

Forms of care: study overview and collated outputs

The Forms of Care study was an ESRC-funded ethnographic study examining instances where palliative and end-of-life care staff, either individually or collectively, sometimes decide that the most caring thing to do for a patient is to stop or not begin new treatments. It was a collaboration between London School of Hygiene and Tropical Medicine and the Open University. The project ran from September 2017 to May 2021.

The research team consisted of Professor Simon Cohn (LSHTM), Dr Erica Borgstrom (Open University) and Dr Annelieke Driessen (LSHTM). Dr Jonathan Martin and Dr Sarah Yardley were clinical collaborators on the study. Dr Katie Dumble joined the research team to conduct a sub-study on prescribing.

Project Summary:

The study documented the range of forms and occasions when not intervening emerges as part of everyday practice. This can refer to deprescribing or not starting a particular medication, or refraining from a general course of action or broader aspect of care. In contrast to cases of neglect, such practices of not intervening are not only routine but form a significant dimension of much routine medical care. Nevertheless, they frequently lead to tensions and clashes with the more dominant clinical logic of active management, and often with patients' and relatives' hopes and expectations.

Taking an ethnographic approach, we explored how these routine practices of not doing, whether they are conscious and deliberate or the result of more distributed social interactions, are nevertheless an active and valuable form of care. We looked at things including how staff interacted with patients, as well as how and when they spoke to family members and staff members. We also looked at how equipment, hospital and home environments, and everyday objects play an active part in these interactions.

By drawing on anthropological theories and methods we analysed the way 'not doing' emerged as an alternative 'logic of care' in practice, and how people themselves differentiated it from both neglect and the medical imperative to act. Through observing staff members on the wards and in multidisciplinary team meetings, we showed how the drive to see patients as persons sometimes led to life-sustaining interventions being stopped [1]. We were able to attend to how different clinical priorities emerged [2, 10]. We highlighted the ongoing efforts to adjust a patient's surroundings, whether a hospital ward or their home, to make the place as fitting to the patient's needs as possible [3,8]. Towards the end of the project, we attended to the ways in which palliative care staff tried to establish a sense of connection and professional intimacy with patients during the Covid-19 pandemic [5,6]. We also published some methodological reflections on how one might go about researching 'not doing' or other forms of absences [7].

The project:

- Described and examined the multiple occasions and forms when palliative care staff actively do not do something, and conceptualised these as productive and meaningful social and material practices of 'actively not intervening'
- Examined if and when 'non-interventions' clash with the more dominant biomedical imperative to intervene, and how individuals, teams, and systems deal with this
- Described how a sample of patients, and their relatives and carers, made sense of these practices of non-intervention
- Invited a range of stakeholders to reflect upon the ethnographic findings and help generate insights into how 'non-interventions' are perceived outside the immediate clinical setting or personal experience through innovative workshop sessions
- Contributed to a growing body of social science research of health concerned with social practice by developing theoretical and methodological approaches that are able to take acts of not doing 'seriously' [1-7]
- Developed a range of resources, freely available for public engagement, teaching and research [8-12]

Publications to date

1. **Human and Person when life is fragile: New relationships and inherent ambivalences in the care of dying patients**
By Simon Cohn, Annelieke Driessen and Erica Borgstrom
Science, Technology and Human Values, accepted for publication (forthcoming).
2. **How much information is 'reasonable'? A qualitative interview study of the prescribing practices of palliative care professionals**
By Katie Dumble, Annelieke Driessen, Erica Borgstrom, Jonathan Martin, Sarah Yardley & Simon Cohn
Palliative Medicine, 2022, online first. <https://doi.org/10.1177/02692163221103471>
3. **Placing death and dying: Making place at the end of life**
By Annelieke Driessen, Erica Borgstrom and Simon Cohn
Social Science & Medicine, 2021, 291: 113974. <https://doi.org/10.1016/j.socscimed.2021.113974>
4. **Multidisciplinary team meetings in palliative care: an ethnographic study**
By Annelieke Driessen, Simon Cohn, Erica Borgstrom, Jonathan Martin and Sarah Yardley
BMJ Supportive & Palliative Care. 2021, 0: 1–4. <http://dx.doi.org/10.1136/bmjspcare-2021-003267>
5. **Ways of 'being with': caring for dying patients at the height of the COVID pandemic**
By Annelieke Driessen, Erica Borgstrom and Simon Cohn
Anthropology in Action. 2021, 28 (1) pp.16–20. <https://doi.org/10.3167/aia.2021.280103>
6. **Virtual patient visits: bringing into view family member-staff relationships in times of COVID-19**
By Annelieke Driessen, Erica Borgstrom and Simon Cohn
BMJ Quality and Safety - blog series, 2020. <https://blogs.bmj.com/qualitysafety/2020/10/17/virtual-patient-visits-bringing-into-view-family-member-staff-relationships-in-times-of-covid-19/>
7. **'We come in as "the nothing"': Researching non-intervention in palliative care**
By Erica Borgstrom, Annelieke Driessen and Simon Cohn
Medicine Anthropology Theory, 2020, 7(2): 202–213. <https://doi.org/10.17157/mat.7.2.769>

Multi-media resources

8. **Project website**
The project website contains up-to-date information on publications and resources, as well as a number of blog posts. <https://www.lshtm.ac.uk/research/centres-projects-groups/forms-of-care>
9. **Forms of Care: A stop-motion animation**: This short animated video tells the story of a woman and her dying mother, focusing on everyday forms of care. The script is taken verbatim from an interview conducted as part of the Forms of Care project. Made by Charlotte Kühlbrandt and Maayan Matz. <https://youtu.be/0h0uAE2LN2E/>
10. **Animation movie "Not intervening as a form of care"**: Have you ever heard the phrase "I'm afraid nothing more can be done" in the context of health care? In this animation film we highlight that the problem is that it can suggest resignation or failure, and that in our study, we have identified this as a moment not when everything suddenly stops, but when a different form of care can be offered. <https://www.open.edu/openlearn/endoflife/>
11. **The Forms of Care podcast series**, featuring the Forms of Care researchers: Simon Cohn, Erica Borgstrom and Annelieke Driessen. Produced by Amy Thomas. Three episodes <https://datacompass.lshtm.ac.uk/id/eprint/2699/>
12. **Dataset Forms of Care: Ethnographic Interviews about Palliative Care with Health Professionals in London, 2017–2021** [Data Collection]. UK Data Service, Colchester, Essex, United Kingdom <https://doi.org/10.5255/UKDA-SN-855055/>
13. **'What does it mean to care'**, podcast in the Royal Anthropological Institute (RAI)'s Public Anthropology Podcast Series 'Being Human'. <https://anchor.fm/public-anthropologists/episodes/What-does-it-mean-to-care-ejbp08/a-a35p6jm/>