunderstand its very means of production, which are relational, contextual, situated and co-creative. And, as we have shown in this article, this tension can spin new ethical dilemmas on the ground. Training researchers to be sensitive to interlocutors needs, both in the immediate interview situation, but also extending into the write-up phase, is far more ethical than ensuring a signature on a cryptically worded form. But this still leaves open the question of how to ensure GDPR legislation is adhered to and to what extent a signature can even guarantee this, especially in the case of working with cognitively impaired older adults, who do not understand the concept of data protection and who find the form confusing and perhaps even threatening.

Statement of funding

This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the MSCA-ITN-2018 under grant agreement No 813928. The financial sponsor played no role in the design, execution or analysis of data, nor in the writing of this article.



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

Declaration of Competing Interest

none.

Data availability

The data that has been used is confidential.

References

- AAA. (2012). <https://ethics.americananthro.org/category/statement/>. last accessed 17 May 2022.
- Appadurai, A. (1986). *The social life of things: Commodities in cultural perspective* (Appadurai, Ed.). Cambridge University Press.
- Atkinson, P. (2017). *Thinking ethnographically* (1st ed.). SAGE Publications.
- Atkinson, P., & Delamont, S. (2018). The ethics of ethnography. In *The SAGE handbook of qualitative research ethics* (pp. 119–132).
- Aull Davies, C. (2007). *Reflexive ethnography: A guide to researching selves and others*. Taylor & Francis Group.
- Banks, C. (2018). Working through ethical and emotional concerns and uncertainties in ethnographic research with people with learning disabilities. In Garnett, J. Reynolds, & S. Milton (Eds.), *Ethnographies and health: Reflections on empirical and methodological entanglements*. Springer International Publishing AG.
- Beattie, E., O'Reilly, M., Fetherstonhaugh, D., McMaster, M., Moyle, W., & Fielding, E. (2019). Supporting autonomy of nursing home residents with dementia in the informed consent process. *Dementia (London, England)*, 18(7–8), 2821–2835.
- Bell, K. (2014). Resisting commensurability: Against informed consent as an anthropological virtue. *American Anthropologist*, 116(3), 511–522.
- Bell, K. (2019). The "problem" of undesigned relationality: Ethnographic fieldwork, dual roles and research ethics. *Ethnography*, 20(1), 8–26.
- Birch, M., & Miller, T. (2000). Inviting intimacy: The interview as therapeutic opportunity. *International Journal of Social Research Methodology*, 3(3), 189–202.
- Birch, M., & Miller, T. (2012). Encouraging participation: Ethics and responsibilities. In T. Miller (Ed.), *Ethics in qualitative research* (2nd ed.) London.
- Birk, R. (2016). From social to socio-material pathologies: On Latour, subjectivity and materiality. *Distinktion. Journal of Social Theory*, 17(2), 192–209.
- Brinkmann, S. (2014). Doing without data. *Qualitative Inquiry*, 20(6), 720–725.
- Dening, T., & Milne, A. (2011). *Mental health and care homes*. Oxford University Press.
- Dewing, J. (2002). From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia (London, England)*, 1(2), 157–171.

- Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia (London, England)*, 6(1), 11–25.
- Felzman, H. (2020). Feminist ethics in nursing research. In H. Kohlen, & J. McCarthy (Eds.), *Nursing ethics: Feminist perspectives*. Springer.
- Fluehr-Lobban, C. (2013). *Ethics and anthropology: Ideas and practice*. AltaMira Press.
- Forskerportalen. (2022). www.forskerportalen.dk/en/safeguarding-rcr-at-universities. last accessed 2 December 2022.
- GDPR. (2016). Eur-Lex. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679>. last accessed 23 August 2022.
- Halahakoon, D. C., Lewis, G., & Roiser, J. P. (2018). Cognitive impairment and depression—cause, consequence, or coincidence? *JAMA Psychiatry (Chicago, Ill.)*, 76(3), 239–240.
- Hamilton, J. (2017). On the ethics of unusable data. In *Fieldwork is not what it used to be* (pp. 73–88). Cornell University Press.
- Hammersley, M. (2009). Against the ethicists: On the evils of ethical regulation. *International Journal of Social Research Methodology*, 12(3), 211–225.
- Hammersley, M. (2018). Values in social research. In *The sage handbook of qualitative research ethics* (pp. 23–34). SAGE Publications Ltd.
- Hastrup, K. (2009). *Mellem mennesker: en grundbog i antropologisk forskningsetik* (1. udgave). Hans Reitzel.
- Invernizzi, Simoes Loureiro, I., Kandana Arachchige, K. G., & Lefebvre, L. (2022). Late-life depression, cognitive impairment, and relationship with Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 50(5), 414–424.
- Knappett, C. (2002). Photographs, Skeuomorphs and marionettes: Some thoughts on mind, agency and object. *Journal of Material Culture*, 7(1), 97–117.
- Lambek, M. (2015). Living as if it mattered (2015). In Lambek, V. Das, D. Fassin, & W. Keane (Eds.), *Four lectures on ethics: Anthropological perspectives*. Chicago: HAU Books.
- Latour, B. (1996). On interobjectivity. *Mind, Culture, and Activity*, 3(4), 228–245.
- Latour, B. (2005). *Reassembling the social an introduction to actor-network-theory*. Oxford University Press.
- Law, J., & Mol, A. (1995). Notes on materiality and sociality. *The Sociological Review (Keele)*, 43(2), 274–294.
- Lederman, R. (2007). Comparative “research”: A modest proposal concerning the object of ethics regulation. *Political and Legal Anthropology Review*, 30(2), 305–327.
- Lockwood, K., Alexopoulos, G. S., Kakuma, T., & Van Gorp, W. G. (2000). Subtypes of cognitive impairment in depressed older adults. *The American Journal of Geriatric Psychiatry*, 8(3), 201–208.
- Lockwood, K., Alexopoulos, G. S., & van Gorp, W. G. (2002). Executive dysfunction in geriatric depression. *The American Journal of Psychiatry*, 159(7), 1119–1126.
- Madden, R. (2017). *Being ethnographic: A guide to the theory and practice of ethnography* (2nd ed.). SAGE Publications Ltd.
- McGranahan, C. (2018). Ethnography beyond method: The importance of an ethnographic sensibility. *Sites (Palmerston North, N.Z.)*, 15(1), 1–10.
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13–14), 1935–1943.
- Morimoto, S., Kanellopoulos, D., Manning, K. J., & Alexopoulos, G. S. (2015). Diagnosis and treatment of depression and cognitive impairment in late life. *Annals of the New York Academy of Sciences*, 1345(1), 36–46.
- Murphy, E., & Dingwall, R. (2007). Informed consent, anticipatory regulation and ethnographic practice. *Social Science & Medicine* (1982), 65(11), 2223–2234.
- O'Connor, D., Mann, J., & Wiersma, E. (2018). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies*, 44, 45–51.
- Ortner, S. B. (2006). *Anthropology and social theory: Culture, power, and the acting subject*. Duke University Press.
- Pels, P. (1999). Professions of duplexity. *Current Anthropology*, 40(2), 101–.
- Pels, P., Boog, I., Henrike Florusbosch, J., Kripe, Z., Minter, T., Postma, M., ... Richards-Rissetto, H. (2018). Data management in anthropology: The next phase in ethics governance? *Social Anthropology*, 26(3), 391–413.
- Plankey-Videla, N. (2012). Informed consent as process: Problematizing informed consent in organizational ethnographies. *Qualitative Sociology*, 35(1), 1–21.
- Prior, L. (2008). Repositioning documents in social research. *Sociology (Oxford)*, 42(5), 821–836.
- Russell, L., & Barley, R. (2020). Ethnography, ethics and ownership of data. *Ethnography*, 21(1), 5–25.
- Simpson, B. (2011). Ethical moments: Future directions for ethical review and ethnography. *The Journal of the Royal Anthropological Institute*, 17(2), 377–393.
- Whitaker, E. M. (2021). Grasping the social life of documents in human service practice. In K. Jacobson, & J. Gubrium (Eds.), *Doing human service ethnography*. Policy Press.
- Wiersma, E., O'Connor, D. L., Loisel, L., Hickman, K., Heibein, B., Hounam, B., & Mann, J. (2016). Creating space for citizenship: The impact of group structure on validating the voices of people with dementia. *Dementia (London, England)*, 15(3), 414–433.
- Wynn, L. L. (2011). Ethnographers' experiences of institutional ethics oversight: Results from a quantitative and qualitative survey. *Journal of Policy History*, 23(1), 94–114.
- Wynn, L. L. (2018). When ethics review boards get ethnographic research wrong. In *The SAGE handbook of qualitative research ethics* (pp. 248–262).
- Wynn, L. L., & Israel, M. (2018). The fetishes of consent: Signatures, paper, and writing in research ethics review. *American Anthropologist*, 120(4), 795–806.