

‘We come in as “the nothing”’

Researching non-intervention in palliative care

Erica Borgstrom, Simon Cohn, and Annelieke Driessen

Abstract

In our ethnographic study of palliative care in a UK medical setting, we concerned ourselves with instances when medical staff chose *not* do something, which we came to call ‘non-interventions’. Such instances raised an obvious question: how does one study something that is not happening? In this Position Piece, we outline three ways in which we have tried to engage with this methodological question, from the initial grant application process to the point we are at now: first, a somewhat positivist approach, which allowed us to delineate the phenomenon of our study; second, a following technique, adopted to understand non-interventions as and when they are conceived by our informants; and third, an approach that tries to trace enactments of ‘not doing’ by mapping the range of different practices and, in so doing, elucidates how ‘not doing’ invariably occurs alongside other forms of doing. We describe what these approaches have taught us so far and reflect on the limits of each. We do so in the hope of providing others with starting points for studying nothings, ‘not doings’, and absences.

Keywords

Methods, Agency, Ontology, Palliative care, Non-intervention

Introduction

Much research is driven by the idea that the object it focuses on must be, by definition, present or active; that this reality constitutes what can be observed and then presented as findings. In contrast, our Position Piece engages with the question of how anthropologists might research what is *not* seen or done. This issue has arisen because, in our ethnographic study of palliative care in a UK medical setting, instances when medical staff do *not do* something—such as when a new round of treatment is not initiated or when medications are halted—represent a significant feature of clinical care, and regularly shape people’s experiences of the end of life.¹ For lack of a better word, we have termed these instances ‘non-interventions’.

Social anthropology has, over recent years, turned its theoretical attention away from questions of epistemological legitimacy and the associated crisis of representation and towards explorations of ontology and the extent to which the notion of multiple ontologies does or does not simply reproduce long-standing debates about relativism and constructivism. Whatever position one may adopt, the overall trajectory of these debates increasingly challenges any useful distinction between the research and the researched, or the subject and object. Here, we ask what this might mean if the object is actually an absence. In this piece, we think about how the topic of ‘not doing’ and the challenge of researching non-interventions not only disrupts old dichotomies, but potentially also intervenes in some of the more recent debates. In addition to illustrating how subject and object are contingent upon each other and mutually constructed, our concern is also with the significance of ‘nothings’ and ‘not doings’, and whether they unsettle any notion of a coherent ontology.

We are committed to studying this kind of non-intervention within palliative care, first and foremost, because a great deal of previous research has emphasised how biomedical practice is largely driven by the urge to ‘do something’ through interventions on the body or a specific disease pathway. This imperative is fostered during medical training and reproduced both within and beyond the profession. It is as though in modern biomedicine ‘doing something’ is everything (see also Gawande 2014).

Action serves as an apparent ontology, both in terms of it being ‘given’ and it being visible to researchers who are interested in medical practice. Conversely, healthcare professionals, and indeed many patients, often regard inaction or constraints on intervention as biomedical failure. In recent public debates, not acting or not intervening have been framed as forms of

1 For more information on the ‘Forms of Care’ project, see the website <https://www.lshtm.ac.uk/research/centres-projects-groups/forms-of-care>, or follow us on Twitter @Formsofcare.

euthanasia or clinical neglect—see, for example, reporting on the Liverpool Care Pathway (see McCartney 2012) and the Francis Report (Mid Staffordshire NHS Foundation Trust Public Inquiry 2013). Staying vigilant for non-interventions can help us to articulate the shifts, forms, and contents that absences take within medical practice, and ascertain what insights we may gain from taking these seriously as an object of research and an essential feature of care. In other words, through shifting our focus onto non-interventions, caring comes to include ‘not doing’ as an essential feature, rather than turning it into its other: neglect.

Despite these dominant representations, there is growing awareness that actively deciding *not* to intervene can sometimes be clinically legitimate and appropriate, as well as ethically and economically responsible. In addition, various ‘patient-centred’ approaches are shifting focus to include the wishes of patients, as well as values beyond those of simply combating disease and preserving life (Borgstrom 2015). This is opening up new spaces to discuss withdrawing or preventing (further) interventions. These various forces are particularly pertinent in the context of palliative and end-of-life care, when patients, families, and professionals may be explicitly confronted with questions about continuing or discontinuing a particular drug, initiating or deciding against a new course of treatment, or considering whether to sign a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form to opt out of attempts at resuscitation.^{2,3}

However, rather than focus on how *decisions* to withhold or withdraw treatment are made (as has been rigorously done elsewhere, e.g., Frost et al. 2011; Wendler and Rid 2011; Anderson et al. 2017), our study is attempting to explore non-interventions. It does this by looking at how non-interventions *emerge* in routine clinical practice alongside the more evident forms of active treatment, and hence how they are part of everyday end-of-life care and embedded in a wide variety of practices. Yet, this framing of the project raises the obvious question: how does one study something that is *not* happening?

- 2 In the UK, many of the decisions that patients and their family members face at the end of life take the form of a decision *against* interventions. For instance, it remains a medical decision whether a patient will be resuscitated or not, meaning that patients cannot demand that this procedure take place, but they do have the choice to *opt out*. Other examples of medical decisions are undergoing surgery and receiving medications or antibiotics. In the National Health Service (NHS), the role of payment does not (or at least should not) factor into treatment decisions for individual patients.
- 3 Notably, the A of ‘attempt’ in the acronym DNACPR has been added to the formerly common term DNR to convey the degree of uncertainty about resuscitation’s likely success and to facilitate conversations about what the order means (Breault 2011).

Anthropologists and sociologists have long engaged with questions of absences and various versions of what is unmarked. This has included work on waiting (Hirschauer 2005), ignorance (Singleton and Michael 1993; High, Kelly, and Mair 2012), secrets and what is not said (Croissant 2014; Sedgwick 1988; Taussig 1999), what is not made visible (Rapport 2008), forgetting and not remembering (Steiner and Veel 2015), various forms of nothing (Scott 2018), and how problems are made present or absent (Battaglia 1992). From a more cognitive slant, absences have also been key to the social study of language, structures of meaning, and semiotics. This body of work has helped us to think productively about non-interventions as practices that enact and condense a wide range of meanings and values. Like presences, absences influence people's experiences in and of the world (Bille, Hastrup, and Sørensen 2010, 4). Far from being free of cultural features, then, absences are as cultural as presences.

Delineating the (non-)phenomenon as a field of study: Categorising non-intervention

For the purposes of the initial grant proposal, we set about imagining how to empirically research what we came to call 'non-interventions' and argued that non-interventions were a valid and valuable ethnographic object in themselves. We emphasised how, even though ethnography can never be about a coherent whole, it can nevertheless identify and make apparent absences and lacunae because they are an inherent part of the logic that connects things in the world. During this period, Erica and Simon spent several months visiting a local palliative care team to build rapport, hone the research question, and reflect on a potential methodology. From these preliminary observations, it was clear that, in order for the clinical team to advocate for non-intervention, a great deal of work had to be conducted. Because of this, we chose to shift from describing our research interest as a noun (a 'non-intervention') to a verb ('not doing').

As a consequence, we decided that a productive way to look at this work of 'not doing' was to shadow staff members in order to look over their shoulders, so to speak, during staff-patient interactions so as to see how they *did* non-doing. Given our interests, we also liked the idea of shadowing because a shadow is the area where light does not fall directly. To complement this one-to-one fieldwork, we proposed observing team meetings in order to capture how team members discussed patient cases and formulated ways forward, including common instances when they collectively decided to reduce, halt, or not introduce a treatment or test. Finally, we said we would conduct a number of more traditional interviews with staff members and patients in order to investigate how different people engaged with and reflected upon our research provocation.

During these early stages, we were constantly reminded how categorising certain activities as ‘non-interventions’ was, in part, just an analytical move on our part, since—as we insisted—in many ways, ‘not doing’ had to be actively done. Yet we did not view this as a conceptual problem that needed to be resolved; rather, this apparent oxymoron increasingly became our focus and, indeed, a productive source of friction.

We subsequently brought in Annelieke, who had already conducted related research on dementia in the Netherlands. She was tasked with fulfilling these initial aspirations during an extended period of fieldwork. We discussed how and what our methods would materialise in practice: would the non-interventions become apparent in ways that were different to those discussed in the literature? Would informants and participants understand what we were interested in, and accept the paradox of our focus? As a team, we developed a keen interest in how the paradox emerged for our interlocutors, how they recognised it, how (if ever) they talked about it, and how they communicated it to others. Regardless, we remained anxious: were we at risk of reinforcing the divide between ‘active treatment’ and ‘palliative care’, thereby reproducing the assumption that only the former constitutes ‘real’ care?

After an initial period of research, during which Annelieke drew on these questions to open up the study, we apprehensively presented our work to the palliative care teams we were working with. To our relief, they immediately recognised the tension we were grappling with, the difficulties we had expressing it, and also its significance within the specialist field of palliative care. Staff members talked about frequent instances when there was an absence of further treatment options when the treatment stopped working or did not work as expected, or when further treatment was deemed inappropriate because the patient was too poorly. They described how sometimes other clinicians unfortunately communicate this by using the phrase ‘Nothing further that can be done’. A clinical nurse specialist added that, as a regretful consequence of this, ‘We [the palliative care team] come in as “the nothing”’. Annelieke would later often refer to this moment when explaining that the project’s focus was trying to understand the ‘nothing’ that palliative care does and how it is achieved.

Following respondents’ notions of the phenomenon: Conceptualising ‘nothing’ as a moving target

While the phenomenon as we initially conceptualised it seemed to resonate with palliative care staff, there were also frictions in how well it mapped onto what they felt was key to their daily work. Indeed, rather than taking up our notion of ‘non-interventions’, some instead took to reformulating the problem at hand. We listened carefully to their own conceptualisations of what we felt to be within the remit of our research. During one of the interviews, Hugh, the clinical service manager of the two teams, said:

‘Active non-intervention’ to me implies there is a non-intervention, and I actually think there is *still* an intervention with the presence of being with someone, both an emotional and spiritual component, even though you’re *not physically doing something* for them, there is still a . . . You’re still supporting that person . . . The presence—the actual *sitting with*—for me, is an intervention. So, I slightly disagree with the paradox of the phrasing but I can see why you’ve done that . . . And then it becomes a much more humanistic *being with*.

He went on:

The actual *being with* may involve words, it may not; it may involve touch, it may not. But it is, you know, almost that walking side by side with somebody through their particular journey. I think sometimes that is the hardest thing *to do*. In focusing your emotional attention on that interaction, you’re not rushing into writing a drug or writing into a solution-focused therapeutic approach, which, if you were a less experienced practitioner, may feel the natural thing to do.

By speaking about ‘not physically doing something’, ‘being with someone’, and ‘sitting with’, Hugh carefully presents the absence of typical markers of medical action as a different kind of presence—one not defined by action, but through patience, attentiveness, quietness, and relating. In doing so, he compellingly articulates that this may be ‘the hardest thing to do’, not simply because it can be interpreted as the opposite of more usual biomedical activity, but also because, by its very nature, it is based on recognising the importance of vulnerability and passivity.

These comments provided a new way to think about non-interventions—not as ‘nothings’, as described above, but as deliberate and careful acts of passivity. This second approach left us with some new questions: for example, how do being passive and being active relate? And, if they are to be thought of not as direct opposites but as qualities, to what extent are they tied to particular forms of action?

From essential qualities to relational practices: Articulating enactments of (not) intervening

In this section, we reflect on an example of one patient’s care that particularly highlights the inescapable relational aspect of doing/not doing. During a medical consultation, Nina, a quiet, reflexive woman in her 60s, was told by clinical consultant that there was ‘no further treatment’ for her and that they had ‘run out of options’. From the doctor’s perspective, this language served to clearly mark out how all possibilities to treat and cure Nina had been exhausted; it

meant the end of intervention and that decline was now inevitable. Nina was told that, as a result, she would be discharged under the care of the relevant palliative care team. However, as she was already under the care of the hospital palliative care team, Nina made it clear to Annelieke that she did not experience an abrupt shift in care or sense that ‘nothing further’ would be done. For her, palliative care was not positioned in opposition to active care, and so this simply meant that she was now going to be looked after by another team, who were explicitly not doing ‘nothing’ but were rather ‘doing something else’. This suggests that, as palpable as the distinction between intervening or not intervening may be within the medical field, by not differentiating ‘active’ treatment from other forms of care, Nina understood the shift as simply one that refocused her medical priorities as her condition changed over time.

In order to capture this aspect, we adopted a third analytical strategy: what if those actions and qualities taken to be ‘nothing’ gained their meaning and effect in relation to what they were not, through contrasts that were always dynamic and changing? This idea was echoed in an interview with Miriam, one of the registrars in the hospital team. She described how, at an early stage of involvement, the palliative care staff can work with a range of different options and choices, but that if there is what she calls a ‘trigger point’ (an abrupt shift from ‘active treatment’ to ‘comfort care’), then the enactment of palliative care as ‘nothing’ becomes stark, singular, and irreversible.

Here, then, is another important insight for our work. Current clinical practice often constructs a binary opposition between ‘doing’ (active or aggressive treatment) and ‘not doing’ (palliative care). This is because the switch often happens very late (and thus abruptly) in a patient’s trajectory, when clinical deterioration has a great deal of momentum and the possibilities of cure have become vastly reduced. When discussing patient Finn, Tanya, another registrar, described being on ‘active treatment’, described how it was important to give the ‘treatment more time to work . . . to see if anything is reversible’. She went on:

In palliative care, we speak about a window of opportunity: it is really important when you do or do not do something. When I first saw Finn, he was well enough to go home. Now, that opportunity has passed. Of course, perhaps they [the family members] would not have been able to handle that level of agitation that he had this weekend at home, and he would have come back in, but I truly feel we have failed him. He is much more poorly now. My unprofessional self wants to call the [haematology] doctors and say, ‘I told you so’. Obviously I won’t, but I want these junior doctors to learn!

From this, we have come to understand that ‘doing’ and ‘not doing’ are never practiced independently, but relate in myriad ways and often occur together. This led us to explore how ‘doing something’ and ‘doing nothing’ often depend on what is made to count or on what is

valued and by whom.⁴ In this way, when clinicians use the phrase ‘nothing more can be done’, ‘nothing’ has no pre-existing meaning, but is the effect of the relations in practice: palliative care becomes ‘nothing’ when a cure is posited to be the only form of success. Yet, other things of value can get lost in this opposition as the window of opportunity to realise them closes. We are convinced it is possible to see the traces of these relations in terms of their effects and things that can be registered as present. Such traces often become more apparent over time, through the changes in those things that are visible and present. In this way, our approach is to increasingly regard the ‘not doings’ and non-interventions as complex socio-material phenomena which, rather than being defined by their absence, are enacted through the relationships set up between different practices.

Discussion: ‘Not doing’ as a methodological reality

Throughout our study, we have had to acknowledge that it is never possible for an ethnographer to directly recognise or ‘see’ non-interventions or acts of ‘not doing’. We have outlined three analytical strategies we adopted to study them: first, a somewhat positivist approach, which allowed us to delineate the (non-)phenomenon of our study to secure funding; second, a following technique, adopted to understand non-interventions as and when they are conceived by our informants; and third, an approach that tries to trace enactments of ‘not doing’ by mapping the range of different practices and, in so doing, elucidate how ‘not doing’ invariably occurs alongside other forms of doing that happen to be shaped by a different set of values.

These approaches are not intended to be an account of refinement or development, even though they emerged for us over time. They serve different purposes and allow for different findings to emerge; importantly, they do not exclude one another. Each, of course, presents particular methodological challenges, both in terms of how we reconcile the data collected and how we theorise the concept of non-intervention.

In sharing our journey of engaging with this paradoxical topic and the methodological questions it raises, we seek to open up conversation about how the not immediately visible may become part of what we take to be the focus of research. At the same time, we are not suggesting that absences and ‘not doings’ can simply be folded into an ethnography; the key

4 Similar arguments about how care is relegated to the realm of ‘doing nothing’ have been made about reductionist biomedical framings of dementia (Moser 2008; Seaman 2018).

challenge is to somehow preserve some of the qualities of shadows, traces, and otherness which are an inherent part of nothings, ‘not doings’, and absences.

Coda

By way of a coda, we feel compelled to add yet another iteration of ‘not doing’ that has also been a feature of our project to date. After a long day of fieldwork that had left Annelieke feeling as if she herself had ‘done nothing’, she wrote in an email to Simon and Erica:

I talked to Nina and her husband about what her participation in our research would entail: a few informal conversations at her convenience, about the care she is receiving, her views on changes that have taken place. It quickly became clear that talking while holding the tracheostomy was so laborious that she, while interested in being interviewed, could not imagine taking part in our study under the current circumstances. And I understand. I said: ‘If you only have so much energy, you must choose what to spend it on’. Knowing that she had been a sociologist and a poet, I asked if she is still writing, wondering if we could perhaps develop alternative means of exchange. ‘Just a bit’, she said, thereby emphasising, in my understanding, that she was not eager to dedicate what energy she had left to participating in our study. Confirming this reading, her husband apologised to me. He said there must be many people who want to tell their life stories at the end of their lives, but that they cannot.

This too is an important reality of end-of-life research; sometimes energy levels and physical difficulties do not allow for participation, even if there is the will to do so, sufficient time, and alternative modes of communication potentially available. Similarly, when the clinical teams were stretched and when they engaged primarily in ‘crisis response’ rather than being the ‘proactive service’ they aspired to be, interviews and observations were routinely cancelled and re-scheduled. In this way, acknowledging and respecting ‘not doing’ is thereby as much our ethical commitment as it is that of the clinicians we are working with. It is perhaps therefore not a coincidence that, ultimately, our interest in ‘not doing’ and ‘not intervening’ is so palpable at the end of life—it is this sense of finality that makes the presence of absence so proximal.

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About the author

Erica Borgstrom is a lecturer in medical anthropology and end-of-life care at the Open University. Her research examines 'core concepts' in palliative and end-of-life care in England, and ethnographically examines how they vary across policy, healthcare practice, and people's everyday experiences with terminal illness. She is co-editor of the journal *Mortality*.

Simon Cohn is a professor in medical anthropology at the London School of Hygiene and Tropical Medicine (LSHTM). His previous research has focused on issues related to diagnosis, contested conditions, and chronic illness in the UK and other high-income societies.

Annelieke Driessen is assistant professor at LSHTM and institute research fellow at THIS. Her work examines care practices and how they shape ways of living and dying in high-income countries. Her research interests have expanded to include questions of how patient narratives of episodes of illness may be used in healthcare provision improvement initiatives, particularly within the context of the COVID-19 pandemic.

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