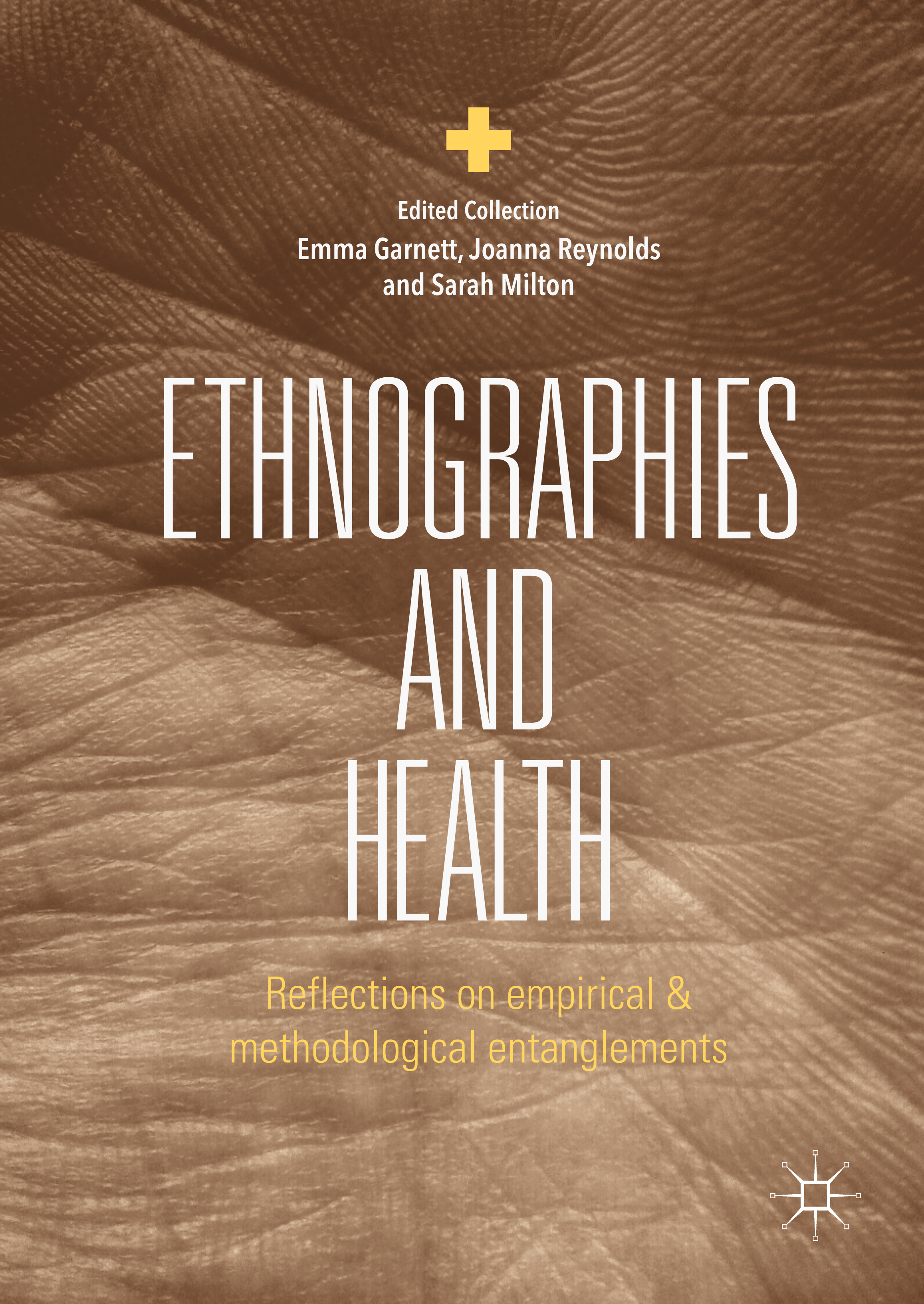

Edited Collection

Emma Garnett, Joanna Reynolds
and Sarah Milton

ETHNOGRAPHIES AND HEALTH

Reflections on empirical & methodological entanglements

Ethnographies and Health

Emma Garnett · Joanna Reynolds
Sarah Milton
Editors

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Reflections on Empirical and Methodological Entanglements

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Editors
Emma Garnett
Faculty of Life Sciences and Medicine
King's College London
London, UK

Sarah Milton
Faculty of Life Sciences and Medicine
King's College London
London, UK

Joanna Reynolds
Faculty of Public Health and Policy
London School of Hygiene & Tropical Medicine
London, UK

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Notes on Contributors

Carys Banks is a doctoral student in the Department for Health at the University of Bath. She has a background in social anthropology, and her current research interests include social care support for people with learning disabilities, including the social, political and economic foundations of policy making and how these aspects are interpreted and played out through people's everyday lived experiences.

Erica Borgstrom, Ph.D. is a Lecturer in medical anthropology and end of life care at the Open University. She has a background in medical and social anthropology. Her research focuses on the interplay between policy, healthcare practices and everyday experiences of living with dying. She is currently the membership secretary of the Association for the Study of Death and Society. You can follow her work on Twitter via @ericaborgstrom.

Emma Garnett, Ph.D. is a Research Fellow in the School for Population Health and Environmental Sciences at King's College London. She has a background in social anthropology and works at the interface of medical anthropology and science and technology studies. Her research is interested in the ways in which less visible, emergent phenomena like air pollution become apparent in science and policy. Her work also critically examines interdisciplinarity and the role of data in research.

Gemma Hughes, M.Sc. is a Health Services Researcher at the University of Oxford. Gemma has extensive experience of working in the NHS and an academic background in philosophy, literature and social policy. Her recent ethnographic work for her doctoral research has contributed to her emerging critical approach to examining the relationships between health and social care policy, practice and lived experience.

Matthew Maycock, Ph.D. is currently working as a Learning and Development Researcher at the Scottish Prison Service College, undertaking research and facilitating staff development across a range of areas. He was previously an Investigator Scientist within the Settings and Organisations Team at SPHSU, University of Glasgow. Throughout various university studies, Matthew has consistently worked on gender issues, with a particular focus on masculinity.

Zoran Milosavljevic, M.D. is a Researcher based in Belgrade, Serbia, and a Ph.D. candidate in social anthropology at the School of Social Sciences, University of Hull, UK. His field of research is public health, medical anthropology and the anthropology of HIV/AIDS. He holds an M.D. degree from the School of Medicine, University of Belgrade/Serbia, and an M.A. degree in gender studies (GEMMA) from the University of Hull, UK and University of Lodz, Poland.

Sarah Milton, Ph.D. is a Research Fellow in medical anthropology at King's College London. She has a background in social and medical anthropology, gender and sexuality studies, and public health. Her current research interests include ageing, particularly non-normative ways of ageing, and its various intersections with health, well-being and welfare, in the UK.

Tiago Moreira is Professor of Sociology at Durham University (UK). In the last 15 years or so, he has researched and published on the role of evidence in health care and on public controversies and activism on healthcare standards. More recently, his research has focused on the contemporary, sociotechnical articulations between ageing and health. He is Visiting Research Professor at the Centre for Healthy Ageing at the University of Copenhagen. Recent publications include: *Science, Technology and the Ageing Society* (Routledge, 2017), *Unsettling Standards: The Biological Age Controversy*, (*The Sociological Quarterly*, 2015) and *Evidence-Based Activism: Patients' Organisations, Users' and Activist's Groups in The Knowledge Society* (with V. Rabeharisoa and M. Akrich, Biosocieties, 2014).

Joanna Reynolds, Ph.D. is an Assistant Professor in social science at London School of Hygiene & Tropical Medicine, and an Honorary Research Fellow at University of Sheffield. She has a background in social anthropology and public health, and her current research interests include health inequalities, the making of public health knowledge through evaluation, and the fringes of 'health' and its intersections with other domains of policy and decision-making. She is also committed to building capacity for engaging with qualitative research—including ethnography—in practice settings.

Annabel Rule is a Specialist Occupational Therapist in older peoples' care at Imperial College Healthcare NHS Trust and a Clinical Doctoral Research Fellow at the University of Southampton. She is interested in relational approaches to the delivery of health care, decision-making and ethics as well as the role of ethnographic methods in understanding complex healthcare practice and processes. She aims to help improve the quality and experiences of acute care for older people with complex needs.

Dikaios Sakellariou, Ph.D. is a Senior Lecturer in occupational therapy at Cardiff University, UK. His current research interests include health inequalities for disabled people, experiences of disability and disablement, and the intersubjective nature of care practices. His most recent book is titled *Disability, Normalcy, and the Everyday*, co-edited with Gareth Thomas (Routledge, 2018).

Márcio Vilar, Ph.D. is a Postdoctoral Researcher at the Research Academy Leipzig at the University of Leipzig. He obtained his bachelor's and master's degrees in sociology and anthropology in Brazil and finished his doctoral study in ethnology in Germany. He investigates the co-production of medico-legal orders in contemporary Brazil as related to global shifting paradigms by focusing on unauthorised immunostimulant therapies. He is interested in relations between biomedicine, immunopolitics, law, public health, personhood, emotion and informal economies.

Narelle Warren, Ph.D. is a Senior Lecturer in anthropology and sociology at Monash University, Australia. Her background is in social and medical anthropology and applied health research. Her current research focuses on understanding the relationship between the lived experience of neurological conditions, biomedical representations of the brain and temporality, from both the perspectives of people living with such conditions and their informal carers. Together with Dikaios Sakellariou, they are guest editors of an upcoming issue on care in Medical Anthropology.

Alison F. Wood, Ph.D. is a Lecturer at Edinburgh Napier University in the School of Health and Social Care. She is also a registered nurse with specific clinical interests in renal and haemodialysis care. This was also the topic of her Ph.D. studies at the University of Edinburgh. As well as continuing to work with renal and haemodialysis patients, families and staff, since completing her Ph.D. her research has focused on the role of biosciences in nurse education and the role of creative and visual research methods.

Lisa Anne Wood, Ph.D. is a Lecturer in social sciences at Lancaster Medical School, Lancaster University, and a member of the Centre for Science Studies at Lancaster. Her research focuses on technologically mediated practices drawing on science and technology studies, organisation studies and feminist technoscience. She is interested in how knowledge is generated and shared in health practices, including looking at practices ‘on the move’, the use of digital technologies in health and the way in which new technologies shape care.

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Introduction: Entangling Ethnography and Health

Joanna Reynolds, Sarah Milton and Emma Garnett

Introduction

Health can be understood as a concept, a practice and a capacity, and is inherently complex, fluid and indeterminate. Ethnography, with its attention to how relations unfold between people, places, practices and things, is well suited to explore the situated meanings of health. However, while there is increasing recognition of the value of ethnography in different health and health-related research fields, there has been little consideration

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J. Reynolds (✉)
Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London, UK
e-mail: joanna.reynolds@lshtm.ac.uk

S. Milton · E. Garnett
Faculty of Life Sciences and Medicine,
King's College London, London, UK
e-mail: sarah.milton@kcl.ac.uk

E. Garnett
e-mail: emma.garnett@kcl.ac.uk

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to date of the multiple ways in which ethnography and health become 'entangled' with one another through the research process, and how ethnographic and health knowledge emerge, take form, shape and challenge one another. This edited collection draws together reflections on a wide variety of contemporary ethnographies investigating health, through a broad range of topics, settings and disciplinary perspectives. We discuss emerging directions in ethnography and health, and raise important questions about how these entanglements produce new ways of doing both.

Ethnography has been employed in studies ranging from explorations of experiences of health and illness to the techno-scientific and organisational practices and processes of health, research and care delivery. There is now a plethora of disciplinary engagements with ethnography around the topic of health, extending far beyond its traditional anthropological origins, including sociology, geography, science and technology studies and in health care professions such as nursing and occupational therapy. This presents a dynamic and evolving landscape in which ethnography and health are entangled in new and different ways. It also provides an important opportunity to reflect carefully and critically on how ethnography and health might constitute and shape each other as part of this wide range of research possibilities. In this edited collection, we not only discuss the strengths (and limitations) of ethnography for engaging with health and health-related research, but also ask: What does ethnography enable, make visible and possible for knowing and doing health in contemporary research settings? And, how do the dynamics of these settings shape our ethnographic practice and the mechanisms through which we seek to engage with, and know, our research topics and fields?

Origins of the Book

This collection grew out of a two-day workshop for early-career researchers entitled *Ethnographies & Health* held in October 2015 at the London School of Hygiene & Tropical Medicine. It brings together empirical contributions by researchers who participated in the workshop, and who have employed ethnography from different disciplines and fields of research. While ethnography has increasing presence and recognition within health research, the researchers themselves can be thinly spread across academic departments or research settings, including both traditional social science departments and, increasingly, more biomedically-oriented health sciences departments. The workshop highlighted the wide range of contexts, approaches and interpretations of ethnography in explorations of health, and the different ways in which ethnographic practice and health become entangled through the research process. As editors, the process of reflecting on the workshop and reading and reviewing the chapters for this book has prompted us to consider and take seriously other ways of knowing and doing ethnography. We have become familiar with new theories and empirical fields, and have embraced different assumptions about what ethnography is and what it can do, even if these come into tension with our own epistemic and disciplinary traditions, rooted in anthropology.

Attending to the intricacies of method and experience led us towards identifying the ways in which situated encounters with health shape the unfolding of ethnography *and* the formation of empirical understanding. The chapters in this collection address a wide variety of topics, contexts and methodological styles, and in each, ethnographic practices are opened up for interrogation, and questions around what health is, or how health is made to matter in different situations, are actively and productively explored. Moving beyond a simple methodological framing of what ethnography can(not) offer, we propose that reflecting on the limitations and possibilities of ethnography in practice gives rise to important and critical questions about the ways in which health can be researched and known.

The subsequent parts of this introductory chapter are arranged into three sections. First, we foreground varied contemporary approaches to ethnography. Second, we explore different ways in which health has been framed and known through ethnography. In the final section, we provide an overview of each contributing chapter, highlighting the breadth of 'ethnographies' and 'healths' addressed in this collection.

Emerging Directions in Ethnography

Ethnography has been variously described as a method, a methodology, a 'sensibility', a 'way of seeing' and a 'practice of description' (Star 1999; Wolcott 1999; Hammersley and Atkinson 2007; Ingold 2014). It has been interpreted as both a form of research and the product of that research (Hammersley 2007). As such, ethnographic practice has been debated, critiqued, applied and interpreted in multiple ways. Increasingly, ethnography is taking place across a range of disciplines and for different audiences and purposes, so that how ethnography is practised and performed can now vary greatly. In this section, we seek to highlight the value of acknowledging ethnography as necessarily situated, drawing on examples (many from health and related research) to illustrate how ethnographic practice unfolds in contingent and often productive ways.

Ethnography is commonly framed as both a methodology and a form of writing (see, for example, Clifford and Marcus 1986; Wolcott 1999; Hammersley and Atkinson 2007). With its earliest roots in anthropology from the late nineteenth century onwards, ethnography's traditional form emerged alongside European colonialism and typically involved immersion in a specific, often remote, geographical location and unfamiliar 'cultures'. Early ethnographers in anthropology were methodologically eclectic but what they held in common, according to Nader, was that '*they went, they observed, they stayed, they returned home and they wrote ethnography*' (2011: 212). In sociology, however, ethnography was applied closer to home from the outset, for example in the studies of (Western) urban environments associated with the Chicago School from the early twentieth century. These ethnographic studies typically presented 'descriptive narratives' of everyday interactions occurring among communities living in cities (such as Chicago) experiencing rapid social and industrial change (Deegan 2001). Ethnography in other disciplines, however, such as geography, remained fairly limited until the shift towards post-positivist and post-structuralist theories of relationships between people and place in the 1990s (Crang and Cook 1995).

Since the 'crisis of representation' in the social sciences, critical attention has been paid to the ways in which ethnographic research is produced and how it can or should be represented as 'knowledge'. While some contemporary ethnography continues to centre on geographically defined 'fields', attention to emerging 'globalised' and 'postmodern' worlds have prompted other kinds of ethnographic engagements with 'unbounded' fields (Marcus 1995; Gupta and Ferguson 1997). Within this framing, the remit of ethnographic inquiry extends along flows and networks of relations to consider how these may 'make up' places rather than simply reflecting static geographic locations (Choy et al. 2009). In the context of health, this may mean, for example, studying a medical intervention that spans multiple countries (Montgomery 2012); tracing health inequalities policy through multiple zones of 'policy practice' and processes of contestation (Qureshi 2013); or following medical metaphors of gendered bodies across multiple sites (Martin 2001). Methods of following, rather than bounding, have also engaged with new kinds of place, such as online worlds. Rather than seeing these as 'virtual' and therefore somehow less real, ethnographic studies have highlighted how these spaces have their own reality and integrity (Boellstorff 2008; Constable 2003).

Multi-sited forms of ethnography have also prompted counter-critiques that question the lack of reflection in other forms of bounding that inevitably occur (e.g. theoretical, epistemological) when the ethnographic 'object' is defined and pursued as de-coupled from specific geographic locations (Candea 2007). Different interpretations of *where* ethnography can and should take place are necessarily bound up with multiple forms of what becomes the focus of ethnographic research and how it is done in practice. This is perhaps most evident in the object-centred, actor-network studies that make explicit the role of non-human actors and how they contribute to human sociality and cultural conditions (Latour 2005). These kinds of approaches have been particularly useful for ethnographers researching medical settings because they account for the multiple and heterogeneous actors in play, including, for example, the mediating role of digital clinical record systems in nurse/patient and nurse/doctor interactions (Bruni 2005). Such studies displace the traditional focus of ethnography (literally, the writing of peoples) and make symmetrical the things and processes (from measuring instruments to microbes) that also constitute social and cultural worlds. In doing so, categories such as health, illness and the body are destabilised, offering new possibilities for exploring how human experiences—such as health—are assembled through diverse agential forms (Cohn and Lynch 2017).

Incorporating other kinds of relations and experiences into the research process expands the corporeal tools and devices employed in ethnography. Participant-observation is often taken as the de facto technique for ethnographic research, but there has been critical reflection on what this means in practice, and how the positioning of the researcher will shift and transform through the ongoing production of ethnographic relations (Ashworth 1995; Mesman 2007; Beaulieu 2010). The place and hierarchy of other (traditional) research methods such as interviews alongside participant-observation have also been considered (Hockey 2002; Hockey and Forsey 2012), in addition to recognition of other tools of knowing ethnographically. For example, attending to the emotions involved in doing ethnographic research have been shown as valuable for shedding light on the dynamics of the social world in question (Lee-Treweek 2000; Beatty 2005; Lumsden 2009). Rather than confining the discomforts and challenges of ethnographic practices to the private field diary, these can be embraced as important examples of different forms of relating (Reynolds 2017) and demonstrate emergent social forms. Evolving forms of 'sensory ethnography' (Pink 2009) have also emphasised how affective and sensory engagements with people, objects and places (and more) can be productive and transformative to ways of being in the ethnographic field.

The chapters in this collection cover a wide range of understandings of what ethnography is, how and where it can be done, and the mechanisms of knowing, in relation to health and related research.

By focusing particularly on the practice and practicalities of ethnography, the authors reveal important insights about the entanglement of knowing and doing.

Multiplying Healths

Through our experiences of conducting ethnographic research around health (in its broadest sense), and in the collation of the chapters for this edition, we have been forced to confront our assumptions about what 'counts' as health, as well as how we can know it. The research presented in this collection reflects a great variety of health topics and settings, as well as confrontations, tensions and negotiations faced when attempting to align ethnography with often biomedically informed expectations for how health can be measured and known. Yet, it is precisely these discomforts that can prove fruitful for critical reflection on the different ways in which health may emerge and take form, and what these emergent multiplicities may mean for the ethnographic researcher. In this section, we outline some of the different ways in which health has been framed and approached as a topic of ethnographic research, to consider what kinds of multiple—and multiplying—health(s) these situated explorations make visible.

Perhaps most obviously, ethnographies of health have framed and explored health as an experience or set of experiences that are produced through the positioning of 'the body' in relation to social and political life. These bodies of work show how health is always relational and mediated by a range of interactions and interpersonal processes (Kleinman and Kleinman 1991). More recently, practices of care have become relational sites for developing other ways of thinking about health more broadly. Indeed, explorations of how health is constituted, experienced and challenged though practices of care have helped to bring into visibility the pragmatic as well as interactional nature of care (Weiner and Will 2018). In this way, health can extend to include the enactment of organisational policies in health care settings which shape caregiving and patienthood (Charles-Jones et al. 2003), or to the 'ordering' of individuals through processes of care in residential social care settings (Lee-Treweek 1994).

In contrast to the messy pragmatics of health and care in practice, ethnographers have also attended to the ways in which disease and categories of health and ill health are performed through multiple processes and actors. Critical work on medical classifications has shown their powerful role in constructing social orders and affecting experiences of health and disease (Bowker and Star 1999). In 'troubling' the apparent fixedness of such classifications, ethnographic research of disease categories has revealed them as powerful artefacts in their own right. This perspective enables examinations of a 'single' disease as performed in multiple different ways through a range of agents, processes and spaces (Mol 2002), and mediated by engagements with different technologies, practices, bodies of knowledge and temporal and spatial contexts (Beisel et al. 2016; Weiner and Will 2018). In enabling a 'praxiographic approach' to the formation of categorisations of health, ill health and disease, ethnographic studies have demonstrated the ways in which diseases are reducible to neither biomedical science nor institutional policy alone, but are active constituents of socio-material worlds and the politics of health.

In other fields, reflecting a continuing influence of the 'evidence-based medicine' and 'evidence-based policy' movements, health becomes framed as something to be intervened upon in order to be improved, reflected in particular kinds of research seeking to evaluate the impacts on individual or population health of interventions, according to specific scientific procedures (Cartwright 2011). Ethnography has been employed within these fields, typically as a method to complement the evaluative aims of the research, and to help explain how an intervention is delivered and why certain impacts on health might be observed (Pool et al. 2010). More recently, the 'added value' of ethnography has been identified in the public health shift towards evaluation of 'complex interventions' (interventions with multiple interacting components that are contextually embedded). Here, ethnography has been recognised in terms of its capacity to explore and interpret how an intervention unfolds within and interacts with the wider context (Cohn et al. 2013; Leslie et al. 2014). These examples frame health as an entity to be acted upon (only) in ways informed by 'appropriate' kinds of knowledge. Increasingly, however, they also position health as something unpredictable and contextually driven, requiring 'new' approaches to evaluating the nonlinear ways in which changes to health occur through an unfolding, 'complex' intervention.

Although by no means an exhaustive list of the different ways in which health can be framed and interpreted, here we have sought to illustrate health as a multiplicity and how ethnographic approaches have been employed effectively in different ways to explore, embrace and interrogate these different healths. Following the overview of the different ways in which ethnography can be done, and the multiple framings of health that are made possible as a result, we propose that what is now needed is an explicit reflection on how the methodological and the empirical are situated, contingent and composed through the research process. By bringing together different kinds of engagements with ethnographies and health, this edited collection provides the empirical groundwork for critical reflection on how ethnographic entanglements and health emerge and take form, in multiple and surprising ways.

Positioning and Producing Ethnographies and Health: A Summary of the Book's Content

The authors in this collection understand and use ethnographic research practices in different ways to shed light on different health topics, and reflect a wide range of disciplinary backgrounds; from social sciences such as anthropology, sociology, geography and science and technology studies, through to health-oriented professions such as nursing, occupational therapy, radiography and public health. Each chapter examines critically the positions, contributions and claims of their different ethnographic approaches, and the implications of these for understanding their particular health 'problems', practices or experiences. They provide rich empirical accounts of ‘doing’ and ‘knowing’ health across topics such as science and the environment, ageing and disability, the organisation and delivery of care, public health and evaluation, and personhood and identity. As such, this collection explores the methodological and empirical intersections characteristic of ethnographic research to consider how paying attention to the social and material work of ethnography are productive for developing more careful and attuned ways of knowing and engaging with health. Below the chapters are summarised around common themes cross-cutting the collection.

Positionality, Ethics and Identity

The complexities of the positioning of the ethnographic researcher in contexts where health is being ‘sought’ is addressed in several chapters which reflect on tensions arising through negotiations of different expectations for caregiving, personal connection, professional status and ethical standards for health research. In the first empirical chapter (Chapter 2), Carys Banks explores the complex relations of being an ethnographic researcher, mediated by expectations of research ethics protocols, in the context of care homes for adults with learning disabilities. Reflecting on these relations, she suggests, was highly productive for identifying contextual tensions arising from attempts to enact policies governing the care of adults with learning disabilities. In Chapter 6, Annabel Rule explores embodying and shifting between different identities as she conducted ethnographic research as both a student and occupational therapist on an acute medical ward. She highlights the value of reflecting on these identities for generating insights into organisational culture, norms and expectations shaping decision-making around and experiences of discharge from care. Furthermore, Chapter 11 sees Matthew Maycock examining his multiple and complex identities unfolding through situated interactions with prisoners participating in a prison-based health promotion intervention. Through consideration of this shifting positionality, he explores how unique forms of identity and relating in the prison context may shape—and constrain—the possibilities for health promoting behaviours with this population.

Embodied Ethnographic Practice

Other chapters explore dimensions of the embodied experience of doing ethnography and what this contributes to how health can be known. Chapter 7, authored by Lisa Anne Wood, draws on actor-network theory to explore the situated, socio-material relations comprising her ethnographic research of the installation of new radiography technology in two hospitals. She argues that attending to her bodily engagements and positioning during fieldwork generated important understandings of the dynamics of situated technological change. In Chapter 9, Sarah Milton describes examining the embodiment, performance and meaning of ageing, femininity and sexuality through women's dating experiences and fieldwork in salsa classes. Through adopting both sensory and narrative approaches, Milton describes her capacity to explore the intertwining of embodied experiences in the present with meanings contextualised over the lifecourse—and the disjuncture between medicalised and personal accounts of wellbeing, lifecourse transitions and ageing.

Uncomfortable Healths

Ethnography's role in exploring uncomfortable dimensions of health, care and identity, and the different kinds of spaces in which these unfold, is also addressed in this collection. In Chapter 3, Zoran Milosavljevic describes the novel use of an ethnographic approach to engage with online communities of gay men in Serbia and to explore how identities relating to HIV status are constructed and communicated in virtual dating fora. He identifies varied and sometimes uncomfortable negotiations of identity online that have implications for sexual behaviour, and potential transmission of HIV, offline. From a different focus, in Chapter 10, Dikaios Sakellariou and Narelle Warren examine differing perspectives of what the 'good life' means to people and carers of people living with neurodegenerative diseases. Whilst calling for an ethnography that is sensitive to the fluidity of people's desires, they explore the intersubjectivity inherent in practices of care, by looking at how people care with, rather than simply for, each other.

The Promise and Possibilities of Ethnography

Several authors also look specifically at the traditional characteristics of ethnography and what they offer to understanding health. Chapter 4 sees Alison F. Wood engage with a familiar ethnographic trope of 'insider – outsider' in surprising ways as she recounts how she negotiated professional and researcher positions as a practising nurse conducting ethnography within the haemodialysis unit on which she worked. She highlights the roles that space and tempo play in her evolving positioning, and in her understanding of the enactment of 'direct patient care' in a clinical context. Erica Borgstrom, in Chapter 5, also presents ethnographic research conducted in a clinical context—here, end of life care—but describes the 'explanatory work' she undertook to communicate the purposes of ethnographic research in this context, and to negotiate her position as an ethnographer. This process, she suggests, led her to reflect on different ways of being in the world, which intersected her ethnographic approach and focus on experiences of end of life care. From the field of public health, in Chapter 12, Joanna Reynolds examines what an ethnographic approach can offer to conceptualising and understanding the dynamics of scale for evaluating 'complex' health interventions. Enabling movement between scales of attention and interaction, ethnography, she argues, can facilitate interpretation of the ways in which mechanisms of change occur as an intervention is delivered into a dynamic contextual system.

Assembling Health Across Spaces

Explorations of how health is assembled across networks and spaces are offered by three authors. Gemma Hughes, in Chapter 8, explores the different spaces in and through which policies of integrated care are enacted. Her ethnographic approach enables bringing together and moving between the concrete and the abstract, highlighting the coexisting spaces in which health policies, as situated practices, are 'done'. Márcio Vilar, in Chapter 13, gives a personal account of identifying and tracing alternative therapeutic responses to autoimmune diseases in Brazil. He describes ‘moving with’ immunostimulants as materials, reflecting on how he positions his own therapeutic case alongside broader therapeutic narratives, leading to new understandings of the body, moralities and medico-legal institutions. In Chapter 14, Emma Garnett takes a critical perspective to explore data practices as a part of interdisciplinary knowledge making through a scientific study on air pollution and its health impacts. She describes the way in which her ethnography unfolded alongside the organisational and material configuration of scientific data, and how scientific and ethnographic research were performed across multiple sites.

The Future of Ethnographies and Health

Finally, a concluding chapter, authored by Tiago Moreira (the keynote speaker at the *Ethnographies & Health* workshop), brings together many different threads discussed throughout the book in terms of the ways in which ethnography can confront assumptions about how health can be defined, measured and known. He proposes a praxiographic approach to ethnography, using the example of ‘healthy ageing’ to highlight the intersection and interrelation of health practices with health mensuration processes.

This collection reflects a wealth of varied ethnographic (re)presentations of health, occurring in different spaces, relational contexts and through a diverse arrangement of practices and processes, challenging more traditional assumptions about where health is located, produced and can been known. Moving beyond a ‘how-to’ guide to conducting ethnographic research on health and care, we suggest the collection demonstrates the importance of acknowledging, and engaging with the entanglement of the methodological and empirical that ethnographic approaches to understanding health necessarily facilitate. As organisers and contributors, we have valued the opportunity to create a shared space for the articulation of ethnographies in all their nuance and specificity, and to discuss explicitly the practical work of doing ethnography in our varied health-related research fields. We hope this edited collection will contribute to continuing dialogue for early-career ethnographers and others engaging with the ever-shifting and complex fieldwork relations that compose contemporary ethnographic engagements with 'health'.

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References

Ashworth, P. D. (1995). The meaning of "participation" in participant observation. *Qualitative Health Research, 5*(3), 366–387.

Beatty, A. (2005). Emotions in the field: What are we talking about? *Journal of the Royal Anthropological Institute, 11*(1), 17–37.

Beaulieu, A. (2010). From co-location to co-presence: Shifts in the use of ethnography for the study of knowledge. *Social Studies of Science, 40*(3), 453–470.

Beisel, U., Umlauf, R., Hutchinson, E., & Chandler, C. I. R. (2016). The complexities of simple technologies: Re-imagining the role of rapid diagnostic tests in malaria control efforts. *Malaria Journal, 15*(1), 64.

Boellstorff, T. (2008). *Coming of Age in Second Life: An Anthropologist Explores the Virtually Human*. Princeton, NJ: Princeton University Press.

Bowker, G. C., & Star, S. L. (1999). *Sorting Things Out: Classification and Its Consequences*. Cambridge, MA: The MIT Press.

Bruni, A. (2005). Shadowing software and clinical records: On the ethnography of non-humans and heterogeneous contexts. *Organization, 12*(3), 357–378.

Candea, M. (2007). Arbitrary locations: In defence of the bounded field-site. *Journal of the Royal Anthropological Institute, 13*(1), 167–184.

Cartwright, N. (2011). A philosopher's view of the long road from RCTs to effectiveness. *The Lancet, 377*(9775), 1400–1401.

Charles-Jones, H., Latimer, J., & May, C. (2003). Transforming general practice: The redistribution of medical work in primary care. *Sociology of Health & Illness, 25*(1), 71–92.

Choy, T. K., Faier, L., Hathaway, M. J., Inoue, M., Satsuka, S., & Tsing, A. (2009). A new form of collaboration in cultural anthropology: Matsutake worlds. *American Ethnologist, 36*(2), 380–403.

Clifford, J., & Marcus, G. E. (Eds.). (1986). *Writing Culture: The Poetics and Politics of Ethnography*. Berkeley, CA: University of California Press.

Cohn, S., Clinch, M., Bunn, C., & Stronge, P. (2013). Entangled complexity: Why complex interventions are just not complicated enough. *Journal of Health Services Research & Policy, 18*(1), 40–43.

Cohn, S., & Lynch, R. (2017). Posthuman perspectives: Relevance for a global public health. *Critical Public Health, 27*(3), 285–292.

Constable, N. (2003). *Romance on a Global Stage: Pen Pals, Virtual Ethnography, and "Mail Order" Marriages*. Berkeley, CA: University of California Press.

Crang, M., & Cook, I. (1995). *Doing Ethnographies*. Norwich: Geobooks.

Deegan, M. J. (2001). The Chicago School of Ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of Ethnography*. London: Sage.

Gupta, A., & Ferguson, J. (1997). Culture, power, place: Ethnography at the end of an era. In A. Gupta & J. Ferguson (Eds.), *Culture, Power, Place: Explorations in Critical Anthropology*. Durham, NC: Duke University Press.

Hammersley, M. (2007). Ethnography. *The Blackwell Encyclopedia of Sociology*. Oxford, UK: Blackwell.

Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in Practice* (3rd ed.). Abingdon, UK: Routledge.

Hockey, J. (2002). Interviews as ethnography? Disembodied social interaction in Britain. In N. Rapport (Ed.), *British Subjects: An Anthropology of Britain*. Oxford: Berg.

Hockey, J., & Forsey, M. (2012). Ethnography is not participant observation: Reflections on the interview as participatory qualitative research. In J. Skinner (Ed.), *The Interview: An Ethnographic Approach*. London: Bloomsbury.

Ingold, T. (2014). That's enough about ethnography! *HAU: Journal of Ethnographic Theory, 4*(1), 383–395.

Kleinman, A., & Kleinman, J. (1991). Suffering and its professional transformation: Toward an ethnography of interpersonal experience. *Culture, Medicine and Psychiatry, 15*(3), 275–301.

Latour, B. (2005). *Reassembling the Social*. Oxford: Oxford University Press.

Lee-Treweek, G. (1994). *Discourse, Care and Control: An Ethnography of Nursing and Residential Elder Care Work*. Unpublished Ph.D. thesis, University of Plymouth.

Lee-Treweek, G. (2000). The insight of emotional danger: Research experience in a home for older people. In G. Lee-Treweek & S. Linkogle (Eds.), *Danger in the Field: Risk and Ethics in Social Research*. London: Routledge.

Leslie, M., Paradis, E., Gropper, M. A., Reeves, S., & Kitto, S. (2014). Applying ethnography to the study of context in healthcare quality and safety. *BMJ Quality & Safety, 23*(2), 99–105.

Lumsden, K. (2009). 'Don't ask a woman to do another woman's job': Gendered interactions and the emotional ethnographer. *Sociology, 43*(3), 497–513.

Marcus, G. E. (1995). Ethnography in/of the world system: The emergence of multi-sited ethnography. *Annual Review of Anthropology, 24,* 95–117.

Martin, E. (2001). *The Woman in the Body: A Cultural Analysis of Reproduction*. East Sussex: Beacon Press.

Mesman, J. (2007). Disturbing observations as a basis for collaborative research. *Science as Culture, 16*(3), 281–295.

Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham and London: Duke University Press.

Montgomery, C. M. (2012). Making prevention public: The co-production of gender and technology in HIV prevention research. *Social Studies of Science, 42*(6), 922–944.

Nader, C. (2011). Ethnography as theory. *HAU: Journal of Ethnographic Theory, 1*(1), 211–219.

Pink, S. (2009). *Doing Sensory Ethnography*. London: Sage.

Pool, R., Montgomery, C. M., Morar, N. S., Mweemba, O., Ssali, A., Gafos, M., et al. (2010). Assessing the accuracy of adherence and sexual behaviour data in the MDP301 vaginal microbicides trial using a mixed methods and triangulation model. *PLoS One, 5*(7), e11632.

Qureshi, K. (2013). It's not just pills and potions? Depoliticising health inequalities policy in England. *Anthropology & Medicine, 20*(1), 1–12.

Reynolds, J. (2017). 'Missing out': Reflections on the positioning of ethnographic research within an evaluative framing. *Ethnography, 18*(3), 345–365.

Star, S. L. (1999). The ethnography of infrastructure. *American Behavioral Scientist, 43*(3), 377–391.

Weiner, K., & Will, C. (2018). Thinking with care infrastructures: People, devices and the home in home blood pressure monitoring. *Sociology of Health & Illness, 40*(2), 270–282.

Wolcott, H. F. (1999). *Ethnography: A Way of Seeing*. Oxford: Rowman Altamira.

2

Working Through Ethical and Emotional Concerns and Uncertainties in Ethnographic Research with People with Learning Disabilities

Carys Banks

Introduction

In this chapter, I reflect upon experiences of conducting ethnographic research with people with learning disabilities in UK-based social care settings, to highlight the complex dynamics, and related implications, of power relations in health-related research. This research is contextualised against a backdrop of contemporary learning disability policy. In attempts to reduce the exclusion and inequalities that people with learning disabilities experience, a range of social, political and economically driven philosophies have come to shape policy objectives. With a view to empowering people through independence and community inclusion, these objectives have constructed a range of identities for people

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Carys Banks is the 2016 recipient of the Radcliffe Brown/Sutasoma award from the Royal Anthropological Institute.

C. Banks (✉)
University of Bath, Bath, UK
e-mail: C.A.Banks@bath.ac.uk

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with learning disabilities, as both autonomous agents as well as vulnerable adults in need of protection. Through my ethnographic research, I wanted to unpick the ways these, often contradictory, identities were experienced in the context of everyday practice.

In adopting an ethnographic approach to explore these issues, I was confronted with a set of concerns and uncertainties. First, concerns emerged relating to the difficulties I experienced in negotiating relations under the conditions of formal ethical codes to conduct research on, and with, people with learning disabilities. Second, I experienced emotional uncertainties around tensions arising from the way people with learning disabilities appeared to view me as someone who could provide them with emotional support, through the research process. Crucially, as the research developed, I was faced with the prospect that, as an ethnographer, I may have been replicating the very power imbalances I was seeking to understand in the context of learning disability social care. Consequently, I was forced to reflect upon the power relations unfolding through my ethnographic approach. Although this led to me consider whether it was ethically 'right' to do this kind of work with people who appeared to find it difficult to understand my positionality as an ethnographer, by reflecting on this through the ethnographic process, I was able to develop a deeper understanding of the power relations inherent to the care settings in which I was researching. Here, I discuss these experiences with a view to thinking about the implications for conducting research around, as well as making sense of, learning disability care as a health-related issue.

The Role of Ethnography in Understanding Experiences of Care Within the Context of Learning Disability Support

Learning disability has historically been positioned and researched within biosocial disciplines, such as medicine, nursing, psychiatry and psychology, and has typically been explored through quantitatively driven methods, such as questionnaires, clinical observation and cognitive assessments (see, e.g., Gillett and Stenfert-Kroese 2003; Adams et al. 2006). There is, however, growing recognition of the importance of understanding the nature of social and political relations within learning disability support through qualitative methods, including ethnography (see, e.g., Redley and Weinberg 2007; Clement and Bigby 2010).

Ethnographic approaches tend to utilise participant observation with small groups of people as the means through which to explore and understand a particular phenomenon in its context. This is based on an epistemological stance that the world can be interpreted through in-depth engagement with phenomena (Schwandt 2000). As such, the closer the ethnographer is able to get to people, in both social and geographical terms, the stronger their interpretations and understanding of the lived experiences they are exploring. With this focus on deep immersion with small groups of people, ethnography enables insight into the complexities and nuances of social relations in everyday life (Willis and Trondman 2000). In doing so, ethnographers are also able to get to grips with the kinds of power relations that make up, and shape, people's lives (Doherty 2015). People with learning disabilities tend to experience complex life trajectories (Hall 2005), inevitably shaped by the power relations that exist in the carer-caree dynamic, and in the organisational settings within which care is often situated (Stalker 1998). Ethnography can be considered an ideal approach to get close to, and generate understanding of, these power relations and how they unfold in everyday life.

Historically, ethnography, rooted in anthropology, has occupied itself with giving voice to '*colonized, deprived and marginalized groups of people*' (Doherty 2015). This disciplinary orientation towards analysing the lived worlds of isolated and disadvantaged groups could similarly be seen to accord with the lives of individuals with learning disabilities, many of whom experience a range of inequalities and social isolation (Simpson and Price 2010). In attempting to understand people's worlds 'through their own eyes', the ethnographic approach lends itself to exploring the lives of people who '*are not of the dominant culture*' (Bercovici 1981: 139). In this way, in attempting to understand the everyday lived reality of people with learning disabilities, their world views can be expressed—or at least approximated—through the ethnographer's interpretations. Furthermore, it is also the ability of ethnography to capture situated experiences that make this approach highly suited to the context of support for people with learning disabilities, who can experience difficulty in verbally accounting for their views and experiences. As such, capturing these voices through the description of situated experiences enables them to be interpreted by the ethnographer, and beyond, through the research.

Building on previous ethnographic research on political constructions of people with learning disabilities (Redley and Weinberg 2007), my research sought to understand how a range of, often conflicting, identities constructed through UK policy objectives were embedded and enacted in learning disability support settings. These policy identities construct people with learning disabilities as different kinds of autonomous agents, whilst at the same time focus on the need to protect them as vulnerable adults (Department of Health 2001). In the day-to-day care context, I found that people's intellectual—and for some, physical—impairments meant they experienced difficulties in assuming the rights and responsibilities that accompanied some of these identities constructed for them through policy. Yet, because these identities were presented as aspects of a 'normal' life, support staff felt compelled to partake in a performance through which they would attempt to enact policy objectives.

My ethnographic research comprised just over nine months of participant observation, of which the majority took place within two learning disability social care provider organisations based in the South West of England. These organisations both fell under the category of social care provider services and provided publicly funded health and social care adult services. Here, I spent time with people with learning disabilities and staff members in a range of settings, including small group homes and day services for people with learning disabilities, such as day centres and employment training services. I also spent time with two independent community organisations, a café that supported people with learning disabilities with volunteering opportunities and a local advocacy service. There were a range of ages and levels of disability, from 18 to late 70s and from people considered to be mild, to severe, to profoundly intellectually disabled.

Ethnography: The Consequences of Immersing Oneself in the Field

Ethnography requires the ethnographer to immerse themselves deeply in the lives of others in potentially very intimate ways. Achieving the depths of immersion required in ethnography asks a great deal of time and energy from both the ethnographer and the people involved in the research. Moreover, the long-term and close contact that the ethnographer and their participants can experience through involvement in fieldwork can present great difficulties for both in maintaining clear boundaries between different positions, such as the professional and personal. Rather than attempting to dissolve the power imbalances that arise through these complexities of positionality, social scientists have been encouraged to reflect upon them and consider their role in the iterative process of generating interpretations (Mascia-Lees et al. 1989).

I argue here that conducting ethnography in support settings for people with learning disabilities brought with it particular challenges around positionality, and in this chapter, I describe two kinds of challenges I faced. First is the challenge of applying traditional ethical codes, derived from biomedical research governance, to ethnographic research in a learning disability social care context. Second is the challenge of navigating emotional uncertainties arising through my engagement with people with learning disabilities in this context. In reflecting on these challenges, I explore how they contributed productively to my understanding of the mechanisms and dynamics of power that shape the everyday relationships between people with learning disabilities and those supporting them within the care system, as enactments of broader policy objectives. Through this, I hope to contribute to both social care studies and health research (in its broadest sense), indicating how an ethnographic approach helped uncover dynamics that were intimately entwined in complex webs of power relations at the heart of this experience of care.

Navigating Participant Consent

Prior to fieldwork commencing, I found that my obligations towards formal ethical codes for research posed difficulties in this setting. Formal frameworks of research ethics, which dominate the design and governance of biomedical and health research, are underpinned by the assumption that individuals have the capacity to rationally self-determine, and therefore to choose whether to participate in research (Fluehr-Lobban 1994). In the context of support and research with people with cognitive impairments, these principles of ensuring people's decision-making rights are underpinned by the Mental Capacity Act 2005, with recognition of the difficulties that some people with learning disabilities can experience in verbally accounting for themselves (Owen et al. 2008).

Similarly to Clement and Bigby (2013), who also conducted ethnographic research in support settings with people with learning disabilities, I found that the codes of ethics and legislation governing capacity proved difficult to apply. The majority of the individuals with learning disabilities with whom I hoped to work did not appear to fit into this notion of what could be described as an 'autonomous individual'. Nor did these rules appear to account fully for the challenges and complexities that I observed people with learning disabilities experience in communicating and expressing themselves to others. Rather, I observed 'capacity' in these contexts to be far more complex because people with learning disabilities tended to be heavily reliant upon their support staff to guide them in making decisions. This indicated, too, a susceptibility to the views of others around them. These dynamics appeared to be heavily ingrained in the institutional context of carer-caree dynamics in social care settings and consequently had implications for aspects of the formal ethical codes that I was required to follow, such as the processes of informed consent.

Research Ethics Committees (RECs), the bodies governing health and medical research practice in the UK, recognise that the processes of seeking consent are not always clear-cut and can be problematic for some research participants, such as people with learning disabilities. They are also becoming increasingly sensitive to the emergent nature of some research approaches, such as ethnography, in which it is not always possible for the ethnographer to describe to potential participants exactly what will happen in the research (Fluehr-Lobban 1994; Seymour 2001; Department of Health 2001). In addition to seeking informed consent at the outset of research, researchers using an emergent methodology (such as ethnography) and working with individuals who may experience difficulties in comprehending verbal descriptions are advised to seek consent on an ongoing basis, described as 'process consent', and/or retrospectively (ibid.).

In the case of my research, retrospective and process consent were authorised by the reviewing REC, but on the condition that they were used in conjunction with traditional informed consent, which was sought before the fieldwork began. Despite adhering to these processes, however, I often remained uncertain about the preferences of the people with learning disabilities with whom I worked, even after receiving their consent in the approved manner. When I made formal requests to people regarding their informed consent to participate, these requests often appeared to be interpreted by them as arbitrary and completely out-of-place in the context of their lives. For example, the people with learning disabilities who I spent time with did not articulate their desires to express their choices or wants through the language of formal legislation, such as the Mental Capacity Act 2005. Rather, they did this in informal ways, and particularly through their relations with the people providing them support. These difficulties in communicating with people with learning disabilities in the research context indicated to me the disparities between formal interpretations of research participation, and my position in relation to people and the care context.

These communication difficulties I experienced with people with learning disabilities generated a continual sense of concern about whether they understood the reason for my presence in their lives, or whether they were responding to and interacting with me because they believed me to be their friend. The ways these concerns were manifested are illustrated by an incident which took place early on in my fieldwork when I was seeking informed consent from a man with learning disabilities, Kevin. The incident took place when I met with Kevin and his house manager, Rachael, at his residential home to provide him with a Participant Information Sheet (PIS). As soon as I presented Kevin with the forms, he stood up from his seat and began to leave the room; as he left he stated, '*I don't want to*'. Yet, despite this, Rachael immediately turned to me and said, '*he'll do it*'. She then explained that Kevin was refusing because he disliked being approached with formal documents, but based on her knowledge of him, she was sure that he would be happy to participate.

Kevin was not one of the primary participants in my research, and so I did not meet specifically with him on a regular basis. However, I did have regular indirect contact with Kevin as I would spend extended periods of time at his home when visiting two other people who also lived there. Despite being reassured by his house manager that Kevin was happy for me to spend time in his home, I remained unsure as to whether this was in accordance with the formal codes of ethics. At the same time, I did not want to undermine the judgement of Rachael. In light of this, when the fieldwork commenced I made a concerted effort to act with caution when in Kevin's presence. Though it was not possible to avoid him entirely, when I was visiting his residential home I never actively sought him out with a view to engaging him in conversation. For example, my visits to his home would usually consist of sitting in the lounge area of the house, where, when possible, I would engage other people in conversation. When Kevin was in this area, I tried to avoid sitting near to him or making eye contact. At first, I observed how he remained wary towards me, though I equally felt that he was intrigued as to why I was regularly visiting his home. Some weeks after my research had begun, however, I noted that Kevin was beginning to actively approach me. At first, this consisted of him choosing to sit or stand near to me and attempting to catch and maintain eye contact. After more weeks still, he began to approach me directly, asking me questions and requesting my support with tasks, such as preparing a meal, a cold drink or a cup of tea.

The fact that Kevin appeared to warm to me as the research progressed could be interpreted as his developing a better understanding of my position as an ethnographer and of my research study. Indeed, it could be argued that as Kevin was present during conversations between myself and other people in his house, he became more aware of what I was doing and felt comfortable about being a part of this. As such, these could be described as informal processes of consent taking place ‘in-situ’, similar to process consent. Certainly, within ethnographic research, it is these kinds of relation building processes that are considered key to getting beneath the surface of people’s everyday lives in the hope of understanding their lived experiences on a deeper level. However, the difficulties I experienced in determining whether people such as Kevin were able to consent could also reflect how they were perhaps unable to escape my ethnographic ‘gaze’, by nature of their situation living in supported care homes, wherein their power over who could enter these spaces was restricted. I began to consider whether these power dynamics were mirroring the wider structural relations of power within the material and social fabric of the support settings that I was exploring. Such considerations, it seemed to me, illustrate the potentially ethically risky nature of ethnographic research in these settings.

Navigating Emotional Uncertainties

The potentially ethically risky aspect of ethnographic research can be considered further through exploring my uncertainties about the emotional nature of my relationships with people with learning disabilities, such as Kevin, and whether they agreed to participate as an opportunity to spend time with another person. People living in support settings have regular contact with those supporting them, and, if in a group home, other residents. However, contact with other members of the community is often rare, and when entering into the field, I observed how my presence was seen as an opportunity for people with learning disabilities to engage with others in this way.

As the fieldwork progressed, I began developing relations with people with learning disabilities and their support staff by spending time with them where they lived and worked, as well as during day placements, such as employment training services. However, through engagement with the practices of everyday life in these contexts, I identified how some people with learning disabilities appeared to become emotionally attached to me. My concern was that doing this kind of intimate relation building with people with learning disabilities could have more negative consequences for them than for other groups who may possess a greater comprehension of the relationship between themselves and the ethnographer. Indeed, it is recognised that people's learning disability, combined with the loneliness and social isolation many people with this condition experience in the community (see, e.g., Scull 1983; Scior and Werner 2016), can cause them to confuse the types of relationships they have with others as more intimate than they are (Owens 2016). Given that my research question was in part borne out of an historical context in which people with learning disabilities were confined to positions of isolation and marginalisation, the prospect of potentially misleading people who are vulnerable and susceptible to attention from others, was particularly troubling.

The unease I experienced at developing relationships with people with learning disabilities for the purposes of the research was compounded further as I began to identify that these very issues were also at the heart of what I was researching. National policy, enshrined in the Care Act 2014, influences the organisational codes underpinning most of the services I engaged with during fieldwork which instruct staff to maintain 'professional relationships' with the people they support. There were rules prohibiting physical contact between people with learning disabilities and their support staff. Formally, these rules are about managing risks posed to people in receipt of care and those providing care, by ensuring boundaries between people are clearly defined. I observed how, within everyday practice, support staff appeared to tacitly understand these rules as necessary because people with learning disabilities could mistake everyday gestures for confirmation of an intimate, perhaps even romantic, relationship.

Throughout my fieldwork, I observed how these formal and tacit interpretations shaped relations between people with learning disabilities and their support staff. Despite the rules governing physical contact, people with learning disabilities would regularly attempt to engage the staff supporting them in these ways, such as attempting to hug them. During these situations, I observed how staff often appeared conflicted as to how best to respond. There were times when staff appeared to feel a need to respond to these calls for affection, perhaps in recognition of the isolation and loneliness that the people being supported expressed. Yet, at other times staff would attempt to ignore these requests for affection. For instance, during one field visit, I accompanied some people with learning disabilities and their support workers on a trip to a local shopping centre. During this trip, I observed how one young man with learning disabilities, Joey, tried to take the hand of one of his support workers, but she very quickly pulled her hand away from him, without verbally acknowledging what had happened.

Within the context of everyday support, staff appeared to understand their concern relating to physical contact in terms of the danger that people with learning disabilities would get the 'wrong idea'. However, these ways of relating to the people they supported may also have reflected how wider structural relations, shaped by policy objectives, were impacting on relational dynamics in these support contexts. In aiming to empower people with learning disabilities with independence in their lives, contemporary learning disability policy has constructed people in receipt of support in ways that promotes their position as autonomous and self-sufficient agents. In response to this, policy now views practices, such as physical contact, which could be described as traditional ways of caring, to be paternalistic and so as a hindrance to people's ability to become as independent as possible. Yet, as I observed, it was in fact often emotional forms of interaction that people with learning disabilities actively sought from their support staff, expressed through physical acts. Policy objectives encouraging staff to relate to the people they supported in professional rather than emotional ways could be viewed as contributing to an existing emotional deficit in people's lives.

These interactions relating to physical contact indicated to me how policies that were aiming to empower people with learning disabilities were in fact failing to understand their situated experiences. Importantly, it was through engaging in processes of reflection on how people with learning disabilities related to me in these ways that enabled me to understand the nature of these relations. During my fieldwork, there were times when people with learning disabilities would try to engage me in physical contact, and I often felt unsure as to how to respond. These uncertainties related both to the organisational policies on physical contact, which I did not want to be seen to flout, as well of my position as an ethnographer, and whether I should engage with participants in these ways.

One such occasion occurred when I was spending time with a young man with learning disabilities, Mark, who was attending an employment training service for developing workplace skills. At one point during the day, Mark and I were sitting down together when Mark leant his head against my shoulder. I responded to this gesture by putting my arm around him. At this moment, a staff member walked past and witnessed this, and after telling Mark that he knew he should not be doing it, the staff member turned to me and warned me that Mark might '*get the wrong idea*'. I felt awkward and conflicted; on one hand, compelled to offer comfort to an individual I could see was lonely and vulnerable. Yet, on the other hand, I was also concerned not to be seen to be flouting 'house rules' and to potentially jeopardise my access to the field site. Ultimately, as my time in the field progressed, I found myself replicating the same responses I had witnessed by support staff, attempting to brush off the requests for physical engagement without any verbal or other acknowledgement.

These experiences can also be seen in the context of the dual role I took on as an ethnographer and as an informal carer to build rapport with people and maintain, as much as possible, the naturalness of the setting I was entering into (Seymour 2000). Despite my role as an ethnographer being explicitly stated, the other informal caring aspect of my role impacted ways that I related to people with learning disabilities in these settings, for instance, when Mark viewed me as someone to provide emotional support. I found reflecting on my experience of these roles, and the tensions between them, a useful way of engaging with concerns and uncertainties in the ethnographic research. Through taking on a dual role of ethnographer and informal carer, I was at once able to experience, first hand, the dynamics of power that characterised the carer-caree relationship, and to reflect on how these relations were shaped by broader policy which constructs certain kinds of, often conflicting, identities for people with learning disabilities. In turn, these were played out through the roles, positioning and expectations of my ethnographic research process.

Discussion

Of course, power imbalances exist in all research contexts and can never be entirely removed. Yet, through my ethnographic research with people with learning disabilities in care contexts, I became aware that my position as an ethnographer intersected the kinds of potentially damaging relations taking place in the support settings I was researching. As such, I began to question whether it was ethically sound to involve such vulnerable people in this type of in-depth and immersive research. Similarly to Stalker (1998: 17), who conducted interviews and observations in learning disability support settings, I was concerned about the '*dangers of parachuting in and out of people's lives, especially if some of these lives are lonely*'. On one hand, acknowledging these complex power relations could indeed be framed as a reason not to do ethnography with people with learning disabilities in these settings. On the other hand, however, it could be argued that such people should not be excluded from ethnographic research pursuits that facilitate an embedded and critical interpretation of the everyday production of relations of power imbalance and identity, shaped by national policy objectives.

I have also argued in this chapter, that, in the context of my research, the concerns and uncertainties I experienced as part of the ethnographic process were compounded further by ill-fitting aspects of formal ethical codes of research conduct. This was indicated, for example, by the rigid rules governing the use of informed consent which did not account for the inherent power imbalances in support settings that render people with learning disabilities heavily reliant on those supporting them. This is important to acknowledge because uncritically following formal ethical rules may serve to mask the complex relations that exist in the lives of people for whom 'capacity' is opaque and highly contingent on their relations with others. Such masking of complex relations would arguably hinder the ability of the ethnographer to understand how they play out in the lives of the people they are seeking to understand. As was exemplified in my experiences of seeking informed consent from Kevin, the process demanded through formal ethics approval could be a frightening and overwhelming experience for some.

In exploring the ways that ethnographers can find themselves in ethically compromising situations when in the field, Goodwin et al. (2003) argues that this is in fact indicative of how participants in the field are not static, passive entities. Rather, they too will dictate what happens in the field, including the situations that the ethnographer may find themselves in, and consequently, what the ethnographer will interpret and analyse. To this end, the feelings of unease that can be brought about by what happens in the field could be viewed as an indicator to the ethnographer of how participants are shaping the research findings. Similarly, the feelings of conflict that I experienced at possibly reinforcing damaging dynamics in the lives of people with learning disabilities could be framed as an indicator of how, in the context of social care, relations are inherently defined in these ways. It was through reflecting on my position and experiences of these relations that enabled me to develop a deeper understanding of how they were being embedded and enacted in these settings. Importantly though, it must also be both acknowledged and accepted that voicing such uncertainties and dilemmas also means having to accept the ethical riskiness of this side of ethnography.

In demonstrating the ways in which ethnographic research with people with learning disabilities gave rise to ethical and emotional uncertainties, I have consequently provided reflexive mechanisms for interpreting and navigating through these concerns. The uncertainties I experienced centred on how my position as a researcher was replicating the very same complex power structures inherent to the care dynamic that I was exploring in my research. Through reflection of my position in the field, I was able to make further sense of these power structures and the ways they were being embedded in the care settings via the everyday enactment of policy objectives. Arguably, it was highly beneficial for the methodological and analytical processes of this research that I engaged in these, albeit uncomfortable, power relations to develop deeper understanding of the lived experiences of learning disability support.

References

Adams, L., Beadle-Brown, J., & Mansell, J. (2006). Individual planning: An exploration of the link between quality of plan and quality of life. *British Journal of Learning Disabilities, 34*(2), 68–76.

Bercovici, S. M. (1981). Qualitative methods and cultural perspectives in the study of deinstitutionalization. In R. H. Bruininks, C. E. Meyers, B. B. Sigford, & K. C. Lakin (Eds.), *Deinstitutionlization and Community Adjustment of Mentally Retarded People* (Monograph 4, pp. 133–144). Washington, DC: American Association on Mental Deficiency.

Care Act (c.23). (2014). London: The Stationery Office.

Clement, T., & Bigby, C. (2010). *Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation*. London: Jessica Kingsley Publishing.

Clement, T., & Bigby, C. (2013). Ethical challenges in researching in group homes for people with severe learning difficulties: Shifting the balance of power. *Disability & Society, 28*(4), 486–499.

Department of Health. (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: The Stationery Office.

Doherty, B. (2015). The state of social enterprise research 2015. *Social Enterprise Journal, 11*(3). https://doi.org/10.1108/SEJ-09-2015-0025.

Fluehr-Lobban, C. (1994). Informed consent in anthropological research: We are not exempt. *Human Organization, 53,* 1–10.

Gillett, E., & Stenfert-Kroese, B. (2003). Investigating organizational culture: A comparison of a 'high'- and a 'low'-performing residential unit for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 16,* 279–284.

Goodwin, D., Pope, C., Mort, M., & Smith, A. (2003). Ethics and ethnography: An experiental account. *Qualitative Health Research, 13*(4), 567–577.

Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & Place, 11*(2), 107–115.

Mascia-Lees, F. E., Sharpe, P., & Ballerino-Cohen, C. (1989). *The Postmodernist Turn in Anthropology: Cautions from a Feminist Prospect.* Chicago, IL: The University of Chicago Press.

Mental Capacity Act (c.9). (2005). London: The Stationery Office.

Owens, A. (2016). *Informed Choices: Relationships* [online]. Mencap, 13 February 2016. Available from https://www.mencap.org.uk/blog/informed-choices-relationships.

Owen, K., Hubert, J., & Hollins, S. (2008). Moving home: The experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities, 36*(4), 220–226.

Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: Interactional impediments to political empowerment. *Sociology of Health & Illness, 29*(5), 767–786.

Schwandt, T. A. (2000). Three epistemological stances for qualitative inquiry: Interpretitivism, hermeneutics and social constructivism. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 189–214). Thousand Oaks, CA: Sage.

Scior, K., & Werner, S. (2016). *Intellectual Disability and Stigma. Stepping Out from the Margins*. London: Palgrave Macmillan.

Scull, A. T. (1983). *Decarceration: Community Treatement and the Individual—A Radical View*. New York, NY: Rutgers University Press.

Seymour, J. (2001). *Critical Moments: Death and Dying in Intensive Care*. Milton Keynes: Open University Press.

Seymour, J. E. (2000). Negotiating natural death in intensive care. *Social Science & Medicine, 51,* 1241–1252.

Simpson, G., & Price, V. (2010). From inclusion to exclusion: Some unintended consequences of valuing people. *British Journal of Learning Disabilities, 38,* 180–186.

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society, 13*(1), 5–19.

Willis, P., & Trondman, M. (2000). Manifesto for ethnography. *Ethnography, 1*(1), 5–16.

3

Virtual Ethnography of HIV: Positive Health Status in Gay Virtual Intimacies in Serbia

Zoran Milosavljevic

Introduction

In this chapter, I discuss virtual ethnography of gay dating sites in Serbia with particular focus on HIV-positive status disclosure online. Virtual ethnography provides a methodological tool for the exploration of intersections between online gay communication and presentations, as parts of gay virtual intimacy, and HIV transmission as the result of unsafe sex among gay men, after online practices extend into offline. The combination of virtual ethnography of gay dating sites, as well as in-depth interviews with gay men, provided excellent methodological tools for exploring the relationship between HIV-positive status and online identities.

Here, I show how gay men use different strategies of presentation online. I offer an insight into identity constructions on gay dating sites in Serbia. Gay presentational strategies of HIV-positive status frequently have a form of strategic (in)visibility in online spaces, which I will go

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Z. Milosavljevic (✉)
University of Hull, Hull, UK

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on to describe in detail. The discussion in this chapter reveals how gay men use, play with, and frequently negotiate anonymity online. Participation in online gay dating opens up the possibility to manoeuver a specific set of identity characteristics that users may find inappropriate to share in other contexts. An excellent example of such negotiation lies in how users decide to disguise or disclose their HIV-positive status in online forums. Unsafe sexual practices, as the result of personal decision-making or as a specific practice of intentional unprotected sex, are widely recognised as responsible for HIV transmission among gay men. In this chapter, I use virtual ethnography to explore the interplay between gay dating site users and negotiations of their sexual identities, particularly around HIV status presentation, which potentially contributes to a context of risky sexual encounters and HIV transmission.

Defining Virtual Ethnography

Virtual ethnography enables contextual and dynamic ethnographic research of cyberspace. The term was first introduced and used by media theoretician Bruce Mason in 1996 (see Mason 1996) and has been taken up by scholars again more recently (Hine 2000; Boellstroff et al. 2012). Virtual ethnographic research is based on the understanding of the virtual communities' '*shared practices, meanings, and social contexts, and the interrelations between them*' (Boellstroff et al. 2012: p. 67). Virtual ethnography can be positioned as a valuable methodological tool for many areas of scientific research, including public health research. The ethnographer can access virtual worlds where people exercise individual and collective agency based on desires and goals (Boellstroff et al. 2012: p. 1). What should be of ethnographic interest in those spaces is not their extraordinary dynamic but '*what is ordinary*' for them (Boellstroff et al. 2012: p. 1).

For Fox (2012), virtual ethnography is a key method for exploring computer-mediated communication (CMC) and how different identities are communicated and mediated via perceptions of cyberspace (p. 58). Virtual ethnography explores and represents a specific context which highlights the inseparability of cyberspace and the 'real life' situation.

It opens up the possibility to analyse websites' content, users' profiles or users' activities, such as activities on gay dating sites where gay online communication takes place (see Race 2015; Mowlabocus 2010; Ahlm 2017). When reflecting on the research of the Internet, Marotzki's work (2003 quoted in Flick 2009), states that exploring online engagements and interactions could be done in the 'offline' context through interviews, online through participant observation or a combination of the two methods. Thus, the inseparability of the virtual and 'real' spaces becomes an important focus in virtual ethnography.

Virtual ethnography is particularly valuable for research on techno-sexuality, or, as defined by Davis (2009), technological impact on the sexual practices and cultures of specific social groups and sexual subcultures, and their online dynamic. It enables the researcher to participate in the researched community and to engage with the nuancing of presentational policies. Dicks et al. (2005) argue that the possibility of cyberspace communication removes the distance between the researcher and researched individuals who are 'hard to reach' in everyday life (p. 1). Fox (2012) discusses the politics of representation in virtual ethnography and the importance of the body and location in virtual–real relations (pp. 217–220).

Furthermore, it can be assumed that online communication and presentation involve a co-construction of the identity of the self and the image of the 'other' or others. Without a clear image of the 'other' in online communications, the process of presentation involves an interpretation of the desires and expectations of the 'other', as well as of the self (Lacan 1998). In the dynamic of online communications, this can be seen in users assuming and reflecting the identity characteristics—such as sexual identities and presentation of HIV status—of other users online. This complexity of human interaction online, which influences (and is influenced by) interaction offline, requires methodological approaches that facilitate in-depth, engaged and contextually sensitive interpretation, for which virtual ethnography is well suited.

The method of virtual ethnography for data collection is also useful in relation to understanding the relationship between visible online practices, such as HIV disclosure among gay men, and specific health issues, such as unsafe sexual practices (see Milosavljevic 2017).

It potentially facilitates the extension of public health campaigns into the realm of virtual communities and their organisation, thus targeting specific practices of social and cultural subgroups online that could have an impact on offline, health-related behaviours.

Exploring Online Gay Identities in Serbia

In March 2017, Internet World Stats (IWS) estimated the number of Internet users in Serbia at 4.7 million users out of 7.1 million or 66.6% with Internet accessibility.[1] My focus in this chapter is on virtual ethnography of gay dating sites in Serbia including PlanetRomeo.com/Serbia and Grindr. Both sites are extremely popular among gay men, and this can be witnessed in discussions of everyday gay life; PlanetRomeo.com is the most frequently used site in gay online CMC. In May 2017, there were around 15,900 registered profiles on PlanetRomeo.com/Serbia in the geographical area of Serbia, with more than half in the area of Belgrade.

The rise of the mobile phone gay dating app Grindr in the last five years has seen a dominance of online communication via mobile phones for dating among gay men in Serbia, with an increasing number of user profiles on Grindr in Serbia. Grindr experiences are an inevitable part of everyday discussions, for example in gay clubs, or when friends meet each other in other settings. This also highlights the inseparable nature of online and offline, of virtual presentations and ‘physical’ reality, and their mutual influence and interdependence.

At the start of my study of how online communication and presentations among gay men in Serbia affect sexual intimacy in relation to HIV transmission, in September 2014, I opened separate user accounts on each of Grindr and PlanetRomeo. During the three years of my research, I logged onto PlanetRomeo.com for a minimum of one hour, on at least one day a week. At the height of the virtual ethnographic part of the work, sometimes it was three or four days a week. I tried

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[1] Serbian context—http://www.internetworldstats.com/europa2.htm#rs [accessed May 10, 2017].

to ensure that I was experiencing the sites at different times of the day, sometimes in the morning, sometimes in the afternoon. I logged in in the evening and sometimes even in the middle of the night. I also used the Grindr app on my mobile phone. Here, I could keep track of my own use, discovering that I was accessing it whenever it crossed my mind to do so, up to five to ten times a day. Depending on my personal impression of users' activities and the relevance of those activities to the research effort, my login could last for several hours. I supplemented these online observations, self-tracking and engagements with in-depth interviews with 25 gay men, to explore further their perceptions and experiences of using online dating sites.

Virtual ethnography of gay dating sites enables direct research of gay intimate life online, but also adds a contextual contribution of gay everyday (including 'offline') life and when conducted over time, enables in-depth observation and interpretation of virtual groups' dynamics. As a result of this time-sensitive sampling in my research, one of the first things that I noticed, mostly on Grindr, was that the overall profile of logged-on users was different at different times of the day but that this phenomenon was less obvious on PlanetRomeo. The daily context was important for this change, as Grindr users inevitably change their geo-location in accordance with their needs and obligations during any given day. The change in users' profiles was also visible across the period of a year, especially in connection with distinct or sudden changes in the social context. For example, there were more faceless profiles (and more torsos, cartoons, landscapes, etc.) when the atmosphere in society was particularly unfavourable towards LGBT issues including HIV-positive status presentations. An example of this occurred during the Pride Parades that usually take place in September each year, when users tended to withdraw some of their online characteristics recognisable to others; i.e. face profile presentations declined. What was more surprising to observe, however, was the situated social patterning of online presentational choices relating to HIV status that occurred throughout the period of ethnographic research and across the different online platforms.

Online Construction of HIV Identities

Health disclosure online, such as the disclosure of HIV status on gay dating sites, is not a stable category. It depends on social context and personal experiences of stigmatisation, discrimination and life-changing consequences. Changes in health disclosure can be interpreted as shifting representations of personal body politics, constructed in relation to other people and also to institutions. Davis and Flowers described such changes as '*intersubjective experience*' that '*constructs identities and relations with others*' (2014: p. 79). Health disclosure has a major discursive effect on gay subjectivity and plays a significant role in the complexity of broader HIV/AIDS discourses. Under its influence, gay subjectivity is shaped by sexuality and HIV health status, intersecting online presentations and communications.

Formally, the Serbian HIV/AIDS epidemic is characterised by a low prevalence of infection with approximately 3500 cases of HIV/AIDS officially acknowledged since 1984 (IOPHOS, n.d.). Anti-retroviral therapy (ARV) was introduced in 1997 (ibid.). However, one of the negative trends that continue to date is that less than 4% of the whole population (of 7.1 million) are regularly testing themselves. At the point where they first sought professional help, 25% of all registered cases in 2014 were already in the terminal stages of the AIDS-related illness (ibid.). In the last five years, gay men, especially young gay men in their twenties and thirties, are statistically predominant in the category of newly registered cases, i.e. 55–60%. A concerning figure from 2015 was the increase of 178 newly diagnosed HIV/AIDS cases: a 37% increase on the 2014 figure (ibid.). With only a small decrease of 8% in 2016 (164 newly reported cases), it appears that the HIV/AIDS epidemic in Serbia is far from over (ibid.). Biomedical prevention, in the form of PrEP (pre-exposure prophylaxis), is not available in Serbia (see Antonijevic-Priljeva 2016). Institutional and social discrimination, as well as double stigmatisation based on illness and gay sexuality, are claimed to be some of the contributing factors driving the continuation of the HIV/AIDS epidemic among gay men in Serbia (see Milosavljevic 2012).

Under such conditions, it is therefore not surprising that HIV 'undetectable' status as a result of efficient ARV therapy has become a sought-after 'gold standard' for medical professionals, as well as a personal goal for people living with HIV (PLWH). An undetectable HIV status appears to be the sign of a successful therapeutic approach against HIV, but it is also a mobilising marker for an emerging 'undetectable' identity position among gay men (see Milosavljevic 2017). This can be seen in gay online presentations, which may be problematic in terms of the meaning of health disclosure. For example, when a HIV undetectable status is conveyed online by HIV-positive gay men as a 'healthy' substitute, it fails to acknowledge the tenuousness and frequent change of viral load (Milosavljevic 2017).

Different strategies of presentation of sexual identity and HIV status online—what I refer to as 'identity play'—can have potentially manipulative effects. This was reflected in, for example, individuals owning multiple profiles and different modes of communication on gay dating sites and through specific politics of presentation online. The simultaneous existence of multiple profiles and consequently multiple health status presentations put forward by individual users on gay dating sites (see Milosavljevic 2017) was consistent with users' perceptions that HIV status information on users' profiles is often regarded as mostly questionable and untrustworthy. This presents challenges for other users as they try to establish which one of those many presentations comes closest to reality, and how to make decisions about sexual practices and interactions that extend from online into offline contexts.

Negotiating Techniques for Communicating HIV Status Online

While many gay men in Serbia struggle with the fear of HIV status disclosure and social rejection as the result of it, some others feel relatively comfortable with it. The strategy of silencing and disguising HIV status is employed by some HIV-positive gay men that fear stigmatisation. Others are very open to discussing their HIV-positive status in online communication. As I have witnessed, silencing of HIV status is not the preferred strategy for them as they try to find a partner on the basis of similar HIV status (called 'sero-sorting') that I discuss further in this chapter. Thus, the dynamic in the gay online community in relation to HIV status disclosure is twofold—while some gay men reveal parts of their health identity, others are trying to hide it.

From my virtual ethnographic research, I identified three forms of online health disclosure on Serbian gay dating sites. Firstly, it is enacted via strategic (in)visibility or when individuals try to present one part of their identity by sending a message without saying or revealing too much (see Davis and Flowers 2014). An example I will explore later is the username 'HIaVvatha' which subtly hints at HIV status. Secondly, there is sero-sorting or the explicit declaration of HIV status in online profiles that is considered by public health researchers as a 'harm reduction technique' (see Parsons et al. 2005; Elford 2007). Examples of these declarations in profiles include '*HIV positive for positive*' or '*HIV positive seeks the same*'. The third way is the combination of the previous two—indirectly by strategic (in)visibility of HIV-positive status as the part of the username and directly by the statement of sero-sorting in the headline of the user's profile. I would call these three practices online health disclosure 'negotiating techniques', through which users negotiate possible risk, but also negotiate interactions with other gay men with a view towards initiating sex.

Similar HIV status has been identified as a factor in bonds between some gay individuals (see Grov et al. 2015), although in a broader gay community HIV-positive status can still pose a threat to gay intimacy (see Bersani and Phillips 2008). Gay men in Serbia are aware that HIV status plays an important role in negotiating sexual intimacy and risk via presentations on online dating sites. In an interview with Vlada, a 46-year-old IT expert, whom I recruited in a gay club, he defined this link simply:

> There are more and more gay people that have profiles on PlanetRomeo in recent years. So, statistically speaking, there must be more HIV positive people and that is reality. You are anonymous online and it covers up your HIV status, too. If you decide to disguise yourself, then we have a question what happens when you move from online to offline? In that case you have to be clear about your status. There is a danger in disguising HIV and the possibility of meeting someone who is hiding his own status is bigger. (Vlada, 46 years old, HIV negative/unknown)

Vlada's reflection on the numbers of possible HIV-positive men on Serbian gay dating sites is his personal interpretation of changing communications online, after spending almost a decade on gay dating sites. Vlada places emphasis on two very visible facts—there are more users' profiles on gay dating sites in Serbia day by day, and there are more HIV-positive status declarations on users' profiles, too, but this is still far from 'established' or 'usual' online practice among gay men.

Communication in cyberspace is considered to diminish tensions faced between openness and closedness in personal relationships in other contexts (Be-Ze'ev 2012), whereby the perceived anonymity underpinning virtual communication relaxes 'hard to tell' or 'hard to disclose' issues for its users. Nevertheless, what is sometimes called 'nonymity' (see Dhoest and Szulc 2016), or the partial anonymity of some websites and social networks such as Facebook, the possibility of online bullying and the fear of the community's reaction towards disclosure, can still result in efforts being made to disguise certain parts of one's identity.

These complex dynamics of presentation, disclosure and concealment of HIV status online reflect Davis and Flowers' argument (2014) that the influence of technology on health identities and disclosure does not only take place in clinical contexts, for example through biomedical tests, but also in the social practices that are configured by online/offline spaces and communication technologies. Thus, the technologies of online dating shape prevention strategies against HIV and STDs as they make visible different, and otherwise 'invisible', sexual subgroups or practices, such as those practised by HIV-positive gay men or practitioners of unsafe sex with intentional HIV transmission.

'Uncomfortable' (Re)Presentations of HIV Status Online

Exploring (re)presentations of HIV status online highlights dimensions of health, sexual identity and sexual practice that might be 'uncomfortable' from a traditional public health perspective, seeking to reduce risks of sexually transmitted infections. My virtual ethnography makes visible different strategies of self-presentation on gay dating sites in Serbia that constitute uncomfortable health issues. These include intentional disguising of HIV-positive status with risky sexual behaviour behind it, recruitment for recreational drug use for sexual purposes (better known as ‘chemsex’ among gay men) which risks HIV transmission, and online recruitment for unsafe sex practices with deliberate transmission of HIV, known as ‘stealthing’ which I explain further in the chapter.

An interesting example of an online gay self-presentation strategy is that of strategic (in)visibility, which is closely connected with online disclosure of HIV status (Davis and Flowers 2014). An online introduction is an opportunity to make HIV status visible (Davis and Flowers 2014). Strategic (in)visibility introduces HIV status as an identity characteristic, and its presence can help users to interact and negotiate their sexual encounters in terms of safety and risk reduction. By revealing their HIV-positive status through more and less explicit strategies, the users’ interaction based on online sexual negotiation obtains a new quality—a more relaxed and trustworthy sexual negotiation. The tension produced by the fear of not getting valid or sincere information on someone’s HIV status in online communication on gay dating sites that divides users based on their HIV status thus becomes reduced.

In the Serbian context, HIV status is frequently presented through strategic (in)visibility among gay men who are HIV-positive and want to meet or bond with other users online (Milosavljevic 2017). During my research, I met ‘HIaVvatha’, a 37-year-old gay man from Belgrade who has been HIV-positive for several years. He developed a specific strategy of self-presentation on gay dating sites. By marking specific letters in his nickname with capitals (H, I and V), he sometimes communicates his HIV status without explicitly saying he is HIV-positive. However, HIaVvatha has multiple profiles, with health disclosure included or excluded from his different online presentations. Using one of these profiles without HIV in his profile name means he is actively disguising it. His online profile is where communication with other users begins and is therefore where he also starts the process of negotiating his HIV status disclosure with others.

Strategic (in)visibility is deployed not only in moments of HIV-positive status disclosure, but also among online drug dealers who are using it as a ‘chemsex’ marketing strategy online. Recreational drug use among gay men for sexual purposes, or chemsex, is a sexual activity connected with HIV transmission (Halkitis et al. 2001; Bracchi et al. 2015; Race et al. 2016; Stuart 2016). Selling drugs online, such as *G* ('gay-rape drug') or *Ecstasy* or *Chrystal methamphetamine*, is illegal in Serbia, and strategic (in)visibility online is a strategy to cover up such actions. Strategic (in)visibility in relation to drug selling could be seen in the usernames employed on these sites, such as some of the examples I came across during my virtual ethnography of Grindr and PlanetRomeo in Serbia: PopEye (selling Poppers and Ecstasy), PokemonG (selling Poppers and G), KEks (selling Kamagra, a type of generic Viagra and Ecstasy), etc. Grindr and PlanetRomeo, for example, provide quick access to numerous users and therefore to a consumer market. At the same time, Grindr and PlanetRomeo forbid drug selling and users can report user profiles selling drugs. As such, these usernames are mechanisms for communicating particular identities covertly, in ways that reflect, and indeed invite, 'forbidden' and uncomfortable practices (from a public health perspective) relating to gay dating and sex.

Another example of uncomfortable representations online is when I came across a username that captured my interest in the PlanetRomeo.com site: 'stealth4health'. I came to understand 'stealth4health' as representing the use of strategic (in)visibility for bareback sexual subcultures recruitment of 'stealthing'. Stealthing is a sexual subculture of deliberate transmission of HIV where one partner infects the other by taking off the condom during intercourse and without the consent of the passive or bottom sexual partner (Klein 2014). It is framed as a form of 'gift giving' where the 'gift of HIV' is given to another gay man (ibid.). There is something interestingly malevolent in this particular username: 'stealth4health'. The username 'stealth4health' can be interpreted as a non-conventional depiction of strategic (in)visibility that points to a very 'unwelcomed' sexual practice of deliberate HIV transmission among gay men. It also evokes fear among online users with whom he communicates that they will be exposed to HIV transmission if they choose 'stealth4health' as their sexual partner. This became evident from one of the responses he received from a user that he invited to meet with him who stated that they rejected him on that basis.

The username 'Stealth4health' was the first time that I witnessed the use of the term 'health' for online presentation on gay dating sites in Serbia, and 'Stealth4health' appeared to represent an oxymoron: you cannot 'stealth' for health. I questioned whether 'stealth4health' was an example of strategic (in)visibility, conveying and inviting an interest in the practice of stealthing, or whether such a username had an alternative meaning. I decided to contact the owner of the 'Stealth4health' username and asked him to clarify it for me. I also shared my own understanding of what stealthing is. He responded and described how he had recently changed his previous username to 'stealth4health' after online bullying. He was not aware what stealthing was, and he seemed worried after learning about the meaning of the term. He said that since he did not have a picture online, a 'stealth' part of his username represents invisibility for him. He added 'health' part as a simple rhyme. This shifted my interpretation of the user, and I came to understand the example of 'stealth4health' as perhaps non-intentional strategic (in) visibility. The online anonymity of this user enabled me, as an ethnographic researcher, to challenge his use of the name.

A week after I had a first contact with 'stealth4health', he wrote to me from a different username. He had changed the previous one. I realised this because the PlanetRomeo.com site automatically changes the name of the user in the previous messages sent under the old username. His message to me was as follows:

> I changed my username since one of my potential hook-ups refused to meet me and he said to me: "I don't want to meet you. I know what is stealthing, so get off my back." I changed it immediately, you were right about it. ('Stealth4health', 37 years old, HIV negative/unknown)

The username 'Stealth4health' meant he lost a potential sexual partner on the basis of mistrust and a different interpretation of his online identity presentation. His claimed unintentional use of a term that signifies a potentially harmful sexual practice resulted in him being rejected online. The 'stealth' word in this username could mislead other users to believe that he is an HIV-positive gay man whose intention is to transmit the virus. It could also mean that gay men should avoid him as potential sexual partner and to prevent getting HIV infection.

This example that emerged through my virtual ethnography shows how the construction of online presentation shapes potential offline sexual activities among gay men. It is an example of online identity creation that is intersected by the uncomfortable issue of possible deliberate HIV transmission and which shapes choices, behaviours and practices in 'real life'. My interactions with 'stealth4health' also show how the researcher can take on an active role in the interaction with other online users through virtual ethnography. By discussing the issues relevant for the research with other online interlocutors, I gained knowledge of online practices, but also engaged with, and explored, the meaning of online presentations that proved uncomfortable from a public health perspective. Unlike more observational approaches, virtual ethnography enacts 'position' itself as an active method of inquiry that enables in-depth understanding of how representations, identities and meanings are communicated online, and the influence of these on offline practices, such as sexual behaviour linked to HIV transmission.

Conclusion

Virtual ethnography of gay dating sites in Serbia provides insight into identity constructions and online presentations among gay men. Gay online communication in Serbia makes visible gay sexual practices and gay sexual subcultures, in a context where stigma around HIV status persists. The play with identity online included health status negotiation, which often centred on a HIV status disclosure–disguise dynamic. The co-construction of identity in online communication between gay men can lead to different perceptions of someone's identity and/or intentions. Through active engagement with online interactions, I was able to identify a range of strategies and mechanisms through which HIV status was disclosed, but also (re)presentations designed for the recruitment of potential sexual partners for unsafe sex subcultures, including chemsex and stealthing. Through the presentation of these partial and strategic identities online, gay men are able to communicate and negotiate their health status in a more open and safe space, to achieve a level of trust necessary for choosing sexual partners and enacting sexual practices offline.

From a public health perspective, some of these online presentations reflect possibly risky or uncomfortable behaviours that might actively contribute to HIV transmission. I argue that virtual ethnography is well positioned to help explore the dynamics of the range of identities, communications and negotiations that occur around gay men's health and sexual status, and to understand the relationships between online and offline practices. It can also offer insight into gay sexual subcultures, their social practices and specific health needs, contributing to knowledge production for public health interventions and campaigns aimed at reducing HIV transmission.

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References

Ahlm, J. (2017). Respectable promiscuity: Digital cruising in an era of queer liberalism. *Sexualities, 20*(3), 364–379.

Antonijevic Priljeva, M. (2016, April). HIV epidemija: Tisina = Smrt. *Optimist-gay magazine*. Available from http://www.optimist.rs/hiv-epidemija-tisina-smrt/. Accessed June 1, 2016.

Ben-Ze'ev, A. (2012). *Love Online: Emotions on the Internet*. New York: Cambridge University Press.

Bersani, L., & Phillips, A. (2008). *Intimacies*. Chicago and London: The University of Chicago Press.

Boellstrof, T., Nardi, B., Pearce, C., & Taylor, T. L. (2012). *Ethnography and Virtual Worlds: A Handbook of Method*. Princeton and Oxford: Princeton University Press.

Bracchi, M., Stuart, D., Castels, R., Khoo, S., Back, D., & Boffito, M. (2015). Increasing use of 'party drugs' in people living with HIV on antiretrovirals: A concern for patient safety. *AIDS, 29,* 1–8.

Davis, M. (2009). *Sex, Technology and Public Health*. Basingstoke: Palgrave Macmillan.

Davis, M., & Flowers, P. (2014). HIV/STI prevention technologies and strategic (in)visibilities. In M. Davis & L. Manderson (Eds.), *Disclosure in Health and Illness*. London and New York: Routledge.

Dhoest, A., & Szulc L. (2016). Navigating online selves: Social, cultural, and material contexts of social media use by diasporic gay men. *Social Media + Society, 2*(4), 1–10.

Dicks, B., Mason, B., Coffey, A., & Atkinson, P. (2005). *Qualitative Research and Hypermedia: Ethnography for the Digital Age*. New York, Thousands Oaks, and New Delhi: Sage.

Elford, J., Bolding, G., Sherr, L., & Hart, G. (2007). No evidence of an increase in serosorting with casual partners among HIV-negative gay men in London. *AIDS, 21*(2), 243–245.

Flick, U. (2009). *An Introduction to Qualitative Research*. Los Angeles, London, New Delhi, Singapore, and Washington, DC: Sage.

Fox, R. (2012). *Gays in (Cyber-) Space: Online Performances of Gay Identity*. Saarbrücken, Germany: AV Akademikerverlag.

Grov, C., Rendina, H. J., Moody, R. L., Ventunaec, A., & Parsons, J. T. (2015). HIV serosorting, status disclosure and strategic positioning among highly sexually active gay & bisexual men. *AIDS, Patient Care and STDs, 29*(10), 559–568.

Halkitis, P. N., Parsons, J. T., & Stirratt, J. M. (2001). A double epidemic: Crystal methamphetamine drug use in relation to HIV transmission among gay men. *Journal of Homosexuality, 41,* 17–35.

Hine, C. (2000). *Virtual Ethnography*. London, Thousands Oaks, and New Delhi: Sage.

IOPHOS. (n.d.). Institute of Public Health of Serbia [Online]. Available from http://www.batut.org.rs/. Accessed October 10, 2017.

IWS—Internet World Stats. 2017. Serbian context, the number of Internet users in Serbia. Available from http://www.internetworldstats.com/europa2.htm. Accessed May 30, 2017.

Klein, H. (2014). Generationing, stealthing, and gift-giving: The intentional transmission of HIV by HIV-positive men to their HIV-negative sex partners. *Health Psychology Research, 2,* 1582–1588.

Lacan, J. (1998). *The Seminars of Jacques Lacan: The Four Fundamental Concepts of Psychoanalysis (Book XI)*. New York and London: W. W. Norton and Company.

Mason, B. L. (1996). Moving toward virtual ethnography. *American Folklore Society Newsletter, 25*(2), 4–6.

Milosavljevic, Z. (2012). *AIDS and Its Discontents: Silencing Gay Sexuality in the Age of iIlness*. Unpublished Master's thesis, University of Hull, UK and University of Lodz, Poland.

Milosavljevic, Z. (2017). Strategic (in)visibility and bareback subcultures: The implications of online communication for HIV transmission among gay men in Serbia. In A. Dhoest, L. Szulc, & B. Eeckhout (Eds.), *LGBTQs, Media and Culture in Europe*. New York and London: Routledge.

Mowlabocus, S. (2010). *Gaydar Culture: Gay Men, Technology and Embodiment in the Digital Age*. Oxford and New York: Routledge.

Parsons, T. J., Schrimshaw, E. W., Wolitski, J. R., Halkitis, P. N., Purcell, D. W., Hoff, C. C., et al. (2005). Sexual harm reduction practices of HIV-seropositive gay and bisexual men: Serosorting, strategic positioning, and withdrawal before ejaculation. *AIDS, 19*(1), 13–25.

Race, K. (2015). "Party 'n' Play": Online hook-up devices and the emergence of PNP among gay men. *Sexualities, 18*(3), 253–275.

Race, K., Lea, T., Murphy, D., & Pienaar, K. (2016). The future of drugs: Recreational drug use and sexual health among gay and other men who have sex with men. *Sexual Health, 14*(1), 42–50.

Stuart, D. (2016). A chemsex crucible: The context and the controversy. *Journal of Family Planning and Reproductive Health Care, 42*, 298–296.

4

Ethnography and Ethics in Your Own Workplace: Reconceptualising Dialysis Care from an Insider Nurse Researcher

Alison F. Wood

Introduction and Background

This chapter reflects on my experience conducting ethnographic research in a setting in which I had an existing professional role as a registered and practising nurse. The position I held and how this was negotiated within the research and clinical environment highlight the role ethnography can play for nurses researching in healthcare settings. In particular, this chapter highlights the positional complexities of adopting both 'insider' ethnographer and professional roles in a healthcare context, and the insights this generated around the partial forms of knowledge that necessarily emerged. The specific research objectives were to explore patient and nursing staff experiences of 'direct patient care', a phrase used within time-efficiency programmes and time in motion studies, which are part of professional audit practices employed

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A. F. Wood (✉)
Edinburgh Napier University,
Edinburgh, Scotland, UK
e-mail: a.wood@napier.ac.uk

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to classify how a nurse spends their time. My ethnographic approach utilised participant observations alongside field notes, informal questioning, photographs and semi-structured interviews to understand 'direct patient care' and how it was experienced in a haemodialysis unit for those living with established renal failure. The unit was an outpatient department and part of a large acute hospital in Scotland, where I held a post as a registered nurse prior, during and after the research was undertaken.

Established renal failure is a condition which requires long-term treatment; one treatment option is haemodialysis which usually involves regular, three times weekly visits to a haemodialysis unit. Nurses and support workers spend time with and care for the patients when they are receiving this three-to-five hour treatment. I was 'in the field' conducting fieldwork over a nine-month period, although I had worked in the unit in a clinical role for two years prior to this and continued to do so on 'non-research days' through the duration of my fieldwork. Moving between different perspectives in 'the unit' was made possible due to my status as both an insider and outsider to the field site. As a nurse and well-known staff member, I was very aware of my shifting status from nurse to ethnographer.

In this chapter, I use my dual status to explicate the formation of my field sites and the ethical questions this raised. It was at the interface of my insider/outsider roles that my ethnographic findings began to emerge. I argue that my unique and blurred positions allowed access to participants and data in a complex setting and shaped the generation of my ethnographic findings around how the concept of 'direct patient care' is performed and experienced in a clinical setting.

Haemodialysis

Haemodialysis is one life-saving treatment option for people who have kidney failure. People, or patients, who have very little or no kidney function, receive haemodialysis by being connected to a machine which replicates some kidney functions and removes electrolytes and fluid from the blood. Without this treatment, or other renal replacement therapies, e.g. kidney transplant, there are significant health implications and the constant concern of mortality (Thomas 2014). In Scotland, the number of patients who receive this in-hospital treatment is increasing, as are the numbers who suffer from kidney failure (Scottish Renal Registry 2016).

The unit where I conducted my research was part of a large acute hospital. There are 38 haemodialysis stations, and these were generally all in-use three times a day. Patients attended either in the morning, afternoon or evening, and over 150 patients attend and receive treatment at the unit in their 'usual' spot alongside the same patients three times a week. When patients attend for their treatment, they are attached to a machine for the duration, somewhere between three to five hours, which is prescribed due to their requirements and blood results. Once attached to the machine, they cannot move around. There were five distinct rooms where the majority of care and interactions with staff took place and nursing staff are allocated to a room where they normally remain for the day. At the unit, treatment and care are delivered by over 60 registered nurses and nine healthcare support workers.

Nursing and Ethnography

Within the field of nursing research, ethnography has been utilised to examine the views and experiences of people within a particular area, setting or aspect of health care from an 'insider's' perspective, thus generating distinct kinds of knowledge that arise only through connection with and embeddedness in the very practices and contexts of inquiry (Thorne 1991; Roper and Shapira 2000). From Madeline Leininger's pioneering work (1970, 1978, 1985, 1988) as a professional nurse conducting anthropologically-informed ethnographic research to explore understanding of the role of culture in nursing and in patients' experiences of health care, ethnography in nursing has gained further ground and is becoming increasingly popular (Savage 2000a; Draper 2015). Robinson (2013: 19) recently claimed '*ethnography is the future of nursing science*', highlighting the potential of this methodology to explore a range of perspectives that are relevant to nursing practice, foregrounding understanding of the meaning of human behaviours and valuing the patient's own voice. Furthermore, parallels have been drawn between the practice of nursing and doing ethnography, whereby value is placed on knowing through observation (of patients and colleagues) and through reflection on practice and positions (Savage 2000b; Borbasi et al. 2005).

Ethnographic approaches have been previously employed in similar clinical settings to the focus of this chapter. Ashwanden (2003), for example, explored the culture of 'patient-centred care' in two haemodialysis units using an ethnographic approach, and the dominance of the haemodialysis machine in the provision of haemodialysis treatment has also been examined through ethnography (Tranter et al. 2009). Other research has adopted ethnographic approaches to explore dimensions of nursing practice in this context, including the dynamics of power that shape the delivery of quality nursing care (Bennett 2010, 2011). These different examples illustrate the wide variety of foci in which ethnographic research has been employed to explore dimensions of nursing and care experiences in renal settings. Yet, there remains an absence of more methodological reflection on how ethnographic and nursing practices intersect within a clinical context with the nurse-as-ethnographer, and what this means for considering the processes and spaces through which 'insider' knowledge is generated about dynamics of caregiving. In this chapter, I seek to examine these tensions through my ethnographic research examining direct patient care in the haemodialysis unit where I practised as a registered nurse.

Research Design

Fieldwork was conducted for nine months (December 2013–August 2014) where I would work one day a week (11.5 hours shift) as a nurse and visit the unit up to four times a week in a research capacity to provide information, consent and conduct data collection. Fieldwork included observations usually lasting five hours, field notes and informal discussions with patients and nursing staff. I also used photographs and semi-structured interviews with a selected purposive sample to include key informants from each participant group. Photographs were taken during the observation sessions to support the research and visualise care in the setting and the spatial and material arrangement of the unit. Initially, it was through this suite of methods that my ethnographic lens sought to generate a holistic picture and context of the unit. However, as I will go on to discuss, in practice constructing a holistic representation was a complex and partial process.

Ethnography in this research allowed me to experience and witness what went on in the unit. I was able to engage with research participants while considering the caring practices and interactions between the staff and the patients who required regular outpatient haemodialysis treatment. My research design enabled me to take into account three key groups of people entangled in the performance of the concept of 'direct patient care': nurses, support workers and patients. Ethnography allowed me to capture data from their perspectives and then construct research findings through reflection on my own position as the researcher (and nurse) and my relationship with the different groups. By observing and capturing the activities, routines, interactions and procedures of the nurses, support workers and patients I sought to gain a holistic perspective of how direct patient care was delivered and experienced in this context. However, trying to gain a holistic perspective of the group was challenging due to particular NHS ethical committee constraints.

Ethical Constraints and Positioning in Time and Space

Ethical rules and expectations, as dictated by the NHS ethics committee who approved my research, meant I could not always access and observe all areas of patient care and treatment as an ethnographer. The ethical committee had stipulated that everyone who was in a room during an observation was required to have previously consented to being observed and participate in the study. Consequently, there were spaces in which patients would congregate in large numbers such as the waiting area or outside in the ambulance bay that could not be observed because I had not received consent from all patients and staff present. At times there were over 50 patients in this space at once, and combined with different staff groups coming through this area, there were a great number of people who would not have consented to participating in my research. This appeared to exclude a significant aspect of dialysis care, the interactions between patients and staff on arrival at the unit and waiting for appointments. I found it particularly frustrating at times where spaces and events became 'unobservable', for example when seven patients in a room had given consent, but one had declined to participate. This also posed problems. On one occasion, a room of patients had all consented, but the staff had not. This ethical stipulation challenged my initial aim of gaining a holistic picture of the haemodialysis unit. By nature of me being an ethnographer in these situations, I faced exclusion from a range of spaces, practices and interactions that I would otherwise be able to access as a nurse.

Instead, I sought to structure my observations around the patient dialysis shifts and rooms, lasting approximately five hours each time, to observe the entire process from the patient's initial arrival in the room to leaving after treatment. Arranging the observational sessions in this way provided a temporal frame for understanding patient experience in interaction with staff (both nurses and healthcare support workers). This was opposed to observing shorter periods of time, focused on different aspects of dialysis care like the starting or ending of treatment, which is typically when patient–staff interaction occurs because of the staff support required. Allowing the timeframe to be the space in which the patient occupied the dialysis unit, rather than individual activities in the process, I was able to explore more closely the entire experience from the patient's perspective. This allowed observation and understanding of how the unit functioned and supported direct patient care as a process and set of relationships rather than as a series of individual actions. Being familiar with the dialysis space and arrangements within the unit and having prior knowledge of the treatment patterns and care facilitated my interpretation of these processes. Moreover, familiarity with the shift times and patterns of practice, as a nurse, enabled me to adjust my research strategies at any given time. From my professional knowledge, I could quickly establish if the area was busy and if there was pressure on staff numbers and thereby adapt my recruitment and data collection so that it did not interfere with treatment or care. As such, a distinctive aspect of my ethnographic research design was moving between both insider and more distant positions with the tempo of the dialysis shift and the rhythms of care on the unit more generally.

The research had imposed boundaries due to the space and consenting procedures in place in line with the ethical procedures required to be followed. The main dialysis care areas were used, but due to the requirement for all present to have provided consent the smaller sections or rooms within the unit provided helpful boundaries to ensure ethical research was being conducted. These boundaries also fitted within the routine and care delivery within the area and therefore supported the structure of the research to observe the entire care process for the patient group and staff allowing the various aspects to be witnessed and add to the conceptualisation of care and its delivery.

Distance and Positioning

Unlike with traditional forms of ethnography which privilege the development of close connections with people in the field, maintaining a form of distance from the field and participants was key to my ethnographic method in that I needed to make sure I was not being 'the nurse' when I was being 'the researcher'. My professional and ethical codes meant I had to maintain particular kinds of positioning in relation to patients and colleagues, so as to not to be seen to take advantage of my professional status as a nurse when conducting ethnographic inquiry. This double identity has been a concern for other nurse researchers (Allen 2004). I used reflexive strategies to maintain awareness of my positioning and distance relative to patients and nursing colleagues, as a researcher. These strategies included open discussion with supervisors of issues challenging my position and the use of a reflective diary which included notes taken during and following observation sessions and interviews. Yet, this conscious positioning was often quite challenging, especially when dealing with patients and staff on the clinical/

non-research days. I had to ignore my research interests and carry out my job without being affected by what I was finding out as the clinical role was my priority. I was unable to talk to staff and patients to explore things they may have said about their haemodialysis experiences when they were disclosed during a clinical day. This challenging scenario of having two identities—professional and research—and being conscious of my positioning was also analytically productive. In furthering my own understanding of the ethical quandaries of being an insider and conducting ethnographic research in a familiar context, it helped highlight the different meanings of 'distance' in research and nursing.

A benefit of the insider position—of being 'close' to both the topic and field of research—was having existing knowledge of the language and jargon used in nursing and haemodialysis treatment. However, as an ethnographer, I was also forced to reflect on my interpretation and understanding of these familiar terms. For example, 'the lull' is a phrase used by various participant groups to describe the period when patients are receiving treatment and waiting for the end of their dialysis. As a nurse, I was aware of this term and used it frequently, but repositioning myself as an ethnographer, attempting to distance myself from this nursing role, I was prompted to explore this 'lull' period in more detail. It became apparent, through my ethnographic practice, that 'the lull' was more than just a period of time where little happened (from a nursing perspective); rather, this period was a key part of the care process and crucial to patients in their care experience and feeling cared for by staff.

> Two staff nurses, Moira and Karen, are sitting writing notes at the desk in room 3. They are writing in the patient folders from the morning shift, all the afternoon patients are on their machines, haemodialysis has commenced, and patients are occupied with magazines, the TV or sleeping.

The importance of this period is highlighted by a patient when questioned;

> Just keeping an eye on the machine, keeping an eye on my needles, that they are still intact, and they are firm, with the tapes, we have had those problems in the past, especially if I fall asleep, that somebody is keeping an eye on me, and I feel quite confident that they are. (Emma, Patient)

By creating a sense of distance from the expert position as a nurse, I was forced, as an ethnographer, to confront and interrogate practices, experiences and categories of meaning around dialysis care in new and different ways.

Another element of the process of positioning and distinguishing between my professional and ethnographic roles concerned my physical appearance and presentation. It was an ethical requirement to use clear behavioural or social signs to differentiate me from my nursing role and job, and also from the other nurses and staff members, when I was conducting research. This was primarily achieved by not participating as a nurse in the regular activities and keeping a distance from the usual staff and practices, but also by holding a notebook and writing field notes which looks very different to the normal nursing position. Alongside this, I made efforts to look different to my regular nursing job through my choice of attire. I wore 'research scrubs' which, while still appropriate for spending time in a clinical setting, visually distinguished me from my existing professional nursing uniform and role, and from other professional staff. Moreover, my different uniform allowed me to feel different, and not quite part of my usual job or position, as well as highlighting to others that I had switched positions. This shift in appearance enabled me to access a different perspective on dialysis care in ways I would not be able to in my usual professional position.

Finally, I used my physical positioning in care situations as a mechanism to distance myself from the role of nurse, when conducting research to avoid unethical and unprofessional practice of participating in care and clinical activities while conducting ethnography. An example which nicely illustrates the different positions I took was the morning 'safety brief' where all staff would come together to hear important updates and staff allocations for the shift ahead. This took place at the start of every shift before any patients arrived. On research days, I would not participate in this or be part of the group discussions by sitting to the side, rather than standing with the staff group. I could witness and document this event if all present had consented. In this way, I was actively distancing myself from my usual clinical role, but also demonstrating to others—my research participants—the particular role and position I was adopting on that day.

Blurring of Positions: Crossing Boundaries in Space and Time

As described above, I adopted a number of different strategies within my ethnographic research to differentiate my roles and positions between research and clinical working days. However, there were occasions where maintaining distance and differentiating between researcher/nurse identities was particularly challenging. Rather than consider these as 'failures', I will discuss how these offered analytical insight into my ethnographic position and data generation which allowed the construction of an understanding of direct patient care and how it was delivered in the haemodialysis setting. Care was identified to be delivered in two ways: actively and passively, where active care focused on the engagement between the staff and patient and passive care was experienced through the availability and visibility of staff.

During the research, the boundary between my two roles became blurred on occasion, due to unfolding events in the clinical spaces in which I was conducting ethnography. For example, during one observation, I was required to put down my notebook and assist the nurse in the room with a situation involving a patient, captured in my field notes:

> I can see that Marie-Anne needs some assistance but she cannot go anywhere as she is holding the bleeding fistula site, she is looking around but there is no staff in the room. There is no one else available in the room to get equipment from the trolley which is about 10 feet away so I get up to get the equipment for her. I open the packs up and put them out and also offer a suggestion of advice to use another type of dressing which I have also laid out which will help stop the bleeding 'take that off, use this and start again' I say. Marie-Anne is an experienced nurse but I want to make sure she is ok with the current situation and offer advice. I then wash my hands beside the patient and then sit back down with my notebook and continue the observation *writing down what has happened and my involvement.*

Ross (Patient): you're meant to be watching (directed to me)
Marie-Anne: bet that's given you something to write about (making a joke)
Ross: 'I had to oblige'.

As there was no one else who was in the room to pass the nurse some equipment she required to stem the bleeding, I felt compelled to put down my notebook and pass and open the bandages and equipment she needed. From my professional role, I knew which dressings were needed from the trolley and how to provide another nurse instruction. Despite the minimal interaction from myself, the duty of care to support the patient and nurse in this situation was priority here. If I had not provided equipment, my professional duty as a nurse would be have been undermined and the patient would have been at risk of harm. This situation further highlighted the importance to patients of feeling safe and cared for due to the availability and visibility of staff alongside the direct engagement with patients to provide elements of care. The relationship that nursing staff have with patients to help and support them underpins this care delivery, and I was unable and unwilling to neglect this in this research situation.

It was crucial to write into my research protocol the professional duty of practice which underpinned the conduct of my research and which therefore shaped my positioning as a nurse and ethnographic researcher. Despite trying to maintain a distance as a researcher conducting data collection and analysis, I followed the Nursing and Midwifery Council's (NMC) code of conduct as part of my research role, as my professional code undermines the research position when patient safety is concerned. The NMC code of conduct stipulates that key to nursing is preserving patient and public safety, alongside prioritising patients and promoting professionalism and trust, and as such that in an emergency situation I would be required to step into assist the staff in whatever way is deemed appropriate to follow the code. Therefore, it was my very 'insider' position as a nurse researcher, and the codes and values on which my nursing role rests that led me, on occasion, to cross the boundary between ethnographer and practitioner. This complicated my attempts to create distance between these two positions through spatial and temporal positioning strategies and also highlights the complexity of traditional ethnographic approaches such as ‘participant-observation’ in clinical contexts such as this. This approach and the challenges I required to engage with assisted me in reflexive practice and exploring care and the various perspectives from the participants through this position.

In addition to these blurrings of positioning within the spaces in which clinical activity unfolded, there were also challenges to my nurse researcher distinction due to the temporal dimension of my fieldwork. Over the course of the fieldwork, the group of patients on whom my research was (partly) focused changed. Some patients no longer required dialysis, due to either receiving a transplant, withdrawal from dialysis or dying, and new patients began receiving care and treatment. Therefore, some patients who started attending the unit did not know me as a nurse but as a researcher. Similarly, some nursing staff moved on or started working on the unit during my fieldwork, and since I was part-time, they often knew me more as a researcher than as a nurse. This identity confusion across the participants over time required continual attention from me, to explain who I was to different people and what I was doing at various different points during the fieldwork. This also required explicit acknowledgement that my (changing) position could be confusing and blurred. The shifting participant groups, both over the course of the fieldwork and on a day-to-day basis, also shaped my use of space for research whereby who had and had not consented to participate in any given space may change. My research boundaries were complex due to the constantly changing staff and patient group in the area, which were then further stratified by the distribution of consenting and non-consenting individuals.

There were concerns voiced by some staff to the researcher on research and non-research days about the kinds of information being collected, what was being observed and for what means. Although staff frequently mentioned they were pleased I was not there to pass on direct problems to the managers, some queried whether I would be ‘spying’ on them. On these occasions, I pointed to the information sheet for guidance which stated clearly the purpose of the research. The sheet gave staff space to make a decision on participation independently and in their own time. As the research progressed, staff began to trust me as a researcher and felt less threatened by my presence and potential whistleblowing actions. Staff began to talk in front of me discussing patients, including me in conversations during their shifts and became less concerned with watching me and what I was doing as fieldwork progressed. Trusting me as a colleague, and as both a practitioner and researcher, was important for supporting data collection and my ethnographic position.

Interestingly, there was a complexity around participation and consent whereby patients would openly identify their participation within the research and fieldwork. At points, staff and patients would really demonstrate their knowledge of their participation in the research process. There were occasions where staff and patients would joke, saying things like: ‘did you see that – do I need to do it again?’ demonstrating their understanding of my observations. These moments also performed a different researcher–participant dynamic where participants were potentially doing things for the researcher’s benefit.

Re-entering the Field Post-fieldwork

After the fieldwork was completed, although my position as ethnographer dissolved, my role as a nurse continued following the same part-time working patterns as during the fieldwork period. This presented new challenges as I remained ‘in the field’, ostensibly in the same capacity as nurse, but now having passed through the position of ethnographer. For example, both patients and staff who had participated and also declined consent for participation began regular questioning about when the research was finished, what I had found out and expressed wishes to read the thesis. Even some patients who had not been receiving care during the fieldwork period showed interest in my research, despite not having any involvement in the project. This showed a need for me to continue managing the dynamic between my roles as ethnographer and nurse even beyond the formal time and space in which the ethnography was conducted.

Re-entering the field (only) as nurse also highlighted challenges to the relationships I held with colleagues. During the fieldwork period, wherein I attempted to maintain distance between my roles as nurse and researcher, I did not actively engage with staff social events to avoid feeling like I was exploiting friendships or blurring boundaries.

Following the end of data collection, it took me a while to start to integrate back into the team as a colleague and participate in these sorts of situations. While data analysis continued after leaving the field, staff would continue to ask about the data collected and the results of the research. This was problematic, and I had to maintain a position of ethnographer and the associated ethical obligations. I could not discuss and engage in discussions about my research progress because of the risk of it affecting my analysis. This highlights that while the fieldwork had ceased, the interest and my researcher role were still present to the staff and patients.

The research focused on nursing practice and within the area there is an appetite to engage with research and evidence-based practice and to utilise research findings to improve care and experiences.

Conclusions

The chapter has illustrated the ways in which, as a nurse and ethnographer, I attempted to maintain the separation of roles which is deemed good practice in biomedical research ethics terms. However, the dynamics of the spaces and tempos through which my research 'object'—the delivery and experience of direct patient care in a dialysis unit—unfolded during the fieldwork period meant that the separation between my dual identities and position was complex and at times blurred. The 'insider' perspective I held, as a nurse practising within my field site, was valuable for navigating these dynamics to ensure my research practice did not interfere with the delivery of care, and for recognising when the distant ethnographic position should be abandoned to ensure the protection of the patient was upheld. However, as an ethnographer, I was also forced to reconsider and reflect upon my insider knowledge, adopting a different perspective and interpretation of the practices and language of caregiving and receiving on a dialysis unit. This chapter adds to increasing literature exploring the value of ethnography for nursing research (Savage 2000a; Morse 2016; Ryan 2017) and highlights the importance of acknowledging the multiple and potentially conflicting identities that are inevitable when conducting in-depth, situated enquiry in a clinical context, underpinned by professional, clinical knowledge and codes of conduct. Furthermore, this chapter extends wider debates around ethnography as a methodology in terms of how feasible a 'holistic' understanding of any field is, and the varying positions and roles the ethnographer might undertake in seeking to engage with and understand the people and practices of that field. As a profession based on values of reflection and observation (Savage 2000b; Borbasi et al. 2005), as well as direct engagement with patients, nursing seems well positioned to embrace ethnography as a methodology for researching health and health care and to prompt important questions for how positionality, identity and knowledge intersect through ethnography.

References

Allen, D. (2004). Ethnomethodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings. *Nursing Enquiry, 11*(1), 14–24.

Ashwanden, C. (2003). Discovering the culture of haemodialysis units: An ethnography. *EDTNA.ERCA Journal, 29*(4), 192–194.

Bennett, P. (2010). Satellite dialysis nursing: Technology, caring and power. *Journal of Advanced Nursing, 67*(1), 149–157.

Bennett, P. (2011). Technological intimacy in haemodialysis nursing. *Nursing Inquiry, 18*(3), 247–252.

Borbasi, S., Jackson, D., & Wilkes, L. (2005). Fieldwork in nursing research: Positionality, practicalities and predicaments. *Journal of Advanced Nursing, 51*(5), 493–501.

Draper, J. (2015). Ethnography: Principles, practice and potential. *Nursing Standard, 29*(36), 36–41.

Leininger, M. (1970). *Nursing and Anthropology: Two Worlds to Blend*. New York: Wiley.

Leininger, M. (1978). *Transcultural Nursing Concepts, Theories*. New York: Wiley.

Leininger, M. (1985). Transcultural care diversity and universality: A theory of nursing. *Nursing and Health Care, 6*(4), 209–212.

Leininger, M. (1988). Leininger's theory of nursing: Cultural care diversity and universality. *Nursing Science Quarterly, 1*(4), 152–160.

Morse, J. M. (2016). Underlying ethnography. *Qualitative Health Research, 26*(7), 875–876.

Robinson, S. G. (2013). The relevancy of ethnography to nursing research. *Nursing Science Quarterly, 26*(1), 14–19.

Roper, J. M., & Shapira, J. (2000). *Ethnography in Nursing Research*. Thousand Oaks, CA: Sage.

Ryan, G. S. (2017). An introduction to the origins, history and principles of ethnography. *Nurse Researcher, 24*(4), 15–21.

Savage, J. (2000a). Ethnography and health care. *British Medical Journal, 321*(7273), 1400–1402.

Savage, J. (2000b). Participative observation: Standing in the shoes of others? *Qualitative Health Research, 10*(3), 324–339.

Scottish Renal Registry. (2016). *Scottish Renal Registry Annual Report 2015*. Edinburgh: NHS National Services Scotland. Available from http://www.srr.scot.nhs.uk/Publications/docs/scottish-renal-registry-report-2015-161107.pdf?4. Accessed November 20, 2017.

Thomas, N. (Ed.). (2014). *Renal Nursing* (4th ed.). Oxford: Wiley-Blackwell.

Thorne, S. E. (1991). Methodological orthodoxy in qualitative nursing research: Analysis of the issues. *Qualitative Health Research, 1*(2), 178–199.

Tranter, S. A., Donoghue, J., & Baker, J. (2009). Nursing the machine: An ethnography of a hospital haemodialysis unit. *Journal of Nephrology and Renal Transplantation (JNRT), 2*(3), 28–41.

5

Using an Ethnographic Approach to Study End-of-Life Care: Reflections from Research Encounters in England

Erica Borgstrom

Introduction

This chapter was inspired by the reflections on the various kinds of explanatory work that I had to do to legitimise and negotiate studying end-of-life care in England ethnographically. This was often on the fringes of the 'actual fieldwork'—in outlining and justifying the methods to colleagues, to the ethics review board and to potential participants—and in so doing, it shaped the study and what could be known. In this chapter, I alternate between reflections on my experiences and how these relate to developing understandings of what doing ethnographic research is in the contemporary (Rabinow et al. 2008), one of not just 'being-in-the-world' of our research sites (Cooley 1997) but of being in particular kinds of ways in relation to the wider research endeavour. I use these reflections to make connections between

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E. Borgstrom (✉)
Open University, Milton Keynes, UK
e-mail: erica.borgstrom@open.ac.uk

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adopting an ethnographic approach and what I was able to observe, hear and later, know and say about end-of-life care in England that spanned beyond a healthcare-perspective of the dying.

Rather than get entangled in debates about what ethnography is, and who can do it—despite such claims to method being important within anthropology (Rabinow et al. 2008; Ingold 2014)—I argue for talking about the ethnographic approach. I adopted 'an ethnographic approach' that encapsulates the techniques of data collection, and more importantly, how these are grounded within a wider understanding of the research endeavour, which can be lost when ethnography is reduced to method. For this, I define an ethnographic approach as entailing: a commitment to make sense of people's lives from their points of view; engagement with the field, however, constructed by the researcher and through the project and not limited to a geographical area (Kisliuk 1997); flexible in the kinds of engagement involved in research, recognising that people who are 'participants' have their own lives outside of the scope of the project; most likely multimodal in that observations often include listening, interviews and note-taking; seeking to place issues within wider context, but acknowledging that researchers shape what is considered context (Hammersley and Atkinson 1983); and analysis that invokes working through descriptions even if these do not always feature as 'thick descriptions' in the various outputs produced by research. In doing so, I am aligning my argument with Law's (2004) encouragement to think and write about (social science) methods as ways of being.

The Study on End-of-Life Care

> It was not uncommon to see absent looks when I told people I was an anthropologist or that I wanted to do 'an ethnography' about end-of-life care…simplistic understandings of anthropology rolled off my tongue to fill the silence… 'traditionally, anthropologists would go off to far away, exotic places to live with people for long periods of time to observe and write about how they see the world'. And with an uncomfortable chuckle, I'd add: 'of course, that's not always appropriate now or in the UK, so what I do is watch and talk with people to understand what they do, etc'… by

> this point, most people would smile and nod, saying 'how interesting' or 'how useful'. Reassured, I was often given the chance to then listen to them or invited to tell more about specific elements of my project, a sign that they could entertain me studying end-of-life care in this way. Perhaps we could have a mutual understanding that watching and listening were important means of studying this topic.

For my doctoral research on end-of-life care in England, due to the prominence of the concept of 'choice' in policy, I wanted to examine what 'choice' was and how it was done as people approached the end of their life, linking together policy discourses, healthcare practices and people's everyday experiences (Borgstrom 2014). The National Institute of Health Research funded the research, and because of this, I was part of a university department focused on primary care and public health. In part, the funding mechanism determined that end-of-life care was primarily a health issue or could be understood through health research.

Nevertheless, I sought to view end-of-life care as something inherently social and to be understood from a cultural perspective—in terms of both how policy is understood and how end-of-life care is done. I also wanted to maintain my identity as an anthropologist within a multidisciplinary department, so without much hesitation I began to define my project as having an ethnographic approach, both in terms of how I did the actual data collection and analysis, but more importantly for me, how I approached the wider project of conducting research. During my master's degree in anthropology, we had learned how 'ethnography' could be used as a shorthand for saying something greater about one's epistemological and moral stance about research. I did so even though it was evident that the project I was proposing did not fit the trope of traditional anthropological ethnography. Moreover, I did so not always appreciating the subtle slips between anthropology, ethnography and ethnographic approach that I was making (see Hockey and Forsey 2012).

The project had three main parts focusing on end-of-life care: policy, practice and everyday experiences of living with life-limiting conditions. The data collection was between 2010 and 2012 and primarily within one county of England. In total, the project consisted of over 300 hours of observations (of policy events; of professional team meetings and patient care provided in hospitals, hospices, doctors' offices and in people's homes), 100 semi-structured interviews, textual analysis and further longitudinal fieldwork with 10 people, which contained more time of observations and informal interviewing. I wrote the research as a single doctoral thesis that combined, juxtaposed and spoke across the three elements (Borgstrom 2014).

The first part was an analysis of local and national policy discourse to examine the use of the word 'choice' and what it was referring to, and what values and practices it was associated with, such as advance care planning. This included studying the text within policy documents, observations at policy events, as well as interviews with policymakers to elicit their understanding of the concepts used and how they came into being within the policymaking process. My focus on policy here was to understand how the discourses set values for care, influenced how healthcare professionals viewed and did their work, and how policy values intersected with people's experiences of their own lives in the context of life-limiting illness. My analysis of policy illustrated how end-of-life care created dying and certain kinds of death as problems that could be solved through managed (and predominately medically supported) care (Borgstrom 2015c, 2016).

The second element of the project involved observing and talking about clinical practice—how choice, particularly through advance care planning, was done or not done. This included observations and interviews with a wide variety of healthcare professionals, covering: a large teaching hospital; several city and community hospitals, including specialist services; a hospice; three care homes; and several general practice and community nursing services. For example, I spent weeks visiting an outpatient hospice day therapy unit where nurses, allied health professionals and volunteers worked with patients on managing their symptoms, including anxiety, talked about care planning and provided general chit-chat and social activities as a form of respite. I also shadowed specialist palliative care teams in hospitals and the community to understand their daily work practices and observe when and how they decided to do advance care planning with patients. Where possible, I also collected and analysed documentation used in these places, such as care plans. This approach to research enabled me to see how forms for advance care planning were used, and in some cases, became pro forma that marginalised the very person-centredness they were designed to capture (Borgstrom 2015a). Overall, what these interviewees and settings had in common, which an ethnographic approach enabled me to analyse, was how they defined end-of-life care as something that was part of their responsibility as a health and care issue and prioritised care on the basis of a person's diagnosis and prognosis.

The third element primarily involved interviews with those who could be considered to be towards the end of their life (defined by policy within the last year of life usually related to a life-limiting illness), or caring for someone in this condition, or likely to be considering end-of-life care issues. I 'recruited' these participants through condition or caring-related support groups (some of which I visited for several months) or through clinical contacts (such as the hospice and specialist palliative care nurses). Most people I only interviewed once or twice with interviews lasting from 45 minutes to several hours, and I 'followed' another 10 people (and their families where possible) for up to 14 months. In the latter cases, I regularly visited them and participated in 'daily living', including going shopping, discussing the news and drinking tea. Where possible and with consent, I accompanied them to clinical appointments and/or had access to their medical records. For this part, the methods I used were about being with people and to experience, to some extent, their ways of being in the world. This demonstrated analytically that whilst end-of-life care policy is very individualistic in its interpretation of choice, people view it and their health in more relational terms (Borgstrom 2015b).

For all parts of the project, interviews took place in a location suggested by the participant—sometimes offices, hospital cafes or in their homes. With consent, interviews were audio-recorded, although for practical reasons longer visits or excursions were not audio-recorded. From all of these encounters, including observations, I made field notes and kept a reflexive field diary. These enabled me to keep a record of things that appeared salient at the time—how a room was laid out, the tone of the encounter and what stuck with me—and feedback to myself on how I may approach questions differently in the future encounters. Not only can such notes be useful for future data collection and provide contextual data in analysis, but fieldwork notebooks are also a space to cultivate the 'imaginative logic of discovery' (Taussig 2011). Therefore, rather than assume that what I observed and heard was fixed knowledge, such notes helped me see how what I came to know and write about end-of-life care evolved and what could be known when different kinds of data and accounts were juxtaposed with one another.

Clinical Colleagues: A Critique of Method

> Within a health department, many of my colleagues had little formal training in 'social science research methods', and tended to label me as a 'qualitative researcher'. But this did not mean they accepted what I was doing… the first line of criticism was the subjective nature of the study. Fieldnotes 'contaminated' by my personal filters about what to record and how to do this, as well as my presence (akin to the Hawthorne effect). Colleagues questioned how I intended to minimise or control these elements; at worst, it was suggested that whatever data I collected and regardless of how I analysed it, it would be somehow inferior to 'more objective' modes of research. Even those who were 'sympathetic to qualitative research' were troubled by the potential variability within ethnography as a method. There were presumptions about the importance of predetermined interview schedules, the numbers of interviewees (the more the better usually)…I was doing something that felt radically different in this work environment, even if 'pro-ethnography' pieces had been published in medical journals before. (e.g. Reeves et al. 2008; Savage 2000)

From conversations I have had with social science colleagues, both within the departments where I have worked and at conferences, these types of reactions to doing ethnographic research are not unique to my experience. It is evident that working at the margins, where an ethnographic approach is not the staple method of one's colleagues, other standards and approaches to knowing that privilege 'evidence' and 'science' are present, and as such, ethnographic approaches can come across as questionable and somehow 'lesser' (see also Dey 1993). My encounters with colleagues suggested that we had different presumptions about what health is and could be, and how it could be known, with their focus on framing research as solving known problems or testing theories. In part, this tension sits at the fault line between qualitative and quantitative methods and debates about art versus science (Fuller 2002).

In response, I stressed the ability of an ethnographic approach that was able to take a topic—such as choice in end-of-life care—but not predetermine what is important in terms of how it is defined, how it is done, and what the consequences of it might be. I noted that I was seeking to understand something that we did not know how or when it happened, and therefore it was only through the uncovering processes of the methods I was proposing that I could begin to locate the object of study. Anthropologists' own comfort with ambiguity, and to assume that the 'taken-for-granted' can be made visible, allows for the suspension of a priori beliefs as part of the research process. I drew on the anthropological trope of 'seeing life from others' points of view' to legitimise this, particularly noting how through engaging with people over time inevitably implied that our encounters would draw on previous discussions and changes in their circumstances since we last spoke. Not only does this mean that an ethnographic approach can be less prescriptive than other methods, but in doing so we accept that our focus of study—and indeed the various kinds of knowledge that a study may produce—can be beyond our current comprehension of the issues at hand.

These encounters with colleagues made me very self-aware of how I was doing 'data collection' as a process, but a different kind of process than just considering it as 'fieldwork' or ethnography as a perspective (c.f. Wolcott 1973). It meant my methods had to be accountable to others even in how I held open the possibility of being flexible and not predetermining the analysis or findings. For example, I recorded number of hours of observations and number of interviews, creating and structuring metadata in ways I had not originally intended. Overall, working within this multidisciplinary environment made me appreciate how, in order for my research to be taken 'seriously' outside of my own discipline, I had to present my research in particular ways, such as quantifying data collection, without compromising my epistemological position.

The Ethics Committee: Ethnographic Approach as Sensitive

> When preparing my applications, many of the questions on the standardised forms pertained to the randomised-controlled trial (RCT) model of research, presuming health research is focused on a prescribed intervention intended to affect someone's health and that effects of this can be observed and measured. The trick to completing these forms it seemed was to be detailed enough about my intentions of actions – breaking it down into components of participant-observation, interview, document analysis, and potential sites – but vague enough to enable me to change direction during the study as it unfolded, and to justify this. I was lucky to have a committee member who was familiar with participant-observation who could vouch for 'the method' during the ethics committee's three-hour long deliberation of my study. Moreover, they were 'relieved' upon meeting me to see I could be sensitive enough not only to handle the topic and 'vulnerable patients' appropriately, but also to manage the flexibility inherent in the project I was proposing.

I will address three issues about my experience with these formal requirements. One is the lack of awareness about what ethnographic research is and the importance in being able to make claims about it. The second, which is related, is how these kinds of committees and governance structure knowledge, and how as ethnographers we can promote the kinds of research we do within these frameworks. Lastly, I will comment on the role of identity in these encounters.

Justifying an ethnographic approach can become about claiming it is '*a practical choice from one of several alternatives*' (Taylor 2002: 3). As I note above, I was 'lucky' that one of the ethics committee members knew about participant observation prior to my application and could 'vouch' for it as a 'legitimate and appropriate' method. Bracketing the collapsing of participant observation with the entire project (even though I outlined other methods), without this person I would have probably had to spend more time in the meeting than I did describing not only the specific methods and study rationale, but the deeper methodological and epistemological commitment the research was based on. Not only were most of the members unfamiliar with the kinds of methods I was proposing, they were also less familiar with inductive styles of research, open questioning and the prospect of flexible research encounters, and therefore felt under-qualified to pass judgement on the relative 'riskiness' of the proposal, as one member told me during the panel meeting.

This was a particular issue because of their concern that, being a study about end-of-life care, participants would be inherently vulnerable (see Koffman et al. 2009). Whilst my research was not the first to interview people during this phase of life or to even do observations on dying (see also Lawton 2000), the ethics of doing death-related research is still discussed (Cook and Bosley 2007; Kendall et al. 2007; Borgstrom and Ellis 2017). It was therefore important that I could make substantiated claims about not only the suitability of the match between research questions and methods, but also the ability of my research approach to be 'sensitive' to this potential vulnerability and, for example, 'meet' participants where they were at emotionally. This flexibility also meant I did not presume what would be important to people to discuss end-of-life care. One of the defining features of social theory is its ability to be sensitising—to point out areas to examine but not claim to be definitive about them (Blumber 1954), and I argued that an ethnographic approach can be both sensitising and sensitive through seeking to follow potential participants' perspectives and lives, and negotiating the research process with them. This is important because ultimately my research on choice and advance care planning contrasts with most of the research on the topic, which seeks to identify barriers and facilitators, rather than, as this ethnographic research suggested, we should rethink what choice is and how it operates in this context.

Now, I realise that for many anthropologists and ethnographers, what I am saying may seem redundant. Yet, it is important to note how they can be deployed strategically as these encounters are moments in which the value of different kinds of ways to produce knowledge is adjudicated on. And that we are actually in many cases in a position of authority to make claims about the method we are proposing. Research ethics committees are supposedly concerned about a risk/benefit analysis of the method within the remit of the particular study (Tolich and Fitzgerald 2006).

This is a false impression as the feedback and 'opinions' (as they are not strictly called approvals) that they provide pass judgement on the value of the study (and components within it) to 'science', clinical practice, the potential participants and overall societal value. Their comments can effectively change the nature of a project.

There is a bias within the forms one must complete as part of process towards certain ways of thinking and doing research; they frame health as something to be intervened upon and social aspects to be controlled for. Others have commented on how these do not necessarily fit a more qualitative or even mixed methods approach (Ramcharan and Cutcliffe 2001; Wynn 2011). The ways in which the forms are constructed suggest particular ways of doing a project—usually in the framework of an RCT—are the preferred ways of conducting high-quality research. What is important then for those like me having to complete these forms is to not only justifying the method, but the kinds of knowledge that this kind of approach can produce. In this instance, as with clinical colleagues, I had to shift their focus from presuming knowledge production should be about how to best do advance care planning or measuring the most effective ways of doing care planning. Instead, I demonstrated how anthropological interests in how policy, healthcare practice and people's experiences interact to enable an understanding of how 'choice' is understood and operationalised in the context of end-of-life care.

Lastly, the committee were also passing judgement on my character as part of their assessment in my ability to conduct this study. Writing about his research with Jewish communities, Shaffir notes how '*the way we are perceived can greatly influence how others respond to our work*', with the most critical response being to '*the researcher's human qualities*' (Shaffir 1998: 58). In my example, as with Shaffir's work, the assessments of the researcher's human qualities are intertwined with how the research objectives are understood by others. Since I wanted to study end-of-life care, both my answers in the boxes of the forms and my personal presence had to 'convince' the committee that I was 'sensitive and sensible' (as stated in the meeting) and therefore considered to be less of a risk to the (potentially) 'vulnerable' people I would be spending time with. As part of their role as 'protectors' of potential participants, they wanted to be 'reassured' that both the methods would not be blunt, but that the instrument conducting the study (me) would be 'sensitive'. I think that in this instance, my ability to display characteristics that 'reassured' them about how I would do the study was as important as justifying the methodological fit and procedural decisions that are detailed in the forms. In essence, they were making a decision about who could do this kind of research: someone with the methodological rationale, technical expertise and interpersonal sensitivity. The consequence this has for understanding ethnography in this context is that it is more than just method, it is also about the ethnographer, and therefore methods are not just about a way of being but also of how being is perceived.

Recruiting: Describing Fieldwork

> Unlike how I was taught about traditional fieldwork, where the anthropologist showed up and lived in a village, serendipitously encountering people and learning about how they lived, I had to actively recruit people to my study. I visited different support groups and hospices, giving short talks about my research to gauge interest and enlist potential interviewees and people 'to follow'. To foreground the ethnographic approach, I highlighted how I was interested in them as people and what their lives were like.

As part of the study, I had to formally recruit people to interview and 'to follow'.[1] To do this, I deployed the trope of traditional anthropological fieldwork as a means to outline the kinds and variety of methods used, particularly the 'hanging out' aspect of the longitudinal element. I also highlighted the wider commitment to not predetermining what the main issues are and therefore being adaptable to both people and circumstances. In this section, I reflect on what the use of this trope allowed for but also limited in terms of how the study unfolded.

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[1] I used the term 'to follow' to describe the longitudinal element of the study, reflecting both the traditional trope for ethnographic fieldwork whilst also being imprecise as to what following means as a method (both practically and analytically as my study also 'followed' choice).

Firstly, I noticed how the use of this way of describing the research, rather than employing only technical terms with predefined number of research encounters, affected who was considered 'an appropriate participant' either by themselves or by others (e.g. institutional gatekeepers in care settings, see also Witham et al. 2013). For those that were interested in the longitudinal element—that is more than a single research interview—they often cited their willingness to talk about anything as a quality that qualified them for the role of participant. Some of them admitted that they wanted the social company that regular research participation seemed to offer, and this was particularly noticeable towards the end of the study when people were upset that our visits would soon stop. In addition to welcoming my presence and listening ear, people had to be to various extents, willing to open up aspects of their lives to a stranger, including elements that are rarely viewed by themselves (such as their medical record). How the 'fieldwork' was described meant that there was an element of (self) selection of what a 'participant' should be like and be willing to do. It also reflects wider issues in end-of-life care about how 'choice' is often perceived only through verbal and active responses from people who have the willingness to share these elements of their lives and perspectives with others after being asked to by a person in authority.

In some instances, nurses recommended patients who they felt 'needed to talk' or who would 'benefit from talking' to me, viewing the research engagement as a potential extension to the care provided. The healthcare professionals viewed what the ethics committee considered as the 'sensitive' nature as 'therapeutic'. This selection of patients as potential participants suggests that the healthcare professionals presumed that there are certain issues that people should process before death, especially through talking, and that perhaps there was not always adequate time or resources to accommodate this talking within the services they provided. Viewing talking about end-of-life care as beneficial shows a shift in care values since the 1960s where many patients were not even told they were dying (Glaser and Strauss 1965); however, the structural spaces of care may not always allow for this as implied by using research to fulfil this need to talk.

There were limits to adopting the ethnographic approach as I did. For example, although we joked that as an anthropologist in Britain (with a husband and a 'job' as they saw it), it was perhaps not as socially appropriate for me to 'live with them' as the traditional trope suggests (see Hockey and Forsey 2012), this lack of ongoing presence meant that there were often gaps in my ability to know about developments in their care (i.e. emergency hospital admissions). These omissions were sometimes willing on their part or they thought I might not be interested. This was further articulated by the ways in which people restricted the engagement of other family members or friends in the project (i.e. suggesting we meet only when spouse was not at home) and the spaces in which I was made to feel welcome. In this way, these boundaries of the research were set by the participants and shed some light on how issues of dying and sharing personal perspectives may be similarly hidden or revealed within families and between families and healthcare professionals. Yet, due to my reliance on and joking about the traditional trope of ethnography to initially explain my research intentions, they may not have always fully appreciated the extent of my interest in their lives more generally as part of my attempts to understand end-of-life care in the widest context possible. The flexibility that had been built in by trying to tap into the mythical ethnographic ability to know the lives of those under study also enabled the very same people to shape what could be the subject and course of the research. This ability to shape what could be known and documented paralleled how people did not always engage with advance care planning documents as policy intended—the gaps, impartial context and incomplete forms mirrored the inability to capture all and the necessity of responsiveness in engaging with the person.

Discussion

By adopting an ethnographic approach, I sought to talk about a 'way of being' within our research contexts (Law 2004), in a way that talking about research as a noun does not allow for. This way of being can include how one wants to do research, how one positions themselves and their identities in relation to others in research endeavours, and how '*being with*' and '*being there*' as part of one's research engagements (Hockey and Forsey 2012: 75).

When I present my research to different audiences, I try to often incorporate these different elements of being alongside the different kinds of data collection and knowledge that the study produced. Through this, I become part of the story I tell. Each (re)telling risks the critiques and comments that I experienced on the way—subjective research, concerns about rigour, bias in sample—as well as the risk that it may not be viewed strictly as 'ethnography'.[2] Yet, I have found that by being able to make links between healthcare policy, practice and people's everyday experiences, what I write and talk about 'makes sense' to people in a new way. For example, hospice workers have told me that hearing how I interweave policy understandings of choice, structural limitations of healthcare provision for advance care planning and accounts of how people live enables them to think differently about how they see patients, and themselves, as people. Not only as people but people whose lives can be influenced by things (e.g. policy, hospital culture) that are not always within their control despite the choice rhetoric. An ethnographic approach, although not always well understood or accepted as a methodology, has the ability to 'speak to' different audiences through the connections it makes and the positionality of the ethnographer.

Adopting an ethnographic approach enabled me to explore facets of English end-of-life care and present different kinds of knowledge about it. Firstly, it enabled me to argue for seeing end-of-life care not only as an element of health care, where biology of dying determines patterns of death, but as a social and cultural construction and process. Through an analysis that juxtaposed policy, healthcare practices and people's everyday lives, I was able to write about how the values, actions and experiences interacted. In this study, I was able to demonstrate how

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[2] Some anthropologists are renowned for attempting to retain authority over what ethnography is and can be, even at the risk of marginalising new approaches to doing ethnography, particularly interdisciplinary projects and research in 'Western' countries (see critiques in Rabinow et al. 2008).

dying and end-of-life care became defined within policy as ‘problems’ for the English healthcare system and what solutions were proposed—predominantly patient choice and advance care planning. I was able to observe where, how and when ‘choice’ was done—but more often not done—and how people lived relational lives outside of the health constructions of end-of-life care. Such an approach brings to the fore and challenges the normative assumptions within healthcare systems and policy about what the focus of end-of-life care should be.

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References

Blumber, H. (1954). What is wrong with social theory. *American Sociological Review, 18,* 3–10.

Borgstrom, E. (2014). *Planning for Death? An Ethnographic Study of English End-of-Life Care*. Cambridge: University of Cambridge. Available at https://www.repository.cam.ac.uk/handle/1810/245560.

Borgstrom, E. (2015a). Advance care planning: Between tools and relational end-of-life care? *BMJ Supportive & Palliative Care, 5*(3), 216–217.

Borgstrom, E. (2015b). Planning for an (un)certain future: Choice within English end-of-life care. *Current Sociology, 63*(5), 700–713.

Borgstrom, E. (2015c). Social death in end-of-life care policy. *Contemporary Social Science, 10*(3), 272–283.

Borgstrom, E. (2016). End of life care strategy and the Coalition Government. In L. Foster & K. Woodthrope (Eds.), *Death and Social Policy in Challenging Times* (pp. 35–52). Basingstoke: Palgrave Macmillan.

Borgstrom, E., & Ellis, J. (2017). Introduction: Researching death, dying and bereavement. *Mortality, 22*(2), 93–104.

Cook, A. S., & Bosley, G. (2007). The experience of participating in bereavement research: Stressful or therapeutic? *Death Studies, 19*(2), 157–170.

Cooley, T. J. (1997). Casting shadows in the field: An introduction. In G. F. Barz & T. J. Cooley (Eds.), *Shadows in the Field: New Perspectives for Fieldwork in Ethnomusicology* (pp. 3–19). Oxford: Oxford University Press.

Dey, J. (1993). *Qualitative Data Analysis*. London: Routledge.

Fuller, S. (2002). *Social Epistemology*. Bloomington, IN: Indiana University Press.

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of Dying*. Chicago: Aldine.

Hammersley, M., & Atkinson, P. (1983). *Ethnography: Principles in Practice*. London: Tavistock.

Hockey, J., & Forsey, M. (2012). Ethnography is not participant observation: Reflections on the interview as participatory qualitative research. In J. Skinner (Ed.), *The Interview: An Ethnographic Approach* (pp. 69–87). London: Berg.

Ingold, T. (2014). That's enough about ethnography! *HAU: Journal of Ethnographic Theory, 4*(1), 383.

Kendall, M., et al. (2007). Key challenges and ways forward in researching the "good death": Qualitative in-depth interview and focus group study. *British Medical Journal, 334,* 521.

Kisliuk, M. (1997). (Un)doing fieldwork: Sharing songs, sharing lives. In G. F. Barz & T. J. Cooley (Eds.), *Shadows in the Field: New Perspectives for Fieldwork in Ethnomusicology* (pp. 23–44). Oxford: Oxford University Press.

Koffman, J., et al. (2009). Vulnerability in palliative care research: Findings from a qualitative study of black Caribbean and white British patients with advanced cancer. *Journal of Medical Ethics, 35*(7), 40–44.

Law, J. (2004). *After Method: Mess in Social Science Research*. Abingdon: Routledge.

Lawton, J. (2000). *The Dying Process: Patients' Experiences of Palliative Care*. London: Routledge.

Rabinow, P., et al. (2008). *Designs for an Anthropology of the Contemporary*. Durham: Duke University Press.

Ramcharan, P., & Cutcliffe, J. R. (2001). Judging the ethics of qualitative research: Considering the "ethics as process" model. *Health & Social Care in the Community, 9*(6), 358–366.

Reeves, S., Kuper, A., & Hodges, B. D. (2008). Qualitative research methodologies: Ethnography. *British Medical Journal, 337*, 1020.

Savage, J. (2000). Ethnography and health care. *British Medical Journal, 321*(7273), 1400.

Shaffir, W. (1998). Doing ethnographic research in Jewish Orthodox communities: The neglected role of sociability. In S. Grills (Ed.), *Doing Ethnographic Research: Fieldwork Settings* (pp. 48–64). London: Sage.

Taussig, M. T. (2011). *I Swear I Saw This: Drawings in Fieldwork Notebooks, Namely My Own*. Chicago: Chicago University Press.

Taylor, S. (Ed.). (2002). *Ethnographic Research: A Reader*. London: Sage.

Tolich, M., & Fitzgerald, M. H. (2006). If ethics committees were designed for ethnography. *Journal of Empirical Research on Human Research Ethics: An International Journal, 1*(2), 71–78.

Witham, G., Beddow, A., & Haigh, C. (2013). Reflections on access: Too vulnerable to research? *Journal of Research in Nursing, 20*(1), 28–37.

Wolcott, H. (1973). *The Man in the Principal's Office: An Ethnography*. New York: Rinehart and Winston.

Wynn, L. (2011). Ethnographer's experiences of institutional ethics oversight: Results from a quantitative and qualitative survey. *Journal of Policy History, 23*(1), 94–114.

6

An Occupational Therapist Ethnographer on an Acute Medical Unit: Using Reflexivity to Understand Situational Identities and the Weight of Expectation

Annabel Rule

Introduction

This chapter is built around my fieldwork reflections on my role in the field and my multiple identities whilst I was completing doctoral research in an acute medical unit in the English NHS. It details some of the insights on cultures, organisations and social norms that I was able to understand through taking a reflexive ethnographic approach. Drawing upon similar experiences of other health professional ethnographers and using a reflective style and excerpts of fieldnotes, I hope to build a picture of the intricacies and difficulties of completing fieldwork in a busy clinical environment, as well as argue for the necessity of reflexivity in doing so. Throughout, I will discuss the three aspects of my identity in the field: occupational therapist, researcher and student. I will discuss how I both consciously and unconsciously shifted between each identity in response to the particular demands of my field site and to manage personal and professional relationships during fieldwork.

A. Rule (✉)
Faculty of Health Sciences, University of Southampton, Southampton, UK
e-mail: a.rule@nhs.net

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The phenomenon at the centre of my research was discharge decision-making for older people on the acute medical unit. A person is discharged from hospital when they no longer require the services of the hospital and their needs can be safely managed at home. Discharge planning is a "*socially produced activity where diverse interests are structurally joined and negotiated*" (Dill 1995: 1293). This should involve "*the development of an individualised discharge plan for a patient prior to them leaving hospital for home*" (Shepperd et al. 2013: 6). Poor discharge experiences with a lack of involvement for older people and relatives are repeatedly reported and examined in clinical, academic and public spheres (Fisher et al. 2006; Bridges et al. 2010; House of Commons Committee of Public Accounts 2016).

This project therefore focussed on understanding how discharge decision-making is carried out in the environment of an acute medical unit where a person would only be expected to stay for a very short amount of time (usually no more than 48 hours) (Bell et al. 2008). Initially, in planning this work and acknowledging the need for multiple sources and methods of data collection, I embarked on undertaking a case study approach. In doing so, I battled to draw the boundaries of the case, a necessary practice in the completion of case study research (Yin 2014). I realised that I was not able to define contextually, geographically or temporally when, where or how discharge decision-making would occur. It became apparent that the very things (context, location, time) I found difficult to draw boundaries around were the factors I needed to consider in order to understand discharge decision-making specifically. I decided I needed a different, broader and more iterative approach that considered the wider contextual and cultural field. In leafing through methodological text books and papers, I arrived on ethnography as an approach that enables the generation of understanding on aspects of care that are difficult to measure and multi-faceted (Savage 2006). In using an ethnographic approach, I was able to a focus on the social world in its 'naturalistic context' through a lens of focusing upon 'culture' (Hammersley and Atkinson 2007; Murchison 2009; Van Maanen 2011).

Two phases of data collection took place: one focussed on patients and relatives, and the second focussed on the clinical practice of discharge planning. These two phases were shaped primarily by the confines of the ethical approval I had sought but also in response to identifying the missing pieces in fieldwork from the first phase. The methods used in these phases included interviews, field observations (including meetings, handovers and job-shadowing observations), documentary evidence and group interviews. The studentship that allowed the completion of this doctoral study was a "clinical academic" doctoral pathway funded by an NHS Trust. This pathway allows a clinician to undertake academic work within the context of their clinical knowledge and experience (Health Education England 2017). For me, this involved two days per week in clinical practice as an occupational therapist and three days per week as a PhD student at the University.

Within the UK context, occupational therapy provides support that enables a person to work towards recovery and to overcome any barriers that stop or hinder them from doing what they need and want to do (Royal College of Occupational Therapists 2017). The practice of occupational therapy is underpinned by an ontology concerned with values, perceptions and existential questions on doing and being (Blair and Robertson 2005). The art and science of occupational therapy practice is achieved through evidence-based practice and a reflexive approach to practice that seeks to understand the social dimensions of practice (ibid.). As an occupational therapist, a reflexive approach to ethnography was therefore a natural fit. As Coffey (1999: 37) imparts, "*it is totally necessary and desirable to recognise that we are part of what we study, affected by the cultural context and shaped by our fieldwork experience*". Allen (2004: 23) discusses the benefits of reflexivity in "*enhancing understanding of research practices and strengthening the quality of studies*". In my doctoral work, reflexivity was instrumental in increasing my depth of understanding of the social and organisational norms of the acute medical unit.

Identities Within the Field

Other ethnographers in nursing or allied health professional roles or health contexts have reflected on their field identities as both negotiated and malleable. One example of perceiving field identity as negotiated is that of Jansson and Nikolaidou (2013), who conducted fieldwork in a Swedish nursing home and expected to be peripheral members of the field because they lacked nursing experience. As their fieldwork progressed so did their awareness that the different aspects of their individual identities seemed to contribute to the development of their relationships with care workers in the field. Both had negotiated unique field relationships and as such unique levels of access (ibid.). The ways in which their identities and levels of access manifested were unplanned and unexpected—an inherent response to the socialisation of fieldwork.

For Ledger (2010), a music therapist, the use of her identity as a tool to negotiate and develop field relationships also became evident. She talks of shifting between her multiple identities of researcher, therapist, friend and student in order to get to know those in the field, develop trust, rapport and access (ibid.). In an exploration of the methodological experiences of nursing ethnographers, Allen (2004) concluded that much of the work in nursing ethnography relies on discussion of "insider-outsider" debates and the management of the "dual role" in completing research. She advocates for a higher level of reflexivity which rejects pre-formulated descriptions of insider-outsider role and instead acknowledges that field identity is to be discovered and negotiated (as in Ledger's [2010] experience) once in the field. In a similar way, Allen (2004) discusses her doctoral work and the social practices through which expectations and emotional responses were managed. In this chapter, I adopt Allen's reflexivity approach, as a mode of doing research that adds clarity to my ethnographic practice through the inclusion of my personal experiences in relation to those of the people I was studying.

In having a negotiated identity, Ledger (2010) described various ethical concerns that arose as a result. If identities are situational and negotiated, so must be ethics in the field, which need to respond to the specificities of each situation as they occur (Goodwin et al. 2003). In her work as a nurse ethnographer undertaking fieldwork in her own professional field of operating theatres, Goodwin et al. (2003) recount being “transposed onto ethically uncertain grounds”, even in a moment where her role of researcher was stable and well defined. These ethically uncertain grounds were brought about through the different arrangements of personal and social relations in the fieldwork setting. For the surgeons and anaesthetists in Goodwin’s fieldwork, they knew she was an experienced nurse and this knowledge led them to behave with her in the context of that relationship, surgeon or anaesthetist to nurse. As such, consultants had “confidential” conversations in her presence and she would notice things like a person’s blood pressure falling with no one else aware and constantly have to re-calculate whether she should act on what she observed or take fieldnotes of everything that she heard. Paying reflexive attention to the need for ethics to be negotiated situationally and acknowledgement of “ethically uncertain grounds” illustrates the symbiotic process of fieldwork and how it is shaped between researchers and researched (ibid.).

The symbiotic nature of fieldwork, access negotiation, situational ethics and situational identities framed my fieldwork. Like Ledger (2010), my identity was on a continuum. It depended upon whom I was speaking to, how comfortable I was or how legitimate I felt in taking up space in the field, and countless other factors. In the following sections, I will reflect on my three-part fieldwork identity—as student, researcher and occupational therapist—and explore the circumstances that led to the prevalence of a particular identity in a given context.

The Student—“*She’s just a student*”

My identity as a student was the most prevalent when my fieldwork first started. As I became more confident and felt more legitimate in the field I became less “student” and more “researcher” or occupational therapist. In the field, I looked like a student—a young female, following and shadowing senior staff, quiet, wearing a University identity badge and carrying a notebook and pen. I was self-aware of the impact my student-status and look would play given that the planning and initial stages of access to a hospital environment is a well-acknowledged sensitive negotiation (Long et al. 2008). I was particularly concerned that health professionals did not seem to recognise me as a researcher and that through my research I would be a burden or get in the way of their everyday work.

Despite this initial discomfort, my visible status as student served to be a facilitator for engaging with a population usually under-represented in research (McMurdo et al. 2011). The older people recruited to participate in this project were very keen to help me complete my studies. Prior to taking part in the research, I discussed with them the potential benefits and risks. This served as an opportunity to both inform them about the research and ensure they understood what they were participating in, whilst also fostering a space for voicing patient experience. I found that rather than query or question the research, participants were more concerned with me getting "*good research*" and completing my studies. They were more interested in me than my research. Although this interest was unexpected, my identity as student appeared to foster a level of endearment and trust. Despite my best efforts to figure the study as important, the research participants' interest in me as a student overrode any other motivator. It may be that being in the "*betwixt and between*" space of a hospital pre-disposes patients to seek to help others as a way of protecting their pre-hospital identities (Long et al. 2008). Or, it may be that in those initial stages my discomfort was so apparent they could only empathise.

For one individual however, the pressure he placed on himself to help me seemed to also unease him, as I wrote in my fieldnotes,

> Throughout the interview he appeared to be concerned that he wasn't answering in the correct way or giving me enough information. I tried to reassure him that it was about his experience so whatever he said was enough but his anxiety about giving the right answer remained. (Post interview field note 08/12/2014)

For this person, no amount of reassurance helped him to manage this self-allotted pressure. Ethically, I felt I had to ensure his research activities (interviews, observations) were kept to a minimum so that he could continue to take part but not be overwhelmed by this pressure.

This motivation to take part was only evident for patient participants. In the initial phases of fieldwork, engaging with health professionals was difficult. Within being and feeling like a student, my anxiety of not being noticed was realised;

> In the meeting this morning I overheard one member of staff say to another, "Who is that?" and the other replying, "She's just a student". I am not sure whether this is a good thing or not. It felt like she was reassuring her that she did not need to worry about me. (Field Note 28/11/14)

Firstly, being viewed as "*just a student*" ensured that those working on the unit did not fear judgement or criticism in the same way they may have done if they viewed me more as "researcher" or "occupational therapist". Health professionals doing fieldwork in a similar field to the one they work in will be viewing and interpreting what they observe through a lens of their own clinical standards (Goodwin et al. 2003). Inevitably, I would have been unconsciously comparing what I observed to my own clinical work. Instead, being seen as a student may have served to reassure them that I had no agenda or judgement. Letting them assume that I was "*just a student*" may have been unethical. However, in advance of fieldwork beginning I had attempted to raise my profile and advertise the research via research information, emails, meetings and posters but this did not seem to have registered with health professionals in a way that meant they could identify me. On balance, I decided that reiterating my exact background and focus would have interfered, potentially obstructing my fieldwork practice but more importantly the work of those within the field.

An element of my fieldwork relied on the information provided by those working on the unit. I needed to ask them about the patients on the unit in order to identify potential participants. This was difficult. My caution over not intruding, not to be a burden and my discomfort about whether I was legitimate in this environment led to me hovering around the nurses' desk awaiting a moment of quiet that seemed never to come. However, in one instance a nurse approached me. I was very happy—perhaps she had remembered me and my research and found a potential participant;

> As I was sat at the nursing station a nurse came up to me and asked if I had come to assess bed 12. I replied apologetically and for simplicity “No, I’m a research student”. She looked disappointed and reassured me, “Don’t worry you’ll be useful one day”. (Field Note 08/01/15)

I reflected a lot on the effort I had made to ensure everyone was aware of the fieldwork taking place and my paradoxical experience of almost complete anonymity in the initial weeks of fieldwork. I wondered whether it could all be attributed to my student identity and discomfort. It seemed very unlikely that more work to promote myself and my research would have made a bigger impact. Once in the field, seeing how busy the clinical environment was and remembering Dixon-Wood et al.’s (2009) metaphor of “*life at the sharp-end*” of medical wards, I reflected on the lack of capacity of those working on the unit to retain information and sustain interest in a researcher or a research project that did not help them achieve the tasks that they urgently needed to complete in that moment. Every day they had new information with varied permanency and importance. Seeing how long it took for those working on the unit to be able to recall who I was and why I was there allowed me some insight into why they may find new change, service models and ways of working difficult to retain.

The Researcher

> “Are you a nurse then?” she says. I self-consciously (again!) say “well actually I’m an OT by background (I hate that phrase but it seems to give me a bit of distance from my clinical role. It affirms that that’s not the hat I’m wearing right now) but I’m here as a researcher today really”. She nods and then continues to explain where she is up to and what she is doing. (Field Note 15/03/2016)

As fieldwork progressed so did my confidence and awareness of my various identities. In being a “researcher” I was framing myself as an outsider. Different to being a student, of which there are always many in different guises in hospitals, as a researcher I had a novel purpose, was confident in my purpose and in my ability to take up space within the unit.

When field relations were built around my identity as a researcher (with distance from my clinical role as the quotation above indicates), people tended to over explain health conditions, interventions and hospital processes. This was useful because I was able to capture verbatim quotations and explanations that aided my analysis. It also offered pragmatic insight into how a health professional could potentially explain things in more effective ways to patients, relatives or anyone else without a clinical understanding.

I was most secure in the role of researcher in the second phase of data collection. Contrary to the experience of the student in the first phase, and due to a change of focus onto health professional's practice, actors in the field started to become more aware of me and what I was interested in. With this increased visibility, although easing some of the access issues faced within being a "student", other difficult negotiations were encountered. It appeared that as health professionals started to position me as "researcher", my research was positioned as able to add weight to their own clinical and professional agendas. In one instance, a nurse had become conscious of my note-writing. Her response to what I chose to note down and what I did not indicated an agenda;

> …another member of staff comes in. She has had to rearrange her days a bit to come in earlier than she had anticipated. She says there is staff sickness at the moment. I write down "sickness" on my note pad as a reminder and she says pointedly, "It's not just about sickness! It's also about the fact that they keep taking my staff to other teams too!" She looks earnestly at my notebook and I make a point of writing that down too. (Field Note 22/03/2016)

Here, the nurse does not trust that I have understood the extent or gravity of the situation. She did not feel a scribble of "sickness" was doing justice to the difficulties she was having. Ledger experienced similar in her fieldwork and recalled a clinician exclaiming on one occasion, "*put that in your thesis!*" (Ledger 2010: 295) after a tense moment had been observed and termed this "*the weight of expectation*". I felt a pressure that those who were most dissatisfied in the field saw my project as a way to get their voices and opinions heard in a way that may benefit their agenda.

Although I was more confident in the field as a "researcher" the weight of expectation also added a different kind of discomfort to the field. In response, I was self-deprecating to try to minimise it. I would explain that my findings would take a long time and be very specific. I would tell them I was only hoping it might be helpful and that I was not sure if those who make decisions would read anything that I wrote about it. This response, although potentially effective in managing the weight of expectation, was a knee-jerk reaction and in hindsight one that may have damaged the perception of my project. A sense that the study was of limited importance could have had a detrimental effect on my field access, especially in a culture where staff have difficulty diverting their energy towards activities deemed as "extra" to the day-to-day busy, task-focussed jobs (Dixon-Woods et al. 2009).

This underselling occurred only in response to the weight of expectation with certain health professionals. I did not undersell the study to patients or families, and I did not undersell it to senior or "powerful" members of staff such as ward managers and consultants. It is therefore interesting that I chose to do it with members of staff "in the middle". Understating the project, its impact and those who may engage with it was a way of ensuring equity of status between myself and the staff in an attempt to foster openness. Reflecting on this further made me appreciate that in getting to know those "in the middle" I became aware of their feelings of being undervalued and not listened to by those more senior in the organisational hierarchy. This context was particularly interesting as the anonymous organisation continuously emerged in health professionals' narratives. In attempting to seek equity and rapport, I was able to gain a deeper level of insight into the norms and disempowerment of being a staff member on the unit. Significantly, in ensuring equity of status I was able to show empathy. If my research and I had been figured as part of the organisation, it is unlikely that the staff members would have been so open.

The Occupational Therapist—"She's one of our OTs"

Underpinning all of my fieldwork was my clinical identity as a practicing occupational therapist. This was a practical challenge but also an epistemological one as this identity inevitably shaped my interpretation of the observations I made in the field (Goodwin et al. 2003). This identity also required self-awareness and demanded careful attention because it was the most politically controversial in the field. In one situation, I was actively trying to minimise and conceal it, and in another, I used it as a tool to successfully build trust and access.

Occupational therapists are routinely part of the multidisciplinary team that work on acute medical units in the UK (Mearns et al. 2015). However, this was not the case on the acute medical unit at the centre of my project. Surprised by this, I asked occupational therapy colleagues of mine working in the hospital why this was so. I learnt that occupational therapists had worked on the unit previously but their service had been withdrawn both for financial reasons and because an alternative team of professionals was deemed to be able to complete a similar remit. On hearing this information, I purposefully chose not to enquire further. It was evident that colleagues were frustrated by these historical events and I did not want their stories or personal feelings influencing the focus of my research. I decided that I would minimise my clinical role in the field with the exception of it being on all of the study information. As I was observing a field without occupational therapists, I wanted to remain open to the context and as uncoupled as possible from any professional motivations that my clinical colleagues may have had.

With the benefit of this historical knowledge, I witnessed in the field a level of history repeating itself. In particular, a team that I spent a large proportion of my time with (because they were often instrumental in making discharge decisions) were under extreme pressure to prove their worth, their metrics and their skills in the wake of new change and initiatives. They discussed these challenges regularly, and it was often the undertone of many conversations and observations;

> They are under examination at the moment as there is a new plan for the merging of two teams. The second team is new and has less history than the community team (and has less experienced staff) but from what I can see better fits the current priorities of the organisation. But they have very similar remits… They now have to share an office and today the sign on their office door got taken down and replaced by a new one where the community team's name was written in small type underneath the new team's name. It felt very symbolic and put everyone in the community team in a bad mood for the rest of the afternoon. … This merge is happening under their feet and continues to happen regardless of how hard they stamp them. (Field Note [job shadowing community nursing team] 22/03/2017)

The fieldnote above shows how something small on the surface, the change of a sign, was symbolic of the greater dissatisfaction this team in particular were facing. As a result, they tended to use me as a springboard for their own cause when they could, with comments such as "*and that's why it's got to be someone with our experience doing this*" (more of the weight of expectation I described previously). What the fieldnote does not capture is that the new team was intended to be made up of a number of different professionals, including an occupational therapist. I knew this information, not because I asked the community team (this would not have fitted with my intention to distance myself from my clinical role) but because I had been told by the consultant. It transpired that the consultant was an integral part of these changes occurring. I spent the majority of my time with the community team and chose a separate time point with the consultant. This was a conscious decision. I was aware that I could not be spending time simultaneously with both groups on different sides of a change agenda.

My field relationship with the consultant was quite different to my relationships with the community team, and this difference was built around how I used my occupational therapist identity. Something that I had felt the need to distance myself from with the community team was necessary in building a relationship with the consultant.

On meeting this consultant for the first time and on hearing her frustrations and visions for improvement on the acute medical unit, I told her some of my own clinical practice frustrations, successes and ideas. Allen (2004) advocates the use of such occupational narratives of clinical practice in a managed self-disclosure to develop trust and openness. In my work, this approach progressed well initially until it reached a point where too much disclosure may have taken place. The consultant was very motivated to be a part of the study and went out of her way to ensure I could spend time with her. It did not occur to me that I may have self-disclosed too much information about my clinical role until I arrived on the unit to spend time with her and she greeted me with, "*It's interesting that you've not come with your uniform on…*". It became apparent that in using occupational narratives and aligning myself firmly within the identity of occupational therapist I had inadvertently distanced myself from my other identities of student and researcher. When a researcher, pen and notepad in hand, arrived on the unit, the consultant was surprised—she was expecting an occupational therapist adorned in green trousers and white tunic (the standard uniform of an occupational therapist in any acute NHS hospital). Following this initial adjustment, she continued to position me as an occupational therapist in the field. At one point, I wondered if she was advertising a job opportunity for me to work with her. As such, another weight of expectation had to be managed.

These two opposing approaches to managing my occupational therapy identity both resulted in a weight of expectation. As a "researcher", the first expectation was that I would promote the agenda of the community nursing team. The second expectation, as an "Occupation Therapist", was that I would promote the need for more therapists. It became apparent that in researching a clinical environment with a culture of dissatisfaction in current practice and organisation, regardless of how I managed my own identity this weight of expectation was unavoidable. Health professionals were consistently searching for something that may prove or help their different agendas.

Discussion

Throughout my ethnographic fieldwork exploring discharge decision-making for older people on an acute hospital ward in England, I found that my identity was fluid and situational. Active reflection on these identities and my different experiences through them contributed towards my understanding of the dynamics of care on an acute ward, as part of a wider organisational context. My student identity was constructed by my own self-awareness and new uncertainty in the field in this role, despite my professional experience of similar clinical contexts. My experience of this identity was shaped by the busyness of the acute unit and the sense that only people or practices immediately "useful" could or should take up space in it. This identity led me to understand the motivations of older people in participating in research as well as experiencing directly what it must be like for anyone slightly uncertain of themselves to be on the unit, for example a newly qualified health professional, patient or relative. My research identity was constructed from a wish to act as an "outsider" to ensure I did not take for granted what I may already be familiar with in this clinical context because of my professional identity. It allowed me to engage with and understand the experiences of health professionals positioned "*in the middle*" of the organisation as I empathised with their lack of power and the nameless, faceless organisation that they felt did not value them. In negotiating my position as a researcher, relative to these professionals, I was often self-effacing in an attempt to achieve equity of status, but risked my research being interpreted as of little value as a consequence. My clinical identity was constructed differently according to who I was with in the field. In some situations, revealing my profession as an occupational therapist, through recounting occupational narratives, enabled me to develop relationships that facilitated access within the field, and helped to build trust. In other scenarios, I was cautious to conceal my profession, realising that this allowed me to understand more about the engrained political and cultural tensions of the unit, relating particularly to historical change in the organisation and repositioning of different professional groups.

The phenomenon I was researching, discharge decision-making for older people, was complex, exacerbated by the greater complexities of the environment, organisation and culture within which it was taking place. What became clear through my reflexive approach on my positions and identities within this ethnographic research was a weight of expectation related to the research process, reflecting health professionals' desire for change and improvement. Reflecting on the motivations of each "weight of expectation" I experienced, how they arose, what identity I was aligning with over another and then considering the motivations of the health professionals helped me lift my analysis to a deeper level of understanding. My fieldwork was peppered with themes of "*everyday battles*", "*pace*" and "*moans and groans*" from time spent with health professionals. Regardless of whether I was consciously or unconsciously feeling more comfortable in student, researcher or occupational therapist identities, these themes and feelings were unavoidable. This allowed me to understand how approaches to discharge decision-making to improve patient experience and align with policy expectations of shared decision-making (Bridges et al. 2010; Shepperd et al. 2013) very often seemed unfeasible given the fast pace of everyday work practices in the acute medical unit. I was also able to examine the effects of this demand, which appeared to heighten health professionals' dissatisfaction because they were continually unable to achieve or live up to these recommendations.

Many of the experiences of other health professional ethnographers were evident in my reflections and experiences (Goodwin et al. 2003; Allen 2004; Ledger 2010). In particular is the necessity to renegotiate field identities and roles to fit the micro aims and objectives of the research and the motives of the participants in each individual moment (Goodwin et al. 2003). My negotiations of identity were also in response to the shifting dynamics of the acute unit, situated within the complex organisational context of the hospital, and the expectations of the different groups of people positioned within it. As such, by taking a reflexive approach to interpreting these situational identities, my ethnographic fieldwork produced knowledge and understanding of this clinical context that both engaged and extended the tacit knowledge available to me as a health professional.

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References

Allen, D. (2004). Ethnomethodological insights into insider-outsider relationships within nursing ethnographies of healthcare settings. *Nursing Inquiry, 11*(1), 14–24.

Bell, D., Skene, H., Jones, M., & Vaughan, L. (2008). A guide to the acute medical unit. *British Journal of Hospital Medicine, 69*(7 MMC Supp), M107–M109.

Blair, S. E., & Robertson, L. J. (2005). Hard complexities–soft complexities: An exploration of philosophical positions related to evidence in occupational therapy. *The British Journal of Occupational Therapy, 68*(6), 269–276.

Bridges, J., Flatley, M., & Meyer, J. (2010). Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies, 47*(1), 89–107.

Coffey, A. (1999). *The Ethnographic Self: Fieldwork and the Representation of Identity*. London, UK: Sage.

Dill, A. E. P. (1995). The ethics of discharge planning for older adults: An ethnographic analysis. *Social Science and Medicine, 41*(9), 1289–1299.

Dixon-Woods, M., Suokas, A., Pitchforth, E., & Tarrant, C. (2009). An ethnographic study of classifying and accounting for risk at the sharp end of medical wards. *Social Science and Medicine, 69*(3), 362–369.

Fisher, M., Qureshi, H., Hardyman, W., & Homewood, J. (2006). *Using Qualitative Research in Systematic Reviews: Older People's Views of Hospital Discharge*. London, UK: Social Care Institute for Excellence. Available from https://www.scie.org.uk/publications/reports/report09.asp. Accessed November 15, 2017.

Goodwin, D., Pope, C., Mort, M., & Smith, A. (2003). Ethics and ethnography an experiential account. *Qualitative Health Research, 13*(4), 567–577.

Hammersley, M., & Atkinson, P. (2007). *Ethnography* (3rd ed.). London, UK: Routledge.

Health Education England. (2017). *Clinical Academic Careers*. London, UK: Health Education England. Available from https://www.hee.nhs.uk/our-work/developing-our-workforce/clinical-academic-careers. Accessed September 9, 2017.

House of Commons Committee of Public Accounts. (2016). *Discharging Older People from Acute Hospitals*. London, UK: House of Commons. Available from https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2015/discharging-older-people-acute-hospitals-15-16/. Accessed November 15, 2017.

Jansson, G., & Nikolaidou, Z. (2013). Work-identity in ethnographic research: Developing field roles in a demanding workplace setting. *International Journal of Qualitative Methods, 12*(1), 152–167.

Ledger, A. (2010). Exploring multiple identities as a health care ethnographer. *International Journal of Qualitative Methods, 9*(3), 291–304.

Long, D., Hunter, C., & Van Der Geest, S. (2008). When the field is a ward or a clinic: Hospital ethnography. *Anthropology & Medicine, 15*(2), 71–78.

McMurdo, M. E., Roberts, H., Parker, S., Wyatt, N., May, H., Goodman, C. et al. (2011). Improving recruitment of older people to research through good practice. *Age and Ageing, 40*(6), 659–665.

Mearns, N., Duguid, I., & The SAM Physiotherapy and Occupational Therapy Group. (2015). *Physiotherapy and Occupational Therapy in the Acute Medical Unit: Guidelines for Practice*. London, UK: Society for Acute Medicine. Available from http://www.acutemedicine.org.uk/wp-content/uploads/2015/05/10.2-PTOT-AMU-Guidance-Document-2015.pdf. Accessed November 15, 2017.

Murchison, J. (2009). *Ethnography Essentials*. San Francisco: Wiley.

Royal College of Occupational Therapists. (2017). *What is Occupational Therapy?* Available from https://www.rcot.co.uk/about-occupational-therapy/what-is-occupational-therapy. Accessed September 9, 2017.

Savage, J. (2006). Ethnographic evidence the value of applied ethnography in healthcare. *Journal of Research in Nursing, 11*(5), 383–393.

Shepperd, S., Mcclaran, J., Phillips, C., Lannin, N., Clemson, L., McCluskey, A., et al. (2013). *Discharge Planning from Hospital to Home (Review).* London, UK: The Cochrane Collaboration. Available from http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000313.pub4/abstract. Accessed November 15, 2017.

Van Maanen, J. (2011). *Tales of the Field on Writing Ethnography* (2nd ed.). London, UK: The University of Chicago Press.

Yin, R. K. (2014). *Case Study Research Design and Methods* (5th ed.). London, UK: Sage.

7

Shaping the Field: A Reflexive Account of Practitioner Interference During Ethnographic Fieldwork in Radiotherapy

Lisa Anne Wood

Introduction

This chapter draws on examples from ethnographic fieldwork at two UK hospitals during periods of technological change. Drawing on reflexive accounts of this ethnographic work, I explore the multiplicity of roles performed when a practitioner[1] turns ethnographer: from confidante, resource, bystander, friend, lunch buddy and observed. I describe how, throughout the course of ethnographic fieldwork, the situated body becomes part of procedures and relations in the field and how denying this is to deny intuition, feelings and position as part of research relationships.

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[1] I use the term practitioner ethnography to denote ethnography that is conducted by someone who observes practices that they could also partake in. This could be an art form or a professional discipline.

L. A. Wood (✉)
Lancaster University, Lancaster, UK
e-mail: l.a.wood@lancaster.ac.uk

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The aim of this reflexive approach is to acknowledge ways in which the ethnographer practitioner creates interference during research processes. It explores how knowledge is constructed through the researcher's own epistemic practices and material-discursive practices that emerge from situated entanglements. Through a number of examples, I demonstrate how, during fieldwork, ethnographers do not play mythical roles of distanced, privileged, neutral, bodiless observers of mythically naive natives (Traweek 1995). I unpack how the subject position of the practitioner ethnographer serves to shape and influence fieldwork relationships, the field and the fieldworker through the ethnographic performance and the consequences this has on understandings of technological change.

The chapter emerges from the intersections of clinical radiotherapy practice and ethnographic practices as informed by Science and Technology Studies (STS). It demonstrates that it is possible and necessary to perform a reflexive analysis of relationships in the field without sinking into a 'self-absorption that negates the possibility of knowledge other than self-knowledge' (Davies 2008: 237). I conclude that, through reflexivity, practitioner ethnographers can clarify findings and provide a trace of intellectual and social paths that lead to conclusions made.

STS-Informed Ethnography

The fieldwork described throughout this chapter was conducted as part of my Ph.D. study exploring the roles of knowledge, evidence and evaluation during a period of technological change in radiotherapy (Wood 2012). I was looking at how a process termed X-ray Volumetric Imaging (XVI) was being introduced into radiotherapy practices. The purpose of XVI was to increase the accuracy of radiotherapy treatment. Using STS-informed ethnography, I was inspired by the works of John Law (1994), Erika Johnson (2004), Lucy Suchman (2007) and her work with Libby Bishop (2000), and Sharon Traweek (2009). The focus of this body of literature served as an introduction to what STS could do for the study of technology, organisations and innovation.

Within this work, the ethnographies focussed on, not just science or technologies, but processes, policies and people associated with them to reveal the continuous, multifaceted relationships which are embedded within technologies. This particular strategy, generated in part from Actor Network Theory (ANT), aims to explore contingencies and turning points within practices, in this case technological change practices (Callon 1986). The *actor network* approach is a theorisation of the relationship between agency, knowledge and machines (Law 1992). Approaching ethnographies of technological systems from an ANT perspective makes it possible to explore technologies outside of a constricting framework of pre-established social categories and, therefore, break down assumptions about the rigid social/technical binary (Callon 1986). Once this binary has been weakened in favour of a research focussing on 'relations' in sociomaterial worlds, it is possible to theorise technology or science as an 'effect' of associations between actors within social worlds. As ANT methods assemble and link entities in material and social worlds without prioritising one actor or entity over another, it is assumed that everything is a consequence of its relations with other actants in that world. Therefore, mapping the actor world of technologies helps show how heterogeneous relations are formed, for example, between patients, illness, staff groups, public groups, technological and computer systems to name but a few. Medical practices are not singular or coherent and presenting them as such obscures contingency, contradiction, complexities and work done among diverse actors (Suchman 2010). ANT-informed ethnography provides an additional dimension to the study of technology adoption by accepting that the meanings of technologies constantly change through relations and encounters, uncovering some of this contingency.

The examples in this chapter show entangled practices at work—stories about how the XVI technology was made to make sense in clinical practice, critically exploring the politics of what this object is. The focus is a machine located in numerous sites, located even where it is physically 'not', a machine which is part of numerous networks and a machine whose presence is not neutral, stable or even static (although it physically does not move). Technology '*is knowledge as well as artifacts*' (MacKenzie and Wajcman 1999: 7), therefore, not only is the XVI located inside and outside of the treatment room, in radiotherapy departments locally and nationally, it is also located in the knowledge of those who work with it, the bodies of those who interact with it (and research it) and even located with those who have been excluded from having knowledge about it. This epistemological position, informed by STS, shapes the ethnographic approach including the detailed observation of material-discursive practices making it fitting to explore the roles of knowledge, evidence and evaluation during the technological change process. Following STS traditions, the fieldwork did not prioritise 'why' XVI technologies were being used or considered desirable or an improvement on current practice but 'how' it was done in practice and, as such, revealed a number of contingent practices.

The Ethnographic Method

The fieldwork took place in two, similar-sized UK hospitals: The Sieverts Hospital and the Gray Cancer Centre (GCC). The Sieverts Hospital had six radiotherapy treatment machines (linacs) and the GCC had five. The GCC had been established much longer and, as such, was slowly replacing existing technologies. The Sieverts radiotherapy department, open for ten years, finished installing its newest linac in 2004 and began a replacement programme for older equipment in 2010. The purpose of conducting the research at two sites was to follow two different manifestations of the XVI technology.

As a practitioner ethnographer, the 12-month period of fieldwork was supported by 10 years of previous experience and training as a radiographer in the field. My observations at the Sieverts Hospital began the day before the X-ray Volumetric Imaging (XVI) equipment was delivered and it continued through the delivery, unpacking (Fig. 7.1), installation (performed by the manufacturer's engineers), commissioning by the Sieverts Hospital medical physicists, applications training and early use.

At the GCC, where the equipment had been in place for over 12 months, my observations were focussed on more established use of the system. In total, this yielded 322 hours of observations including observations of what was being done by clinical and non-clinical staff working with the system.

Fig. 7.1 Photograph taken during the arrival of the XVI at the Sieverts Hospital (I had been asked by a charity that had funded the installation of the equipment to take some photographs throughout the delivery of the XVI equipment at the Sieverts Hospital. As I did this and frantically took down notes, the deliverymen insisted on taking my picture pretending to open one of the crates. This particular crate contained the mount for the X-ray tube)

By focussing on the mundane practices around installing and working with the XVI, the interplay between machine and human was revealed. In 'following the thing', a name given to the process developed by Marcus (1995), the material object of the XVI could be traced through several different contexts. This was informed by the approach adopted by Erika Johnson in her study of medical simulators (Johnson 2004). Johnson's study, following 'the thing' in both the educational simulator room and out in hospital sites, explored how simulators are situated in the context of the teaching hospital. In support of the ethnographic approach, Johnson states:

> It is unusual to focus on what is actually being done with the simulator rather than on what the simulator is or what the simulator's results will be. (Johnson 2004: 23)

Therefore, alongside the observations of what was being done by clinical and non-clinical staff working with the machine, I attended staff meetings and training sessions, I joined practitioners in coffee breaks and for lunch, I conducted presentations of my research for participants and held group discussions with those I had observed. In addition, I examined documents such as training manuals, protocols, patient information leaflets, newsletters, local press and minutes of meetings in order to explore the way that these materials shape, and are shaped by, the technologies they are associated with.[2] I spent portions of my fieldwork observing the machine when no one was 'doing' anything with it, learning how it became part of the establishment through action and non-action.

In essence, I aimed to focus on not only what was being done with the machine but also what the machine does back. Whereas Johnson followed students during their training with the simulator, and later when they put that training into practice, I followed the *machine* through its various manifestations. In adopting an ANT approach, it was possible to unpack the multiple domains where the XVI technologies reside. Physically observing the XVI by being in the same room with it or by 'watching' it on CCTV cameras revealed only a small aspect of the network; following paperwork in the planning department where future treatments were being calculated or discussing doctor–patient consent procedures allowed a deeper exploration of this network. Through the fieldwork, I discovered that the XVI was not a thing to be followed, it was a cloud to be stood in, absorbed in and absorbed by. The ethnographic approach allowed the assembly of the ethnographic object to be explored, and hence disentangled, in the multi-sitedness and multi-temporality of the field.

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[2] In addition, I created a Web-based discussion space for both of the departments where I conducted my fieldwork; however, the use of this space as a method for interacting about the XVI technology was not successful with only one participant posting on the forum and that was to congratulate me when she discovered I was pregnant!

Practitioners in the Field

Practitioner ethnography can be defined as ‘a research approach that provides practitioners with a way of exploring the culture of their workplace’ (Barton 2008: 7). Barton has argued that practitioner ethnographers are advantaged due to their prolonged engagement and persistent observation enabling relationship building and immersion into the field site (ibid.). Drawing on practitioner ethnography of nursing programmes, Barton argues that objectivity in both seeing and analysing experiences is a hindrance to the process. This empiricist analysis of the ethnographic method could (and should) be challenged within the context of practitioner ethnography. Indeed, it is the very notion of entanglement that benefits the practitioner ethnographer, rather than a lack of distance or neutrality being a failing. One argument for the authority of practitioner ethnography over a ‘stranger’ perspective is that practitioners are more able to tailor the research directly to policy given the opportunity to take control of the research process. Yet, practitioner ethnography is not without an underlying critique and political history. Hammersley (2013) is critical of the development of practitioner ethnography as superior to ethnographies conducted by others. Hammersley (2013) concludes that research can only be identified as ethnography if it produces knowledge that is of general rather than specific relevance to practice. Yet to delineate research by its end purpose or goal (which can be multiple: of specific and general interest) seems elitist and not conducive to improving or informing ethnographic practices. More relevant are the inescapable paths of knowledge creation before, during and after fieldwork. There is, as Haraway (1988) has told us, no view from nowhere.

As Hammersley and Atkinson (2007) state, ‘*the ethnographer needs to be intellectually poised between familiarity and strangeness*’ (Hammersley and Atkinson 2007: 89). For me, this implies *awareness* of familiarity and *openness* to strangeness, rather than a definitive subject position. To demonstrate this, it is important to discuss my ten years of previous experience in the field of radiotherapy and how this shaped the research. Through learning how to become a radiographer, I developed a situated awareness of the field: how to behave, to speak, to understand the language and to be understood in using that language. Through my research training that followed (as part of a master's research programme and subsequent doctoral research training), it could be argued that I developed a reflective awareness. The 'strangeness' (or rather the 'critical position') began during this movement into a university setting; however, that is not to say I became defamiliarised with the field of radiotherapy. Indeed, practitioner status afforded critical reflection on details of XVI introduction through retention of my familiarity with the field. Becoming critical is a process in developing new ways of seeing, building on what is already known or embodied. But this deep entanglement raises a number of challenges and dilemmas for the practitioner ethnographer.

Ethical dilemmas faced by researchers in research fields are well documented (Murphy and Johannsen 1990; Grinyer 2001; Marzano 2007). Being privy to professional knowledge gives the practitioner ethnographer a number of dilemmas to contend with during data collection periods, for example the possibility of observing malpractice or unethical practice. For example, Goodwin et al. (2003) discussed issues of situational ethics arising during fieldwork in anaesthesia drawing on Dawn Goodwin's experiences of conducting ethnographic observations from her position as an anaesthetic nurse. Goodwin was faced with the dilemma of whether to intervene during her observation of a situation that was potentially life-threatening to a patient during a surgical procedure, concluding that the 'process of shaping the data is a symbiotic one in which the researcher and the community being studied construct the data together' (Goodwin et al. 2003: 567).

Furthermore, being employed and practising in the fieldwork site enables the practitioner researcher to gather far-reaching information about the field of study; however, it may also prevent access to some spaces (Simakova and Neyland 2008). The negotiation of roles is not purely something that is within the practitioner ethnographer's control, it is often bestowed upon the researcher. It shapes the resultant data, and throughout the fieldwork, the nature of roles of researcher are constantly changing. Consequently, exploring the connectedness between researcher and community goes beyond issues of procedural, situated or relational ethics. Rather, these are material-discursive practices, constitutive, configuring and performative (Barad 2007). Considering ongoing, dynamic and relational enactments and how interactions between entities shape the world extends beyond representation or identifying relationships between people and things (Orlikowski and Scott 2015). Thus, reflection in this study of technological change goes beyond description of change processes but considers how interactions between researcher, researched, sociotechnical subjects and objects cause interferences shaping the fieldwork site and the fieldworker, leaving traces on people, places and materialities.

In the sections that follow, I provide some reflections on specific fieldwork incidents in order to demonstrate how my presence and role negotiation created, not only the data, but also the field in which I was entangled and thus the processes of technological change I aimed to uncover.

Notes on Reflection

Shaping Relationships

I want to begin by thinking about my own body and its part in shaping this research. It turned out that I became pregnant whilst carrying out my fieldwork. I see that how I was feeling during these stages of the data collection affected where I positioned myself to observe the installation of the XVI technology at the Sieverts Hospital. In these early stages of fieldwork and pregnancy, I was able to work with the exclusively male group of engineers in the tight spaces behind the linear accelerator. I crouched on the floor for hours on end, peering around machines, and bodies, whilst they traced faults in circuits or threaded cables around the existing linear accelerator machinery. I used moments of sickness to write up my notes and observe the 'action' from outside of the treatment room via the hospital's CCTV camera system.

By the time I was conducting my fieldwork at the GCC, I was obviously pregnant. I used this in justifying my decision not to follow the radiographers in and out of the treatment room for every patient as it enabled me to position myself in one place in the control area and partake in informal conversations with staff members who stayed outside of the treatment room and those passing by. Although I will never know, I feel that should I have been obviously pregnant during those initial stages of data collection at the Sieverts Hospital, rather than the stages dominated by clinical practice where pregnancy is a common circumstance in the workplace, my rapport and acceptance by the engineers would have been different. I would not have been able to join them crouching in confined spaces for hours on end, and I doubt they would have had confidence in me being present in all of these situations, particularly when the radiation lights all turned on when we were all in the treatment room. In contrast, at the GCC, where work was more routinised, I believe that my pregnant body aided the rapport I developed with the practitioners. I became not only 'one of them' due to my professional background but I believe it 'humanised' me. There was no opportunity to hide that I was not solely a researcher, my body revealed another side to me, one which the mainly heterosexual, female, mothers I was observing could relate to. So we did not just talk about radiotherapy and imaging, we talked about birth plans (they told me not to bother), baby names (they did not approve of mine), school trips and childcare. As a result, when I offered to send staff copies of any reports from my research, they seemed more interested in me letting them know when the baby was born. As Wolf (1996) writes:

> …the researcher may realize that she is also the other which is being subject to observation and analysis by the local community. (Wolf 1996: 34)

The relationships between myself and those in the research defied '*tenets of positivism and objectivity*' (Wolf 1996: 4). My relationships in the field were created on personal and professional shared understandings and shaped the development of data collection. In addition, they enabled the cultivation of friendship and led to a closeness that made it possible to share experiences, insights and points of view.

However, relationships that extend beyond those of researcher and researched are not always constructive. As I had previously been employed at the Sieverts Hospital, I was familiar with a number of the staff members there. In a similar situation to that described by Simakova and Neyland (2008), I was unable to access vital meetings in which the role of the XVI was discussed with medical doctors. Although the department manager had approved my attendance at these meetings, the radiographer who had been put in charge, Louise, repeatedly told me that they would be irrelevant to me and repeatedly avoided giving me details of their timing. Although I like to think that Louise was trying to protect me from wasting my time, I believe this was a consequence of my insider–outsider role. In my previous role in the department, I would not have been allowed to attend these meetings and I therefore believe Louise was reiterating my status in these decisions.

In the following and final example of how fieldwork relationships influence ethnography, I describe the reverse of 'cultivating friendship' within the field. In the Sieverts Hospital, one of the department engineers had earned himself the nickname 'Angry Adam' by radiographers and physicists alike. Due to previous confrontations with Adam when employed at the centre, I was nervous when it became apparent that he would be involved in my observations. The resulting observations were affected by this. Whenever I walked into the room and he was there, he would say, 'oh here she is, The Spy'. I learned how to laugh this off; however, there is no doubt that my previous encounters with him are reflected in my field notes. In particular, I would choose not to observe what he was doing if there was someone else to be observing present in the room or chose not to make notes on conversations he was involved with due to his, in my opinion, radical personal views. Coffey (1999) has stated that in fieldwork we are dependent on our field relations and often can be engaged in conversation with people whose views we particularly despise or participating in social activities which leave us feeling awkward or uneasy.

Angry Adam demonstrates an example of my enacting field relations where I suppressed my true opinions in order not to antagonise those I was interacting with. A further sociophysical shaping of interaction included something that was pointed out to me by another radiographer when observing clinical practice, 'I see you've not lost your radiographer's quick walk'. In this brief reflection on the frustration of entertaining visitors and their lack of awareness regarding the pace when moving from treatment room to control area, I cemented my role as radiographer rather than pure observer. My performance with my appropriately fast walk in and out of the treatment room shaped my dual identity of the fieldwork self, both radiographer and ethnographer. It validated my presence but enabled practices to continue a pace of routine.

Shaping Sociotechnical Systems

As a past employee, I was often mistaken for someone who should have an input in decision-making during the installation of the XVI. There were times when engineers, both those sent by the manufacturer and those employed by the hospital trust, would ask me 'from a radiographer's perspective'; and my role changed from ethnographer to informant for others. I was therefore involved in making the decision (ultimately a bad and frequently criticised decision) about where to locate the XVI footswitch (see Wood [2016] for more on this) amongst others. My enduring presence made me the most constant connection to the machine; I was identified with it and the most physically connected to it and my actions affected the relationships others had with the technology and my research practices.

The following account describes an event that occurred towards the end of the equipment installation. After all installations, the manufacturer's engineers are required to get a department representative to sign customer acceptance tests (CAT). These signatures indicate the start of the equipment warranty and the transfer of remaining funds for the XVI. It is, therefore, in manufacturer's interest to get these signed quickly.

At the Sieverts Hospital, before the CAT began it became apparent that there was a problem with an element of the XVI system, the touch guards on the imaging panel. Touch guard functionality was part of the CAT and their malfunctioning was a problem, delaying when the engineer, Simon, could leave and when the manufacturers could ask for the remaining funds. However, one of the department engineers, Brian, was happy to replace these touch guards at a later date. Simon stated that Jack would still have to sign the CAT and Jack agreed to this.

The CAT continued in a relaxed but rushed atmosphere as Simon was eager to start his long journey home. During the CAT, further problems were experienced with one of the tests, the flexmap. During the frequent repetition of the flexmap test, the mood amongst those present became solemn. Much later than planned, the flexmap tests were passed, leaving one more part of the CAT to complete. Jack questioned the need for this given that the touch guards still needed replacing. Everyone stopped what they were doing. It was clear Jack was 'going back on' his agreement to sign off the CAT, without the touch guards. At that point, I felt I could not write anymore as it would be obvious I was writing about this situation. This 'off-phase' note-taking, as termed by Goffman (1989), stopped those involved detecting what I was taking notes about, a tactic I used on many occasions throughout the fieldwork. Later, I write:

> Simon says that Jack had said he would sign the CAT without the touch guard. Jack says he doesn't think he did. Simon picks up his phone, he is angry…Simon says 'the point of an installation is to leave with the acceptance in place'. Jack asks if Simon wants to finish 'this' and Simon says no. (Friday, 17 October 2008, p. 8)

After this initial confrontation, Jack tried to continue with the CAT but without Simon's assistance was unable to do so. There was a further heated exchange before Jack walked away from the control area. The experience of observing this conflict between Simon and Jack made me very uncomfortable; in fact, even rewriting it here makes me so. I was disturbed by the fact I had clearly written in my field notes what Jack had said earlier in the day. I quickly decided that, should either party ask to see my notes, I would say I had nothing written down. This was contrary to what I had previously decided about participants being able to access my field notes. This situation clearly demonstrated that it was not possible to allow this without compromising the role of the ethnographer.

The functionality of the touch guards had implications for the organisation and individuals. Initially, Brian was the hero, prepared to replace the broken part of the system, and Jack too, willing to overlook this element and sign the tests, enabling Simon to leave with the acceptance in place. The touch guards were part of the sociotechnical system, affecting relationships and finance, and all documented in my field notes.

Accepting myself as part of the society, as part of the installation setting, meant picking up on social norms and acting as natives would act in the field. In this situation, I had felt uncomfortable with my position as an observer of a conflict between two of the individuals. There were others who observed this conflict and contradiction by Jack, but they also chose to remain silent. There were other occasions when my position was affected by the written observations of the past events I held in my notebook. I was frequently asked if I remembered the outcomes of discussions and decision-making, and radiographers and other staff members from the department would ask me for updates on the installation. Concerned with how this information would be disseminated if I had not been there, was I acting inappropriately in speaking up? On some occasions, I would say I did not know; give a non-committal response, 'it's alright'; or pretend I thought they were talking about my data collection and discuss my aching hand or how many notebooks I had filled. There were other times when this was less appropriate, when saying I did not know or changing the subject would undermine my own research credibility or the status of my own knowledge about the installation. In other situations, particularly when someone was explaining the XVI incorrectly or trying to work with it in a way I knew would not work, I chose to keep quiet. My decision to speak out or keep quiet was not consistent. Yet these decisions shaped and interfered with the emplacement of the XVI in the Sieverts hospital.

Conclusion: A Re-formed Radiographer[3]

In this chapter, I have described how my entanglements in the field shaped the dissemination of information regarding the XVI system within the site and how my previous positions shaped my fieldwork. Through describing such emplacement, the effects of the located body of the researcher are considered, extending beyond embodiment. This reflects the ANT approach I set out in the introduction to this chapter. By taking the epistemological position that everything is a consequence of its relations with other actors in that world, the reflexive and emplaced ethnographer is required to understand how she or he is interfering in the places in which they are researching.

The experiences of the conflict during the CAT and the way in which I shaped the fieldwork site relate to the overall subject matter of the research, in how technological change is made sense of. The stories of interference occurring throughout the fieldwork, as described in this chapter, shape understandings of the XVI equipment and how these understandings are performed and enacted in multiple ways and locations, not only in the research but also by others. The reflections give an insight into my part in shaping the field in addition to the way in which the field acts back on the researcher. Simply put, the events affected my role as note-taker, I wasn't distanced and neutral as I had intended, but a very present actor in the situations I was observing based on my own positionality.

Like Coffey (1999), I found it difficult to separate my life outside the data collection to my life inside it, as did my participants. But why should there be this separation of life in the field and life outside of the field? By entering into fieldwork, the ethnographer is:

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[3] It was Maureen McNeil introducing herself as a 're-formed Historian' that led me to think of this concept.

> …subjecting yourself, your own body and your own personality, and your own social situation, to the set of contingences that play upon a set of individuals…. (Goffman 1989: 125)

Where I have demonstrated my presence changed the events in the field, these events furthered or preserved my relationships with those I was observing. The roles I performed varied from day to day, situation to situation, but no less than the roles performed by the community members in carrying out their ordinary routines. Based on an epistemological position of embodiment and performativity, when the individual is a practitioner ethnographer who affects events in the field in some way, the personal becomes even more connected to the objects of study.

The ethnography I conducted throughout the fieldwork was one of critical reflexive practice. My interactions in the field were very much shaped by my position in that field. Through this critical reflexive ethnography, it was possible to provide a history for the meanings which are made, not only my connections to the machine and to the field but multidirectional relations within a web of connections. Like the inclusions and exclusions that shape perceptions of technological systems, it is the situated and acknowledged partiality of my ethnographic accounts that enable me to be answerable for the conclusions made. Through 'stepping back' from empirical work and reflecting upon the ethnographic production of knowledge, it is possible not only to answer the research questions but also describe how the practitioner ethnographer, as a researcher and a practitioner amongst other positions, affects the field and the sociomaterial objects within that field and how, in turn, the researcher is also affected by it. As with all practices, ethnography cannot be separated from the sociomaterial relations in which it is embedded.

Shortly after completing my Ph.D. thesis, I returned to practice as a radiographer. During this time, it became apparent that, through my fieldwork and in the subsequent analysis, I never lost my professional identity, even if at times the critical eye I developed challenged my ability to accept previously unquestioned aspects of work. By relocating back to a clinical radiotherapy department, it was difficult to maintain the critical reflexive position that I nurtured during the research process.

When writing about the effect of attempting to deconstruct claims made about science, Donna Haraway stated:

> …we end up with a kind of epistemological electroshock therapy, which far from ushering us into the high stakes tables of the game of contesting public truths, lays us out on the table with self-induced multiple personality disorder. (Haraway 1988: 578)

In conducting critical reflexive ethnography, there are equally consequences of the field on a personal level. Therefore, as a practitioner ethnographer in the field, affected by that field, it is important to accept that the process of critical reflection is destabilising. In order to embrace the possibility that we will shape and interfere with research sites, we also have to acknowledge our own transformations during the fieldwork process. Consequently, practitioner ethnographers have to be prepared to acknowledge and challenge previous beliefs and allow ourselves to be shaped and changed by the worlds that we encounter during fieldwork. This goes some way to avoiding the 'self-induced multiple personality disorder' of which Haraway writes. As such, practitioner ethnographers should not consider themselves 're-formed', rather re-forming.

References

Barad, K. (2007). *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. Princeton: Duke University Press.

Barton, T. D. (2008). Understanding practitioner ethnography. *Nurse Researcher, 15*(2), 1351–5578.

Callon, M. (1986). The sociology of an actor network: The case of the electric vehicle. In M. Callon, J. Law, & A. Rip (Eds.), *Mapping the Dynamics of Science and Technology: Sociology of Science in the Real World*. London: Macmillan.

Coffey, A. (1999). *The Ethnographic Self: Fieldwork and the Representation of Identity*. London: Sage.

Davies, C. A. (2008). *Reflexive Ethnography: A Guide to Researching Selves and Others*. Abingdon: Routledge.

Goffman, E. (1989). On fieldwork (Lyn H. Lofland, Transcribed and Ed.). *Journal of Contemporary Ethnography, 18*(2), 123–132.

Goodwin, D., Pope, C., Mort, M., & Smith, A. (2003). Ethics and ethnography: An experiential account. *Qualitative Health Research, 13*(4), 567–577.

Grinyer, A. (2001). Ethical dilemmas in nonclinical health research from a UK perspective. *Nursing Ethics, 8*(2), 123–132.

Hammersley, M. (2013). *What's Wrong with Ethnography?* London: Routledge.

Hammersley, M., & P. Atkinson. (2007). *Ethnography: Principles in Practice*. London: Routledge.

Haraway, D. (1988). Situated knowledges: The science question in Feminism and the privilege of the partial perspective. *Feminist Studies, 14*(3), 575–599.

Johnson, E. (2004). *Situating Simulators*. Lund: Arkiv Forlag.

Law, J. (1992). Notes on the theory of the actor-network: Ordering, strategy, and heterogeneity. *Systemic Practice and Action Research, 5*(4), 379–393.

Law, J. (1994). *Organizing Modernity*. Oxford: Blackwell.

MacKenzie, D., & Wajcman, J. (1999). *The Social Shaping of Technology*. Milton Keynes: Open University Press.

Marcus, G. E. (1995). Ethnography in/of the world system: The emergence of multi-sited ethnography. *Annual Review of Anthropology, 24*(1), 95–117.

Marzano, M. (2007). Informed consent, deception and research freedom in qualitative research. *Qualitative Inquiry, 13*(3), 417–436.

Murphy, M. D., & Johannsen, A. (1990). Ethical obligations and federal regulations in ethnographic research and anthropological education. *Human Organization, 49*(2), 127–143.

Orlikowski, W. J., & Scott, S. V. (2015). Exploring material-discursive practices. *Journal of Management Studies, 52*(5), 697–705.

Simakova, E., & Neyland, D. (2008). Marketing mobile futures: Assembling constituencies and creating compelling stories for an emerging technology. *Marketing Theory, 8*(1), 91–116.

Suchman, L. (2007). *Human-Machine Reconfigurations: Plans and Situated Actions*. Cambridge: Cambridge University Press.

Suchman, L. (2010). Epilogue: Moving nature/culture. In E. Johnson & B. Berner (Eds.), *Technology and Medical Practice: Blood, Guts and Machines*. Surrey: Ashgate.

Suchman, L., & Bishop, L. (2000). Problematizing 'innovation' as a critical project. *Technology Analysis & Strategic Management, 12*(3), 327–333.

Traweek, S. (1995). Bodies of evidence: Law and order, sexy machines and the erotics of fieldwork among physicists. In S. Foster (Ed.), *Choreographing History*. Bloomington, IN: Indiana University Press.

Traweek, S. (2009). *Beamtimes and Lifetimes*. Cambridge, MA: Harvard University Press.

Wolf, D. L. (1996). *Feminist Dilemmas in Fieldwork*. Oxford: Westview Press.

Wood, L. A. (2012). *The Ray of Hope: Hidden Work and the Pursuit of Accuracy*. Ph.D. thesis, Lancaster University.

Wood, L. A. (2016). Organising the machine: Material-discursive practices and mobile medical equipment engineers. *Applied Mobilities, 1*(2), 161–175.

8

Symbolic, Collective and Intimate Spaces: An Ethnographic Approach to the Places of Integrated Care

Gemma Hughes

Introduction: Extending Ideas of Integrated Care from Intervention to Practice

The integration of health and social care is a long-standing feature of UK health policy. Concerns about how to afford and organise different kinds of care, particularly for people who need multiple services, have resulted in policy initiatives that seek to integrate health and social care. The policy intention is to manage resources more effectively whilst meeting increasingly complex needs, particularly those of the ageing population. The policy solution of integrated care promises to save money, for example, by reducing hospital admissions, as well as being more person-centred. Integrated care attempts to solve so-called wicked problems, such as fragmentation of care, that are difficult to formulate, resistant to evidence-based approaches, long-standing and socially complex (Shaw and Rosen 2013; Parkhurst 2016).

G. Hughes (✉)
University of Oxford, Oxford, UK
e-mail: gemma.hughes@gtc.ox.ac.uk

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Evaluations of integrated care interventions have shown mixed results in consistently demonstrating benefits, including an impact on hospital admissions. My interest in the disparity between the normative policy expectations of integrated care and the apparent lack of evidence of successful outcomes of implementation of this policy led to an inquiry into the practice and experience of integrated care for my doctoral research. I adopted an ethnographic approach which resulted in an exploration of the different places where integrated care was performed.

Steeped in the policy rhetoric of integrated care from my experience of working as an NHS commissioner, I sought to extend the idea of integrated care from being an intervention to a conceptualisation of integrated care as a social practice. I set out to explore the social complexity of the activities and experiences of "doing" integrated care. Informed by a tradition of case study inquiry into issues within their social and cultural context (Stake 1995; Simons 2009; Burawoy 2009; Flyvbjerg 2006), I turned to ethnography to examine connections between individual experiences and the broader social phenomena of integrated care. I undertook an 18-month period of ethnographic fieldwork that incorporated participant observation with people living with multiple long-term conditions in home and healthcare settings, and with organisations involved in the provision, planning and management of health and social care services in one region of England. Policy analysis provided a broader discursive context for my fieldwork.

During ethnographic fieldwork, I was unexpectedly compelled to pay close attention to the *locations* of the experience and practice of integrated care. These locations were not the generic concepts of "*home*", "*community*" or "*hospital*" encountered in the policy and research literature. Instead, the geography of the region, the buildings, roads, rivers and vehicles I encountered were implicated in the sensory experience of the field (Pink 2011) and integral to the lives of research participants. At the outset, I had not considered the factors of location or place as being particularly relevant to the object of study, but in fact found these inescapable, not only in navigating fieldwork, but in attempting to understand how care is experienced and practiced. This led me to reflect on the relevance of the specific, situated nature of *where* integrated care takes place and to literature on space, place and health. The result was the development of an ethnographic sensibility to the different spaces of my fieldwork and interpretations of the multiscalar nature of integrated care through a lens of critical spatial awareness.

Theorising About Health, Space and Place

Integrated care is found as an object of study in health services and policy literature, where it is evaluated as a programme, strategy or complex intervention by researchers from the disciplines of health economics, medicine, public health and policy studies, such as studies of the economic impact of integrated care (Nolte and Pitchforth 2014), and the effect of integrated care programmes (Martinez-Gonzalez et al. 2014). My research seeks to extend the understanding of integrated care by treating it as a different kind of object of study, drawing on critical social science in conceiving of it as a practice, that is a collection of activities that are interwoven within their social, political and organisational contexts. This approach conceives of context not as a container but as created by practice (Gherardi 2013). Practices are part of, produced by and contribute to, the social world where they are performed. Geography, and spatial theory, offers opportunities to examine the importance of place as integral to the situated nature of practices.

Places, including those where health and social care are practised, are produced by social relations and inherent power dynamics (Foucault and Rabinow 1991; Lefebvre and Nicholson-Smith 1991). An understanding of place as more than merely a location, but produced by and contributing to broader systems of power and control, underpins critical examinations of where care is located (Cartier 2003; Exley and Allen 2007), which is particularly relevant when efforts are made to change the place of care, as happens in the implementation of integrated care. Integrated care is concerned with providing more care in the home instead of in hospital. Going beyond the superficial acceptance of location as a neutral backdrop to social activity opens up possibilities of examining objects of study across multiple and coexisting scales. Hall does just this in her “trans-ethnography” of diversity, examining the symbolic space of the city, the collective space of the street and the intimate space of the shop interior in order to connect different ways of framing activities and places (Hall 2013). I use these ideas of three different kinds of distinct but interrelated spaces, symbolic, collective and intimate, in writing about the places of integrated care.

Integrated Care in Practice: A Case Study

Studying integrated care in practice requires connecting policy discourses with organisational activities and individual experiences. Integrated care describes a range of activities, including efforts to make health and social care services work together more effectively. This is complicated in the UK by the separate funding and governance regimes for health and social care. My ethnographic study of integrated care entailed participant observation of organisational changes, pooling of budgets and the coordination of care for individuals with complex health and social care needs. My fieldwork took place in NHS and council offices, in meeting rooms, health centres, clinics, hospitals and in people’s homes.

To connect the different places encountered in ethnographic fieldwork, I draw on Hall’s work to conceptualise the places of care as overlapping symbolic, collective and intimate spaces. I take the symbolic space to mean the study site as a whole; the collective space as places where different people and practices congregate, described here in the hospital; and the intimate space as research participants’ homes. These concepts developed iteratively throughout fieldwork, with questions about how the spaces are shaped informing interviews and selection of documents, as I physically moved around the field, encountering the different spaces and locations where care was practiced. My descriptions of the symbolic, collective and intimate spaces of integrated care follow.

The Symbolic Space of the Health Planning Unit

I start with the planning space, writing about how the space is conceived, organised and how people live in this space. The "symbolic city" creates a notion of the city as a whole, giving an overview of the object of study (Hall 2013). I take the symbolic space in this study to be a sub-unit of the city, a cluster of three clinical commissioning groups (CCGs) coterminous with three city councils. It is represented pictorially in planning documents as three outlined shapes grouped together at the edge of the city boundary with the river providing a border along one side. Health planners take this as a single unit because of the financial flows from the three CCGs to the single hospital trust that provides services to most of the people who live in this area. This is a purchasing, commissioning view, focused on hospital health care. CCGs are statutory bodies that manage funds allocated by central government, via contracts with health service providers (*Health and Social Care Act* 2012). Combining the three CCGs into a single planning unit is intended to create a balanced relationship between the purchaser (the three CCGs and their combined purchasing budget) and the provider (the acute hospital trust). Other health-based organisational perspectives, such as community services provided by the local NHS Trust, cover different geographical patches. The city councils have no such commonalities; their budgets are allocated by a different central government department and are set through local democratic arrangements. The elected representatives in these councils have little in common; the full range of English politics from left wing to right wing via independent candidates is found here. Officers from the NHS and social care in this space are, however, pursuing ideas of integrated care partnerships, seeking to find ways of rising above single organisational perspectives to balance budgets and improve care through new organisational structures, for example creating an Accountable Care Organisation,[1] or through devolution of powers and budgets.[2]

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[1] See https://www.kingsfund.org.uk/topics/integrated-care/accountable-care-organisations-explained.

[2] See https://www.kingsfund.org.uk/publications/devolution.

A view of material things in place shows how people live in this area. Local place names containing fords and bridges reveal how human settlements have been shaped by the rivers running through the landscape. These settlements have grown and spread, shaping the location of health services by density of population (the main hospital built near the location of Poor Law Infirmary) or conversely spaciousness (the community hospital is on the site of the old isolation hospital, located in a meadow when it was built in the nineteenth century). Busy areas, high streets and transport hubs are where general practices and pharmacists are clustered, not located in areas of poor health where people might need them most (Tudor Hart 1971) but where they can best balance business costs and income. Residences also cluster together; the areas of high population density are linked by roads and rail, with parks, forests and a golf course patched in between. Health Profiles are available of each of these boroughs (*Health Profiles* 2015) charting population health summaries and comparing indicators of disease and life expectancy with national averages. Deprivation is mapped to show the geographic distribution in each borough. One of the three has much worse health outcomes and deprivation. Here, the remains of heavy industry can be found, with housing purpose-built after the Second World War still providing homes for old men, long retired from the factory. The resulting brownfield sites are earmarked for regeneration, with the vision of a "new town" on the riverside (*NHS Five Year Forward View* 2014).

Over time, the symbolic space changes shape as the view of health planning changes. The three CCGs currently grouped together are the descendants of previous NHS bodies which were configured in different ways. Health planning unit boundaries have been continually drawn and redrawn by the establishment and dissolution of different NHS organisations. Each time, the jigsaw pieces of the boroughs create slightly different shapes within the frame of the city boundaries. During fieldwork, the unit started to change again, being incorporated into a larger "STP[3]" footprint, a larger pot of health funding.

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[3] Sustainability and Transformation Plans *Delivering the Forward View: NHS Planning Guidance 2016/17–2020/21* (2016): NHS England. Available from: https://www.england.nhs.uk/wp-content/uploads/2015/12/planning-guid-16-17-20-21.pdf.

In contrast, local government has continued to hold elections, set budgets and run services according to the same borough boundaries since the 1963 London Government Act while the NHS planning units shrink and grow with the tides of NHS reorganisation.

The health planning unit is therefore symbolic of ideas about health care that are based on the financing of health care and is dominated by the cost of hospital services, as it is this which shapes this notion of a whole. This view changes as administrative and financial plans change. The symbolic space is overlaid on other administrative, historic and geographic spaces in a way that prioritises planning of health care over social care, and hospital care over primary care and community services. Empty maps and diagrams are used to represent the area, smoothing out the tangled history, roads, rivers and stories of the area and so making invisible some of the other ways in which health services are shaped.

The Hospital as a Collective Space

The collective space is a recognisable bounded area, within which a shared range of connected intercultural practices emerge (Hall 2013). The public place of the hospital, open night and day, features in the notion of integrated care as a place to be avoided. I explore how this notion is constructed by ideas of integrated care, as well as how the hospital in the case study is organised and experienced.

Hospitals have multiple meanings (Jones 2015). They are destinations for ambulances with blue flashing lights and sirens, high-tech places of life-saving surgery, after unlucky accidents or catastrophic illness. This vision of the hospital is reinforced by integrated care policy that sets out what the hospital is not: not a place for people with long-term conditions, chronic illnesses and social needs. Often elderly and frail, hospital admission for these people is seen as a “failure” (*Integrated Care and Support—Our Shared Commitment* 2013). Instead, integrated care should negate the need for hospital-based care, joined-up health and social care available at home will proactively prevent emergency hospital admissions. No one wants to be in hospital anyway, a place of iatrogenic risk, health care-acquired infections, decreased mobility and independence. People prefer to stay at home, with home visits from community nurses, even to die in the comfort of their own beds with their loved ones around them. This particular hospital has a vision of efficiency built into its fabric (Martin et al. 2015). It is a distinctive modern building that has won architectural awards for its innovative design of interconnecting "clover-leaves" or turrets. External windows, helpful for human orientation in time and place, are sacrificed in this design which is intended to increase staff efficiency, effectiveness and save maintenance costs. The architect is quoted as saying "*it's bad use of hospital manpower* (sic) *to get people lost in corridors*".

To experience this hospital in place requires navigating a network of main roads and retail outlets. Arrival at the grand main entrance, rather than in an ambulance round the back or to A&E at the side, gives an impression of busy spaciousness. The white-walled atrium, decorated with brightly coloured art, rises high above the crowds. The Chief Executive ascends the escalator to the management offices, waggling the sandwich he has bought from the snack bar and smiling at someone spotted across the big space—there is no staff canteen here. Polo-shirted Sodexho cleaners and porters tread purposefully through the bustle. The Information Desk has four "Wayfinders", checking papers held by anxious visitors and pointing to the long lists of signs: orange zone cardiorespiratory, clinical diagnostic unit, neurophysiology, neuropsychology, nuclear medicine, outpatients 3 and 4, blue zone, elders receiving unit (ERU), HDU & ITU, medical receiving unit (MRU), neurocritical care, outpatients 5… The noise of people talking, the thump and hiss from the coffee shop and the constant movement are reminiscent of a train station or an airport, as are the retail outlets and the cashpoint, positioned conveniently for passers-by. There is even a market stall draped with black velvet, today selling jewellery, last week handbags. Who is allowed here and what they can sell is governed by the Private Finance Initiative (PFI) contract, down to the detail of a ban on selling chewing gum on site.

The building design rankles with staff. It would not win any awards from those in the A&E department, ever-pressured, ever-struggling to meet targets. "*This is not a British NHS hospital!*" exclaims a senior doctor. "*Designed to confuse*", says a nurse. The vast number of individual rooms and doors interrupt the sightlines that are expected in a hospital ward; each door has to be opened and each room checked regularly, lest a patient wanders. The senior staff cannot "*lay eyes*" on all their patients and staff simultaneously. Instead, they hold regular "*board*" rounds, reviewing the electronic boards displaying patient details. The model of traditional NHS hospital care is compromised by this layout. And this building is not easily altered due to the complex PFI contract (all 18 volumes of it) that governs not only the repayment terms of the building ("*a bit like a glorified mortgage*") but all the contracts for the "*hard*" and "*soft*" facilities which have to be amended if the fabric of the building changes.

The collective practices that shape the hospital go beyond the clinical practices of health care and encompass contracting processes to secure cleaning, laundry, catering and security services. The hospital is maintained by servicing a loan and renegotiating contracts; these practices create the hospital within a framework of financial and legal constraints governing the fabric of the building and the activities within. The hospital embodies the vision of an efficient and intensively utilised space pervasive in UK health policy that has reduced the number of hospital beds well below the European average, leaving little room for human needs beyond the clinically constructed nature of a particular notion of medical care.

The Intimate Space of Home

The intimate space of this study is the domestic setting, the microcosm of interaction and expression, where forms of identity merge with the imperatives of day-to-day living with chronic illness (adapted from Hall 2013). The notion of home for integrated care is as an unproblematic and preferred alternative to hospital or other institutional care. A universally recognisable concept (Exley and Allen 2007), home is associated with independence, with independent living the other side of the coin of institutional care. Independence in this discourse means funded from personal finances, not state funded. Home therefore becomes idealised, representing financial security as well as social and emotional safety, entangled with ideas of positive, supportive intimate relationships (Roberts and Mort 2009). I examine the way homes are lived, entering into these private spaces by invitation of those who dwell there.

I enter different homes during fieldwork, after securely locking my own front door a few miles away. My ability to both secure my home and leave it, in order to return at the end of the day, is in sharp contrast to the experience of the people I visit. Many are unable to open their own front door unaided due to restricted mobility, so visits are planned around the availability of a friend, carer or spouse to open the door to me. Others have technology that mediates entry, still others forgo security and simply leave the door on the latch. Home is not somewhere that is easily left and returned to for these people; they leave rarely and only with considerable effort and assistance.

Marge and Harold illustrate between them two versions of mobility. Harold, aged 83, has multiple long-term conditions affecting his breathing (relying on oxygen to manage the symptoms of chronic obstructive pulmonary disease) and his digestion (he suffers the painful and at times embarrassing condition of diverticulitis) as well as diabetes, hypertension and cancer. Unable to walk independently, he has not left his home for many months. Harold's community matron provides case management, organising his care including home visits from specialist community services and domiciliary care, as his ability to stand, wash and dress deteriorates. Marge, his wife, is 78, also with respiratory problems which combined with the painful symptoms of osteoarthritis, restrict her movements. She has recently been diagnosed as being in the early stages of dementia. I recruit Marge and Harold as research participants by virtue of their participation in case management, the approach used in the case study to coordinate health and social care for people identified as being at high risk of hospital admission. I sit in their comfortably decorated living room for many hours during fieldwork. It has deep-pile carpet and crystal light fittings. Shelving units hold framed photos, a collection of ornaments and books. A tidemark of dust on these shelves demonstrates the extent of Marge's reach, her painful shoulder prevents her doing any more, and she does not want the woman who does her hoovering and heavy cleaning to dust these precious things. Although stiff and slow with arthritis and asthma, Marge leaves the house early every morning to drive to the paper shop, returning in time to let in anyone coming to see Harold. Harold can barely stand unaided, and once he has travelled downstairs in the morning on the stair lift, stays seated on the sofa for the day, attached to the oxygen machine which hisses and bumps next to him. Tucked by his leg are his most important medicines in a zipped washbag, and his reading glasses and newspaper are placed nearby, along with a grabber stick to retrieve items from the floor. A footstool is needed to elevate his feet, too swollen to fit into his slippers. Tablets are laid out neatly in rows on the coffee table next to a pint of weak lemon squash and a tall glass of water, necessary to swallow multiple prescriptions. A small square of dark chocolate waits to be consumed, for its health-giving properties. A stack of postcards from friends, letters from charities and adverts has slipped and scattered across the table, knocking over a toilet roll and a tube of haemorrhoid cream. Behind the armchair is the brown, black and white plastic commode which Harold, mortified, has to use urgently when his gastric problems flare up.

The disruption of the living room by the placement of the commode is not unusual in these settings (Angus et al. 2005). I often see beds in living rooms too, as the house shrinks around the increasingly immobile person. These arrangements magnify the intimate nature of being in the home. We are already in close bodily proximity to each other as we sit and talk and are physically near the bedroom and bathroom where intimate and private acts usually take place. This intimate space is more than a neutral setting for care, rather it is created by this couple during their lives together, accomplished out of the efforts and resources they draw on (May et al. 2014). As they have aged and become unwell and re-organised their selves (Charmaz 1983), they have had to re-organise their home. The intimate space has been disrupted, not just by their health, but by the encroachment of the objects and practices of care. Things are displaced in the home, which simultaneously serves as a workplace as community nurses and domiciliary carers carry out their duties. I observe a community nurse carefully unpacking her bag, laying out instruments to create a temporary clinical space at the end of the sofa so she can check vital signs and take a blood sample. The uniformed agency carer bustles past us to lift the telephone to “clock in” and out again as she leaves.

Interconnected Spaces

Having approached the object of study, the practice and experience of integrated care, with both an ethnographic and spatial awareness and found ways in which places are produced by ideas of integrated care, I now aim to stretch across the different spaces by discussing the connections between them, which coexist geometrically and conceptually.

The home and the hospital are physically located within the geographical confines of the planning unit, and there are a series of conceptual relationships between the three spaces that are mutually reinforcing. The planning unit and the hospital are mutually productive. The planning unit has been created to provide an organisational shape that will roughly reflect the geographical location of people who use the hospital and has been allocated the funding that will secure hospital services for people living in the area. The hospital is, in turn, shaped by the planning unit. The hospital needs to be super-efficient to stay within the constraints assigned by the planning unit; the modern building is deliberately designed to save space and money, run through tight contracts reissued regularly to achieve better "value for money". The hospital and the planning unit are both shaped by ideas of the home as a place that can offer an alternative to hospital. With home as a designated place of alternative care, the hospital is constructed as a place that is only for acute medical needs, with other kinds of hospital admissions being unnecessary and avoidable and therefore excluded from plans. The home remains the alternative, preferred, place of care to the public, collective space of the hospital.

The three spaces of home, hospital and planning unit are therefore connected by the financial flows that shape the symbolic space around the collective space of the hospital and ideas of how the home is an alternative to hospital. The spaces are mutually produced, and this production of spaces further affects the practice of integrated care. The creation of the efficient acute hospital affects the practice of integrated care by compelling a continued focus on keeping people out of hospital, even when there is limited evidence that this is possible. The notion of the hospital as a purely medical space promulgates the idea that medical needs can, somehow, be entirely separated from other human needs, whether these are described as nursing care, social needs or in other terms. Separation of medical needs in this way runs counter to the aspiration of integrated care, intended to be person-centred, defined by the individual's perspective and not that of the services they need. The production of home, the "*material and affective*", (Blunt 2005) private, domestic space, is compromised by the effects of multiple chronic conditions and disrupted by the provision of care in the home. People receiving home-based care, already restricted in their mobility, are kept in this private place by ideas of avoiding hospital admissions and providing care in the community.

The different spaces encountered are therefore both shaped by ideas of integrated care, and further shape the practice and experience of integrated care in unexpected ways. Instead of bringing together health and social care services and budgets, divisions are reinforced by the dominance of the health budget in shaping the planning unit, private domestic care is separated further from hospital-based public care, and the structure of the hospital serves to reinforce the necessity of this approach. These spaces can be connected by comparing the ways in which these spaces are shaped by ideas of integrated care and how the spaces shape integrated care. The administrative processes of the NHS, through the process of managing financial flows, strongly influence how these spaces are shaped. The lived reality of the collective and intimate spaces reinforces divides between hospital and home, public and intimate in ways that resist the aspirations of integrated care. In these multiple ways, ideas of efficiency in health care are perpetuated.

Conclusion

Much of the health services research into integrated care focuses on the organisational activities required to coordinate care more effectively for people with complex needs and is concerned with establishing how effective these interventions are. I have turned to ethnography to find an alternative way of considering integrated care, by constructing the object of study as a social practice. In doing so, ethnography provides insight into the particularities and contexts of individual experiences.

My experience of undertaking an ethnographical exploration of integrated care, incorporating extended fieldwork and participation observation, led to an appreciation of the geographical locations as well as the socially situated nature of the practice I was investigating. The process of undertaking fieldwork and developing an ethnographic sensibility to the object of study foregrounded the spatial features and locations of integrated care that are rarely present in the literature on integration. This led to a critical inquiry into the multiple spaces—symbolic, collective and intimate—where integrated care happened, which encompassed multiple epistemologies, and connected particular places with more general insights. Ethnography provided new insights into the way in which efforts to integrate care reinforced and reproduced divisions between health and social care, hospital and home care.

Paying attention to the geography of integrated care in this way supports the process of moving from the spatially and temporally located empirical experience of fieldwork to more generalisable theory. The inescapably situated nature of ethnography can be embraced with a geographic sensibility that offers the opportunity of critically examining where the object of study unfolds. In this way, the concrete and the abstract can be brought together to create ideas of coexisting spaces that can be analysed to study the dynamics of a situated practice. An enhanced critical spatial awareness can assist in connecting specifically situated fieldwork with more generalisable learning points. In conclusion, ethnography, empirically grounded, materially located and theoretically informed, compelled me to take a geographically, as well as a socially, situated view of my object of study. Exploration of the situated nature of health care, and the multiple factors that shape the places where care takes place, can provide new insights into the experience and practice of care and therefore to the successes or failures of efforts to integrate care.

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References

Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B. (2005). The personal significance of home: Habitus and the experience of receiving long-term home care. *Sociology of Health & Illness, 27*(2), 161–187.

Association of Public Health Observatories. (2015). *Health Profiles*. Available from http://www.apho.org.uk/resource/view.aspx?RID=50215&SEARCH=B*. Accessed September 14, 2015.

Blunt, A. (2005). Cultural geography: Cultural geographies of home. *Progress in Human Geography, 29*(4), 505–515.

Burawoy, M. (2009). *The Extended Case Method: Four Countries, Four Decades, Four Great Transformations, and One Theoretical Tradition*. Berkeley: University of California Press.

Cartier, C. (2003). From home to hospital and back again: Economic restructuring, end of life, and the gendered problems of place-switching health services. *Social Science and Medicine, 56*(11), 2289–2301.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168–195.

Exley, C., & Allen, D. (2007). A critical examination of home care: End of life care as an illustrative case. *Social Science and Medicine, 65*(11), 2317–2327.

Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry, 12*(2), 219–245.

Foucault, M., & Rabinow, P. (1991). *The Foucault Reader*. London: Penguin.

Gherardi, S. (2013). *How to Conduct a Practice-based Study: Problems and Methods*. Cheltenham, UK: Edward Elgar Publishing.

Hall, S. M. (2013). Super-diverse street: A 'trans-ethnography' across migrant localities. *Ethnic and Racial Studies, 38*(1), 22–37.

Health and Social Care Act. (2012). Available from http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted. Accessed May 11, 2014.

Jones, L. (2015). What does a hospital mean? *Journal of Health Services Research and Policy, 20*(4), 254.

Lefebvre, H., & Nicholson-Smith, D. (1991). *The Production of Space*. Oxford: Blackwell.

Martin, D., Nettleton, S., Buse, C., Prior, L., & Twigg, J. (2015). Architecture and health care: A place for sociology. *Sociology of Health & Illness, 37*(7), 1007–1022.

Martinez-Gonzalez, N. A., Berchtold, P., Ullman, K., Busato, A., & Egger, M. (2014). Integrated care programmes for adults with chronic conditions: A meta-review. *International Journal for Quality in Health Care, 26*(5), 561–570.

May, C. R., Eton, D. T., Boehmer, K., Gallacher, K., Hunt, K., MacDonald, S., et al. (2014). Rethinking the patient: Using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Services Research, 14*, 281.

National Collaboration for Care and Support. (2013). *Integrated Care and Support—Our Shared Commitment.* National Collaboration for Care and Support, UK. Available from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198748/DEFINITIVE_FINAL_VERSION_Integrated_Care_and_Support_-_Our_Shared_Commitment_2013-05-13.pdf. Accessed July 23, 2013.

NHS England. (2014). *NHS Five Year Forward View*. UK: NHS England. Available from https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf. Accessed November 10, 2015.

NHS England. (2016). *Delivering the Forward View: NHS Planning Guidance 2016/17–2020/21*, UK: NHS England. Available from https://www.england.nhs.uk/wp-content/uploads/2015/12/planning-guid-16-17-20-21.pdf. Accessed December 29, 2016.

Nolte, E., & Pitchforth, E. (2014). *What is the Evidence on the Economic Impacts of Integrated Care?* Copenhagen, Denmark: European Observatory on Health Systems and Policies, WHO Regional Office for Europe. Available from http://www.euro.who.int/__data/assets/pdf_file/0019/251434/What-is-the-evidence-on-the-economic-impacts-of-integrated-care.pdf. Accessed January 24, 2017.

Parkhurst, J. (2016). Appeals to evidence for the resolution of wicked problems: The origins and mechanisms of evidentiary bias. *Policy Sciences, 49*(4), 373–393.

Pink, S. (2011). Multimodality, multisensoriality and ethnographic knowing: Social semiotics and the phenomenology of perception. *Qualitative Research, 11*(3), 261–276.

Roberts, C., & Mort, M. (2009). Reshaping what counts as care: Older people, work and new technologies. *Alter—European Journal of Disability research [Revue européen de recherche sur le handicap], 3*(2), 138–158.

Shaw, S. E., & Rosen, R. (2013). Fragmentation: A wicked problem with an integrated solution? *Journal of Health Services Research & Policy, 18*(1), 61–64.

Simons, H. (2009). *Case Study Research in Practice*. London: Sage.

Stake, R. E. (1995). *The Art of Case Study Research*. Thousand Oaks, CA and London: Sage.

Tudor Hart, J. (1971). The Inverse Care Law. *The Lancet, 297*(7696), 405–412.

9

Temporality and the Intersections Between Ageing, Gender and Being Well: Reflections from an Ethnographic Study in Salsa Classes

Sarah Milton

Introduction

The ‘greying’ of countries in western Europe and beyond has emerged as a problem of biopolitical governance, as societies contend with the social, ethical and financial implications of ageing populations. In the UK and elsewhere, demographic changes have led to increasing proportions of people aged fifty and above in the population and the current political and social climate is increasingly dominated by concerns about the consequences of this (Dolan and Tincknell 2012). Discourses surrounding ‘active’, or ‘successful ageing’, span thousands of articles, books, policy documents and websites (Lamb 2014), laying the responsibility of ‘ageing well’ on the individual—who should energetically strive to remain independent and productive. Alongside this run discourses surrounding sexuality; that in order to age well one must also remain sexually active and functional in certain ways (Vares 2009;

S. Milton (✉)
Faculty of Life Sciences and Medicine, King’s College London, London, UK
e-mail: sarah.milton@kcl.ac.uk

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Meah et al. 2011). These discourses have been criticised by sociologists and social gerontologists for ignoring the inevitable materiality of ageing and for infusing age-related dependencies with negative affectivity. They have also been criticised for only applying to those who have the financial and social means to maintain certain activities and lifestyles (Williams et al. 2007), and for being highly gendered and culturally specific (Potts et al. 2003; Calasanti and King 2005; Sandberg 2011). Ethnography provides the opportunity to step away from these discourses and debates and allows for a deep engagement with what ageing and being well can mean to older people themselves. Through the space that ethnography produces, the complexity, multiplicity and change of daily lives, experiences and meanings can begin to emerge.

This chapter engages with my ethnographic research on ageing, femininity and sexuality in mid and later life. To explore questions surrounding the experience of dating and relating in mid and later life, I undertook participant observation in salsa classes in two locations in the UK along with life history interviews with women in their 50s and 60s. The choice of the research focus came from an awareness of a shift in the understanding of ageing and sexuality in public health and sociological research and knowledges. Vares (2009) argues that pre-1990s, the primary understanding of sexuality and old age was that they were contradictory, oppositional or incompatible—and ageing a process of transformation whereby women became socially invisible. This was reflected in many ways: from the absence of those of post-reproductive age in national surveys about sex to sociological writing on bodies, which focused on the young (Twigg 2010; Dolan and Tincknell 2012). However in the last twenty to thirty years, older bodies have not only become more visible, but are increasingly depicted as erotic and sexual (Calasanti and King 2007; Vares 2009). The ‘fifty-plus’ have fallen under the surveillant gaze of public health research and older people’s sexual health has started to be monitored, for example through quantifying sexual health clinic attendance and measuring the increase in sexually transmitted infections in the age group (Gott et al. 1998a, b; Drew 2008). Some say the shift in the discursive presence and popular understanding of sex and sexuality in later life has been caused by the generation of ‘baby boomers’ and their supposedly liberal values ageing into their later years (Weeks 2009). Others have located the shift alongside a 'cultural scientific shift' in the 1990s, which with the advent of pharmaceuticals such as Viagra and HRT began to see successful ageing as one in which sexual function was a primary component (Vares 2009: 505).

Discussions surrounding ageing, then, can feel polarised between the descriptors 'active' or 'in decline'. The same applies to sexuality in later life, where terms such as 'functional' or 'dysfunctional', 'present' or 'invisible' are frequently deployed. The fieldwork choices that I made took my focus away from these binary imaginations of ageing and sexuality in later life, in order to engage with daily, lived experiences. An ethnographic focus on the everyday can draw our attention beyond envisaging health as a spectrum of 'states' such as 'active', or 'functional'. This chapter explores the knowledge produced by the type of ethnography I practised, and in particular the value of doing ethnography in non-health settings in order to understand questions surrounding health and wellbeing. I will explore what the combination of participant observation with a focus on the sensory, and life history interviews, produced and contributed towards the understanding of what it means to age well. It involves a stepping away from professional 'knowledges' about health and wellbeing in later life and delves into the messy, contradictory and complex ways that sexuality, gender and ageing are understood and practised in different spaces and times.

Sensory Ethnographies of the Sensual

Understandings of and experiences surrounding age, gender and sexuality are often so ingrained and taken for granted that we tend to think of them as 'natural'. Following Bourdieu (1990), and the developments of his theories to account for gender and sexuality (see Adkins and Skeggs 2004), for this research I understood the self as gendered, sexualised and reproduced through everyday practices. Whilst internalised as second nature (Bourdieu 1990), these understandings and ways of being are not consciously learnt, ideologically imposed, or 'naturally given' but acquired and made through practice over time, and dependent on cultural and historical circumstances (Lovell 2000). As a result, these 'second nature knowledges' can be difficult to talk about and reflect upon in interviews alone. Participant observation is well suited towards exploring these taken for granted ways of living and being, providing an opportunity to observe and experience much more than just talk. During participant observation in salsa classes, I paid particular attention to how people moved, who they moved with, whom and how they touched, how they dressed and held themselves—and how all of this changed over the course of the fieldwork. I interpreted these as ways of 'doing' gender and sexuality in daily life (Milton 2017). Similar approaches have been referred to as sensory ethnographies (Howes 2003; Pink 2007; Blake 2011), or embodied ethnography (Wade 2011). Whilst others undertaking sensory ethnographies have focused upon the visual senses (Pink 2007), smell (Classen 1997) or taste (Farquhar 1994, 2002), my focus during participant observation was upon touch and movement.

As well as attention to the embodied experiences and practices of others, I also paid attention to my own embodied experiences during the course of participant observation. I attended the salsa classes regularly throughout my fieldwork, and an invaluable part of my data collection was going through the process of learning the dance alongside my participants. This provided me with invaluable insight and shared understandings that I could then use during interviews to deepen discussions. Similar experiences have been recounted by others informed by Bourdieu's understanding of the body, and subsequently gender. Commenting on his ethnography of boxing in which he learnt how to box himself, Loic Wacquant (2004) describes his own embodied experiences as important and essential sources of data; '*(the) first and most direct source of data was my own body – a tool of inquiry and vector of knowledge*' (Wacquant 2004: 11). Similarly, in Wade's 'embodied ethnography' of lindy hop, her own dancing was a mode of data collection; '*alongside this deep data on the body designed to tap into how it feels to do gender as a lindy hopper, I watched how dancers used their bodies (recording observations in fieldnotes) and I listened to dancers describe how they dance*' (Wade 2011: 393). Wade interpreted her ability to dance as offering some cultural capital with her participants, and with the ability to interpret and make insights that were available only to those whose own bodies had achieved a high level of familiarity with the dance. In similar ways to these studies, I envisioned the researcher as '*a socially embedded and embodied being, engaged in rich emotional and sensual experiences in the field*' (Blake 2011: 1).

In addition to participant observation, I performed life history interviews. For those interested in the experience of ageing, Phoenix and Sparkes (2008) have recommended taking account of the whole life in order to understand the various age-related norms experienced along the lifecourse, which shape how we experience different ages. Life history interviews enabled a way of contextualising the experiences in the salsa classes within the participants' lives and lifecourses. Health and ethnographic research can often provide a 'snapshot' of people's lives, yet a focus on the whole life can help to understand the messiness and contradictions of daily living. In ways in which I will explain further throughout the chapter, life histories complemented a sensory approach to participant observation and helped to develop my understanding of gender, ageing and ways of being well.

Safe, Sensual Spaces

Salsa classes were chosen as ethnographic spaces and a 'way in' to meet people in the particular life stage and age that I was interested in. Salsa classes have become increasingly popular in the UK (and beyond)—spanning local classes to national and international networks that organise workshops, holidays and even 'salsa cruises'. The salsa classes that I went to were particularly popular with men and women over 50. The salsa classes that I visited were in hired spaces, for example in rooms above pubs, in available club spaces and in village or church halls. The teacher or group of teachers often hired different spaces for different classes on different nights of the week, and therefore the classes had a temporal and mobile nature; salsa nights often cease periodically and then spring up again elsewhere. This impermanence was something I experienced during my fieldwork; the class that I undertook most of my participant observation in had moved to its current location only a couple of months earlier, and the teacher was in the process of setting up another class in a different part of London. The salsa classes and their teachers existed in networks all over the UK, often with the same teachers known among participants of the research from different places.

There was an empirical back-and-forth dynamic between the observations I made in the classes of other people learning the dance and becoming accustomed to the salsa space, my own embodied experience of learning to salsa dance, and the interviews that I conducted with salsa class attendees. The back-and-forth dynamic enabled different kinds of data to complement and enrich each other. For example, the impermanent and changing nature of the salsa classes mirrored the stories participants told me in their interviews regarding their changing, impermanent and shifting experiences over time. The salsa classes provided an important space for experimenting with different ways of being. The impermanent and temporal nature of the class (once a week, from 7 to 10 p.m., for example) was part of what made the space seem safe; slightly outside of 'real life'. Recognising that many participants saw the space as 'safe' was key to my developing understanding of the experiences and expectations of gender and sexuality in midlife. In particular, this seemed to link with a common theme emerging in the interviews surrounding the discomfort that many felt in public social spaces as single women in midlife.

Whilst the salsa classes felt safe, outside the classes in 'real life' many spoke of how it felt difficult to find a space that felt natural and welcoming to them that was not family or couple-orientated (further explored in Milton 2017). Participants felt unusual being un-partnered in spaces that they associated with their age group, but in addition they associated other social spaces—such as pubs and clubs—with younger people. Sexuality and being newly single was difficult to manage, and this was linked to normative expectations surrounding ageing and relating, i.e. that sexuality, at their age, should be within long-term relationships or marriages. This was interesting to explore within salsa classes, where the dance itself is close, can be sensual, and is often practised with strangers, or at least with people that are not known outside of the class space.

On top of the impermanence and temporality of the class, an integral part of the class that produced the space as ‘safe’ was the rules associated with participating in salsa. The salsa class was a highly gendered and structured space, with rules such as the ‘salsa etiquette’, which determined who and how dancers touched and moved together. The ‘salsa etiquette’ dictated things like only dancing one dance at a time per partner, never saying no to an invitation to dance, and maintaining eye contact with your partner during the dance. For those uncertain about how to act in social spaces, the rules provided relief and reassurance. The rules also enabled a way to manage the close physicality of the dance, as shown in following fieldnotes describing a class I attended where the rules were less apparent,

> At first I felt a lot less safe than I feel in Russell’s class. There were no instructions to look into your partner’s eyes, so it felt weird to do so. And because it felt too much to have the eye contact I didn’t know where to look! It’s as if you need the permission for the intimacy, otherwise it doesn’t happen – and it’s a bit uncomfortable to dance without it. (Fieldnotes; August 2011)

Along with other beginners in the class, during participant observation I experienced the increased confidence and comfort with touching others once these rules had been learnt and practised.

This experience of learning how to touch and move, and how to manage the closeness of the dance with strangers, then became a point of discussion with participants in the interviews, who often expanded on the ‘rules’ and related them to their wider experiences of dating and relating to men. Despite participants describing during interviews that they were interested in meeting romantic male partners, it seemed to be very important not to display or indicate this during the salsa class or indeed beyond it. The participants for example worked hard to ensure that the touch and movement of the salsa dance was not ‘misinterpreted’. Molly, who was just beginning the dance classes at the time of our interview, described how she found it difficult to place the closeness of the dance, which she referred to as ‘*like a lover’s dance*’ and how she had begun to work on desexualising the dance;

> I just try not to think, I'm just here to learn the dance and I try and kind of, blank out the emotions, well not that it's emotional, there's no feelings there, it's just a man and a woman learning some moves and dancing, going through the motions, I try and think about it in a more technical way as in learning the steps …
>
> I like to think that they're all gay in my head and then I um, so that I don't feel like it's, coz I'm a bit, it's being tactile with a stranger and holding hands and putting your hands on their shoulder and especially when they do some of the moves, some of the moves are quite intimate … (Molly; 50s)

Whilst feeling unusual among their peers for being un-partnered, and unusual in other social spaces such as pubs and clubs because of their age, for the participants the salsa class offered a safe and comfortable space where age and other identity factors did not matter. Within the salsa class spaces, learning to touch and move in certain ways, by attending to the rules of the space, encouraged a transition towards a 'safe sensuality' (Milton 2017). This safe sensuality was a new way of moving. It was '*sensual*' and not explicitly '*sexual*' or inviting sexual advance. When thinking about new sexual, romantic and or intimate partners, the risks were complex and intricate. For those just starting on the dating scene, the most pressing issue was how to act in this new field, (re)learning the rules of different spaces. Significantly, participants often bemoaned the fact that they had no examples to follow; their mothers had aged differently (i.e. within marriages/relationships, couple and family-orientated), and they were therefore entering 'new' territory. What was important was finding a space in which they felt safe, and finding safe ways to interact and be social. Safety seemed to be linked with maintaining a respectability within different spaces, i.e. not being explicitly 'sexual', that they conceptualised as appropriate for their age and gender. I observed this in the salsa dancing spaces and then discussed it in the interviews.

Negotiating Temporal Selves

Alongside participant observation in salsa classes, I carried out life history interviews with women and some men that I met in the salsa classes, in order to situate the stories about their experiences within the context of their wider lives both outside of the classes, and over time. For many of the participants that I spoke to, attending salsa classes marked a significant wider moment in their lives. The salsa classes were seen as an important hub from which support, joy and experimentation could be drawn, but these findings could only be made sense of alongside the stories told in the life history interviews. I found that experiences and expectations today were shaped by the participants' experiences in the past as younger women, married women, and also by the perceptions that they held about their mothers. As I will explain, this made sense of, contextualised and reinforced some of the things I had observed in the salsa classes.

During the interviews, many of the participants told me of their happiness surrounding the increased independence and sociality that they had experienced after a life transition such as divorce, and as something that had come happily with age. Current dating experiences were compared to the experiences they had had themselves in their teens and or in their twenties, which, for the majority of the participants, would have been in the 1970s and before they were married. Many mentioned how with age they had become more conscious of and deliberate in 'making choices', compared with when they were younger, when events 'just happened' to you. Jemima, for example, reflected that when she was younger there was an emphasis upon 'keeping things smooth';

> I wasn't told in my upbringing that I could say no to people, you were always told to comply, don't make a fuss, go along with things, don't challenge. I was there to please and I was there to make things smooth. And that's how, that was a whole generation you know … (Jemima; 50s)

Jemima had married at 22 and reflected that this socialisation in her younger years had prevented her from making a conscious choice about the marriage; '*I wasn't bold enough to actually, I wasn't bold enough to say no or to have more awareness* [of choices]*… you know that's how I was brought up*'.

For many of the women these ideas around passivity and choice had changed significantly with age, and the changes were celebrated, '*… as you get older you become wiser, fussier, and you know what you're* *looking for and you're not just gonna put up with any shit*' (Sandra; 60s). Going out to the salsa classes seemed to coincide with wider changes in the participants' lives, such as beginning adult education or becoming more active and social in general, which often came after a life transition such as divorce. In addition to situating these celebrated changes that had come with age as different to their own pasts, participants also commonly described the changes as different specifically to how their mothers had experienced ageing into mid and later life. Reflections on their mothers' ways of ageing were usually accompanied immediately in their narratives as something that they did not want, and also something they were seeking to actively resist, as Molly said, '*I never want to turn into my mum*'. Whereas the participants now saw themselves as active, independent and social, the mothers of the participants were commonly described as having 'inside lives', which with ageing and the advent of a family became less social and less active, reflecting perhaps a more 'traditional' experience of ageing and how the participants had once expected to be ageing themselves. The experiences within the salsa classes then reflected wider biographical changes and were situated within wider ideas about generation, gender and ageing.

Like in most ethnographic work, before I went into the salsa spaces and before I began the interviews, I reflected on what I was bringing into the field. In particular, I was concerned that my age would inhibit discussions surrounding dating and relating in mid and later life. I was younger than the participants, often by at least thirty years. As the participants described their mothers as reflecting a different, generational embodiment of gendered ageing to themselves, I anticipated that I might also reflect generational, or different, embodiments of femininity—and I considered how this would shape or inhibit what I was told. Illouz (2013), who has analysed contemporary, cultural models of intimacy, has described woman's selfhood today as shaped by psychological and liberal feminist discourses surrounding equality, fairness and emotional communication. Much like the participants above, Illouz (2013) says that this commonly involves discourses of 'knowing yourself', 'becoming aware' of your own needs and being independent. I was uncertain whether the participants might present themselves during the interviews as aligned with this kind of femininity, making the assumption that this might be culturally favourable, and avoid discussing other experiences.

The participants of this study were mainly white British, with various social backgrounds, all of which would intersect with how gender and ageing were experienced and understood, and the stories that were told. However, I found that attending the salsa classes and learning the dance alongside most of the participants worked to 'level out' the age difference and potentially other differing identities that I had with the participants. Our conversations were easy and open, and as I describe in the next section, often complicated. Different versions of 'culturally favourable' femininities were presented by the participants during the interviews, and being with the participants in the salsa classes seemed to signal that I was a safe person to discuss this with, irrespective of who I was or might have represented outside of the class space. This 'levelling' effect of the salsa classes was again then part of what produced the spaces as 'safe'. As described in the previous section, the classes were temporary spaces where differences that might matter outside of the class did not hold sway; you could dance and talk easily with people that you might interact with differently outside of the class spaces.

Complicating Femininities

For these women, describing memories of the past and other significant people in their life histories worked to co-produce embodied and valued contemporary femininities. Ageing well meant ageing differently to their imagination of the ageing of others, such as their mothers, and differently to how they imagined themselves ageing if they had remained married or had not changed from their younger days. Although the participants often described not necessarily having role models of their own age to follow, they strongly spoke about who they did *not* want to be like. The joy experienced in the salsa classes made sense when they talked about how their lives had been beforehand. In addition, the concept of 'safety' that emerged so often, and seemed linked to maintaining boundaries around sexuality in order to be seen as 'respectable', was again reinforced by the ways in which they described the characters in their wider lives.

Complications emerged when participants went from describing who they were now, to what kind of relationships they desired, how to act in those relationships and how to attract those relationships. For example, although participants worked to distance themselves from the home and family-orientated lifestyles associated with their mothers, the durable marriages of their parents were often described as something they desired. Nearly all of the participants described their parents' relationship as long-lasting, reflected upon as an achievement that many of the participants idealised and aspired to. Maureen's parents for example had met when her mother was 24, and her father was 34, and had been married for 38 years until her father died;

> I never met two people more happy with each other than my parents. They were so in love … That's how I know it can happen because I've grown with my parents … He did everything for her, he, he lived his life for her. And, and um, she did everything for him. (Maureen; 50s)

Whilst their mothers' family-orientated lifestyles were described as undesirable, ironically the interdependency within the relationship between parents was often described very romantically.

Nostalgic recollections of the durable relationships of the past were another way of producing themselves as 'respectable' in their new or renewed place in social life as single women: they were not actively looking for sexual partners, and the appropriate place for their sexuality was in long-term, durable relationships. This complemented, complicated and put into context the concepts of respectability and safety that had arisen through participant observation and the discussions of the salsa class.

Another layer of complexity came when thinking through the kinds of women that they assumed men of their age would find attractive. The independence and confidence that they experienced as women in their 50s and 60s was very much valued among themselves, but understood as potentially incongruous with others' expectations. Divorced and single men of the same age were very often described as needy, emotionally scarred and dependent—and participants distanced themselves from these attributes as they had from the lifestyles of their mothers. Many participants were wary that their newly developed attributes would not be seen as attractive to men of their age. Laura and Rosie for example both reflected on having to negotiate their confidence and independence;

> I know who I am, I'm comfortable with who I am in my skin, a lot of people, men particularly they might be a bit intimidated by me because I'm quite strong, I dress well, and so they might be a bit more hesitant of actually approaching you. (Laura; 60s)
>
> I think that all of the men in the, in the world are frightened. Ok? Frightened by a, a very self-confident woman… They like them but at the same time … it is quite difficult to handle. (Rosie; 60s)

Whilst they talked about embodying contemporary modes of femininity, this was difficult to negotiate with potential new partners and it was tricky to know how to behave. Maureen for example, who described herself as independent and strong in her work life as a manager of an accountancy business, and presented herself in our meeting as confident and loud, described enacting a deliberate pretence of passivity and 'appearing stupid' whilst trying to attract men. In her narrative she directly associated this passivity with what she saw as a 'normal' femininity, despite it not being a 'normal' way of acting for her. This however had not been working for her and she described how a male friend had pointed out to her that not all men would find this attractive;

> … he commented, that I was being too feminine … he said because I'm being that feminine, I'm gonna actually lose some guys who are looking for an intelligent woman. So, it's a fine line between um, being feminine and then also appearing stupid. Coz the last, one of the aspects of femininity is, you don't have your own opinion, because someone else gives you your own opinion. That is an aspect of femininity… (Maureen; 50s)

Multiple ideas and expectations surrounding appropriate ways to act as single women in mid and later life then circulated at the same time, shaped by normative understandings of and expectations surrounding gender and age. When discussing the risks of intimate relationships, the discussions were about performing and embodying the 'right' kind of femininity. There was anxiety around causing offence if the wrong femininity was done during a date, and also trickiness in negotiating which understandings of femininity were seen to be attractive to potential partners. In the end, different femininities were practised and negotiated at the same time.

Discussion: What Counts as Wellness?

My intention during this ethnography on the intersections between ageing, gender and wellness was to step outside of formalised 'health spaces' and to delve into the messiness of everyday lived experiences. With a combination of participant observation with a focus on the sensory (movement and touch) and life histories, I sought to understand the experiences of women in their 50s and 60s looking for romantic partners. Participant observation in salsa classes produced partial knowledge of their contemporary contexts, the life histories provided depth to this context, and the data produced by both were intertwined and interrelated. Through my own embodied engagement with salsa classes, I could observe the embodied anxieties that were experienced by the participants as single women in midlife—and by some extent experience the anxiety of learning news ways of moving myself—all of which we went on to discuss in the interviews. Being in the classes alongside the participants 'levelled out' the social differences between us and gave us common ground on which we could base our discussions.

'Ageing well' discourses have been criticised for producing images of 'correct' ways to age, which are unattainable for most as they seem to translate into the imperative that one should not age at all (Marshall and Katz 2002). Yet, for the women I spoke to, age and getting older were significant and important factors in their wellbeing; with age they had learnt to put their own needs first, to maintain social activities for themselves and to be more confident than when they were younger. During life history interviews and participant observation, discussions surrounding what might 'count' as wellness in a bio-medically healthy way did not occur. The menopause, for example, was hardly mentioned in accounts of older women's lives and did not figure as a large transition event whilst looking back over the lifecourse. Their lives were not mapped out onto discrete lifestages determined by biological events. Rather, who they were today and what they wanted were discussed by producing different pasts—of their mothers' lives, of when they had been dating the first time round, and of their experiences whilst they had been married. Ageing well was therefore conceptualised as ageing differently; from their mothers and their past selves. Discussions of the lifecourse were based upon these stories, rather than on reproductive or sexual health transitions.

Despite anxiety in public health circles about this age group in terms of their 'increased sexual behaviour' and the risks associated with this (FPA 2010), these kinds of risks and risky behaviours were rarely discussed. Rather, the risks they encountered were to do with negotiating the right kind of femininity as appropriate for their age with different people. It was perceived as difficult and risky to negotiate newly found confidences and independence within relationships, and with male partners who might not find this attractive. Without role models to follow, it was also a challenging process to find suitable spaces to socialise and to (re)learn how to behave in these spaces. Wellness was being able to maintain respectability in new spaces as single women in midlife, and they did this in a multitude of ways; for example, by practising a 'safe sensuality' in the salsa classes, and by talking about desiring the durable, long-term relationships of their parents' in the interviews.

By going beyond binary understandings of complex issues, ethnography can reveal and make sense of the messiness of daily, lived experiences. Ethnography can allow an exploration of health and wellbeing that expands beyond specific illnesses and enables the situating of health in spaces outside those normally associated with health research, such as clinics and hospitals. Exploring beyond these normative discourses and spaces for health, health and wellness can take on new meanings that are inclusive of different people's experiences and how these shape and intersect with the lifecourse. What it means to be well changes over time and can change depending upon what you are talking about. In this study, being well or healthy only made sense alongside multiple understandings of what it was to be a woman of a specific age, and what it was to be a woman was only understood with reference to different pasts. Ethnography allows us to sidestep professional knowledges about the health and wellbeing of groups of people and allows space for the complexities and contradictions inherent in perceptions of ageing, gender and wellness to emerge—at a particular time in history, embedded within intricate personal histories.

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References

Adkins, L., & Skeggs, B. (2004). *Feminism After Bourdieu*. Oxford: Blackwell.

Blake, R. J. C. (2011, February). Ethnographies of touch and touching ethnographies: Some prospects for touch in anthropological enquiries. *Anthropology Matters, 13*(1). ISSN 1758-6453. [S.I.].

Bourdieu, P. (1990). *The Logic of Practice* (R. Nice, Trans.). Cambridge: Polity.

Calasanti, T., & King, N. (2005). Firming the floppy penis: Age, class, and gender relations in the lives of old men. *Men and Masculinities, 8*(1), 3–23.

Calasanti, T., & King, N. (2007). “Beware of the estrogen assault”: Ideals of old manhood in anti-aging advertisements. *Journal of Aging Studies, 21*(4), 357–368.

Classen, C. (1997). Foundations for an anthropology of the senses. *International Social Science Journal, 49*(153), 401–412.

Dolan, J., & Tincknell, E. (2012). *Aging Femininities: Troubling Representations*. Cambridge: Cambridge Scholars Publishing.

Drew, O. J. S. (2008). Sexually transmitted infections in the older woman. *Menopause International, 14,* 134–135.

Farquhar, J. (1994). Eating chinese medicine. *Cultural Anthropology, 9*(4), 471–497.

Farquhar, J. (2002). *Appetites: Food and Sex in Post-socialist China*. Durham: Duke University Press.

FPA. (2010). Sexual health week 2010: The middle aged spread. Professional Briefing. FPA.

Gott, C. M., Ahmed, I., McKee, K., Morgan, K., Riley, V., & Rogstad, K. (1998a). Characteristics of older patients attending genitourinary medicine clinics. *Health Care in Later Life, 3*, 252–257.

Gott, C. M., Rogstad, K. E., Riley, V., & Ahmed-Jusuf, I. (1998b). Delay in symptom presentation among a sample of older GUM clinic attenders. *International Journal of STD and AIDS, 10,* 43–46.

Howes, D. (2003). *Sensual Relations: Engaging the Senses in Culture and Social Theory*. Ann Arbor, MI: University of Michigan Press.

Illouz, E. (2013). *Cold Intimacies: The Making of Emotional Capitalism*. Oxford: Wiley.

Lamb, S. (2014). Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal of Aging Studies, 29,* 41–52.

Lovell, T. (2000). Thinking feminism with and against Bourdieu. *Feminist Theory, 1*(1), 11–32.

Marshall, B. L., & Katz, S. (2002). Forever functional: Sexual fitness and the ageing male body. *Body & Society, 8*(4), 43–70.

Meah, A., Hockey, J., & Robinson, V. (2011). I'm a sex kitten, aren't I …. *Australian Feminist Studies, 26*(67), 57–71.

Milton, S. (2017). 'Becoming more of myself': Safe sensuality, salsa and ageing. *European Journal of Women's Studies, 24*(2), 143–157.

Phoenix, C., & Sparkes, A. C. (2008). Athletic bodies and aging in context: The narrative construction of experienced and anticipated selves in time. *Journal of Aging Studies, 22*(3), 211–221.

Pink, S. (2007). *Doing Visual Ethnography*. London: Sage.

Potts, A., Gavey, N., Grace, V. M., & Vares, T. (2003). The downside of Viagra: Women's experiences and concerns. *Sociology of Health & Illness, 25*(7), 697–719.

Sandberg, L. (2011). *Getting Intimate: A Feminist Analysis of Old Age, Masculinity and Sexuality*. Linköping: Linköping University Electronic Press.

Twigg, J. (2010). How does vogue negotiate age?: Fashion, the body, and the older woman. *Fashion Theory: The Journal of Dress, Body & Culture, 14*(4), 471–490.

Vares, T. (2009). Reading the 'sexy oldie': Gender, age(ing) and embodiment. *Sexualities, 12*(4), 503–524.

Wacquant, L. J. (2004). *Body & Soul: Notebooks of an Apprentice Boxer*. New York: Oxford University Press.

Wade, L. (2011). The emancipatory promise of the habitus: Lindy hop, the body, and social change. *Ethnography, 12*(2), 224–246.

Weeks, J. (2009). The remaking of erotic and intimate life. *Politica y Sociedad, 46*(1 y 2), 13–25.

Williams, A., Ylänne, V., & Wadleigh, P. M. (2007). Selling the 'elixir of life': Images of the elderly in an Olivio advertising campaign. *Journal of Aging Studies, 21*(1), 1–21.

10

Caring with Others: Constructing a Good Life with Incurable Illness

Dikaios Sakellariou and Narelle Warren

Introduction

Ethnography provides an approach through which intersubjectivity—shared experiences and meaning-making—characteristic of and inherent in practices of care can be explored. Through prolonged and ongoing research encounters, ethnography facilitates an examination of how people care *with*, rather than simply *for*, each other. Such research relies upon a dialectical approach, one that both relies upon dialogue, and emphasises the negotiated processes, between people. In this chapter, we consider how a dialectical ethnographic lens can emphasise the affective and relational aspects of care, extending beyond the practical and instrumental dimensions of care. These are not readily discernible; instead, they demand close attention to the everyday interactions that comprise acts of 'care'.

D. Sakellariou (✉)
Cardiff University, Cardiff, UK
e-mail: SakellariouD@cardiff.ac.uk

N. Warren
Monash University, Melbourne, Australia
e-mail: narelle.warren@monash.edu

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This chapter brings together perspectives from an applied health care profession, occupational therapy, and medical anthropology to focus on what happens when different ideas about what comprises the desired 'good' life—a concept which may itself be produced by and simultaneously realised through care relationships—come in contact and need to interact with each other. In doing so, we draw upon Mattingly's (2014) work on the 'Moral Laboratories' of everyday life to emphasise how transformative moments are not the exception to everyday life, but rather are embedded within the micro-encounters and micro-practices that occur within care relationships. It is through such transformations that a 'worthwhile' life (itself determined intersubjectively) is sought. As we demonstrate below, having choice about what care practices to use, what technologies to allow into their life and the kind of care they need can turn people into active agents who have the power to effect change to achieve a desired outcome and thus move a little bit closer towards the construction of a good or, at the least, better life.

The links between medical anthropology and occupational therapy have been thoroughly explored (see, e.g., Block et al. 2008; Frank et al. 2010). Several publications attest to the convergences between the two fields of study (see, e.g., Mattingly 1994; Pollard and Sakellariou 2012; Thomas and Sakellariou 2018; Warren and Manderson 2008) and to the development of a politics of daily living approach (Pollard and Sakellariou 2012; Sakellariou and Pollard 2016). On the one hand, medical anthropology challenges occupational therapy to problematise notions of participation in daily life and how this can be realised across contexts (Leibing 2010). Thus, medical anthropology pushes occupational therapy to engage politically, especially in response to the effects of structural violence and vulnerabilities encountered by many of the populations with whom occupational therapists (OTs) work (Sakellariou and Pollard 2016). At the same time, occupational therapy offers inspiration and innovation to medical anthropology (Leibing 2010), opening up new spaces of enquiry and identifying sites through which the familiar can be interrogated critically. It asks medical anthropology to engage at a practical and applied level; in doing so, the medical anthropological inquiry is given structure, focus and a mechanism by which the theoretical and conceptual insights generated can be put into practice.

Both disciplines are concerned with subjectivities of experience. Of specific interest here is the focus of both disciplines on observing daily life through an ethnographic or a clinical gaze; the two disciplines share an interest in the seemingly mundane yet important minutiae of actions, interactions and reactions that fill the spaces between people. Through our dialectical lens in this chapter, we provide concrete examples of ways in which the two disciplines cohere and how they can both inform an ethnography sensitive to the intersubjectivity inherent in practices of care. Examining discrete acts of care and how these can lead to the creation of an inhabitable world touches upon questions of central importance in both disciplines: How do people live with illness? How are practices of care negotiated, encountered and performed between people? The examples presented below speak to these issues and offer our own answers to these questions.

A Good, or Better, Life

Ideas of a 'good life' are central to the research we discuss in this chapter. Bodily contexts of disablement themselves shape what a good life looks life, and for whom. For health professionals, people living with and caring for those with illness, and the community at large, the good life (often discussed in terms of 'quality of life') is conflated with good health and the absence of both disease and disability (Warren and Manderson 2013). For those living without disability, *the* good life often involves a type of bodily stasis untouched by disablement or illness; in contrast, *a* good life—one which involves happiness, joy and quality—is both available and readily realisable for those living with chronicity.

The assumptions underlying this 'disability paradox' (Albrecht and Devlieger 1999) extend to care relationships, both formal and informal. Biomedicine promotes the belief that access to a good life has its locus in the clinic: by following prescribed management pathways, a life of quality and meaning can be achieved. In contrast, through ethnography, occupational therapy and medical anthropology attend to the intersubjective construction of the good life. Both disciplines highlight the complexity of human experience, including structural vulnerabilities and the precarities of life, which themselves shape practices of care. Happiness, or at least the alleviation of suffering, may be an implicit goal of such care practices, in which the carer and the caree work together to find strategies to alleviate the social impacts of illness (as described by Warren and Ayton 2015).

The process of health care is not about always finding solutions. After all, there might not be any solutions available. Instead, it is about understanding and negotiating the positions of everybody involved (Mol 2008). This understanding is achieved little by little, through synthesising the different voices and making sense of the intersubjective (shared) and heteroglossic (diverse) worlds of illness (Good 1994). In terms of the latter, health professionals may—and often do—have very different perspectives on informal care than the carers and carees themselves: it behoves occupational therapy to attend to such heteroglossia, precisely because multiple understandings of care can lead to different effects and affects. Disability, illness, chronicity and care are all terms that are understood in different ways by the different people involved: patients, their partners and family, carers, health care professionals all have their own ideas about what needs to be done, what is 'best', both as a process and as an outcome (Good 1994; Sakellariou 2016).

Below, we explore how the two disciplines can inform the construction of dialectic ethnographic data collection methods, such as joint or couple interviews, or observations, which attend to the multitude of micro-encounters that occur between people. We use data from two empirical studies, collected in two countries (UK and Australia), which are both centred on practices of care for neurodegenerative diseases (Motor Neurone Disease and Parkinson's disease), to highlight how people, together, can reach an understanding, or not, of what is desirable and good, and what needs to be avoided. In doing this, we speak to literature from medical anthropology, occupational therapy and also disability studies, with an explicit focus on understanding how people live with a disability and create an 'inhabitable world' (Friedner and Cohen 2015).

Background

The Empirical Studies

The data used in this chapter are drawn from two narrative-based ethnographies: one conducted with 4 couples in Wales between 2011 and 2013 exploring experiences of Motor Neurone Disease (MND), and the second study on Parkinson's disease conducted with 51 couples in Australia between 2012 and 2015 (full descriptions of the two studies can be found in Sakellariou 2015a, b, c; 2016; Warren and Manderson 2015; Warren and Ayton 2018). Each study was initiated from different disciplinary backgrounds—occupational therapy in the case of the MND study and medical anthropology for the Parkinson's study—yet employed similar research methodologies, undertook similar modes of analysis and generated compatible—or at least complementary—research findings, as we demonstrate below. Both studies also started with a narrative concern about how people do the best they can—with the personal, social, economic and other resources available to them—to make sense of, and find meaning in, their experiences of a profoundly disruptive health event (Riessman 2001).

In this chapter, we aim to discuss the development of dialectic ethnographic methods with people living with neurodegenerative diseases and their partners. Our primary method was participant observation, whereby we spent extended periods of time with participants, sitting and talking in their homes, observing as they went about their daily lives and 'helping out' wherever possible. Anthropological methods involved activities of daily life and therefore the very activities that concern occupational therapy, such as sharing a cup of coffee or food, which often provided the opportunity for extensive narration. Observations were not only focused on each individual actor, but also concerned with intersubjective experience and the interactions between participants. By focusing on practices of care and exploring how these couples tried to construct an inhabitable world they were satisfied with—that is a good life—we highlight how each person involved in relationships of care enacted subjectivity.

Neurodegenerative conditions offer especially important insights into subjectivities of care: bodily capacity and functioning become increasingly constrained as the condition progresses. As degeneration occurs, practices of care become reflexive, adapted and consciously enacted. Due to their differing disease courses, the two conditions are accompanied by variable timelines, thus prompting differences in the both timing and nature of renegotiations of practices of care. MND often affects people over 50 years of age, and its average duration, from diagnosis to death, is between 3 and 5 years, although this can vary between people and different disease subtypes. In contrast, Parkinson's typically affects people in mid- to late-life, characterised by tremor and bradykinesia (difficulty in initiating—akinesia—or maintaining and executing movement), and has an average duration of 10 years, with considerable variability in life expectancy (Marttila and Rinne 1991). With both conditions, disease progression is accompanied by greater need for personal and functional care.

Scene 1: The Percutaneous Endoscopic Gastrostomy (PEG)

A PEG, a tube surgically inserted through the abdominal wall into the stomach to enable feeding of a person who experiences difficulties in eating or swallowing, is a process that produces a 'fusion of the technological and organic' (Manderson 2011: 58), leading to the reclaiming of lost function (nutrition in the case of the PEG), but can also act to highlight 'the departure of the individual from normatively able bodies' (Manderson 2011: 86). A PEG signifies a radical change of what bodies are supposed to look like and can make people feel subjected to medical technology: the act of ingesting food itself is transformed, bypassing the usual site of consumption (the head or, more specifically, the mouth) and the act of eating altogether. Social activities such as cooking or sharing meals with a partner can be affected although, as Pols and Limburg (2016) note, this varies idiosyncratically depending on individual tastes.

In the following excerpt, Dafydd described how Siobhan, his wife, who had been living with MND for several years, started eating again after receiving nutrition exclusively through percutaneous endoscopic gastrostomy (PEG) for several years:

> Now she started to eat again. She can't eat meat, but she can eat almost anything else. I am having dinner, she wants a bit of it all the time, you know. So, she eats pasta. I was doing a poached egg with cheese in it, mash it up, she eats that. Mashed potatoes, she would eat that. Anything, like. Yesterday we had cream cake, she had that [Siobhan laughs] and then she had my half of it. [more laughter]

The story above was narrated by Dafydd, but Siobhan actively participated in it by nodding acceptance and by laughing, sharing emotion and confirmation of the story relayed by her husband, while she was taking a rest from typing on her lightwriter. This narration by Dafydd, enriched by Siobhan's participation, offered a glimpse of a daily experience shared between the couple: Siobhan and Dafydd had not been able to share a meal for a long time, during which she was fed exclusively through a PEG.

Scene 2: Living for Now or Anticipating the Future?

In the context of illness, multiple discourses exist: official and vernacular, explicit and implicit, scientific and narrative and so forth. It is important to listen to the voices of people living with illness and their partners because people experience living with illness in different ways. The standpoint and perspectives of people living with an illness and their partners do not always coincide; indeed, they may be radically divergent. Sometimes they experience illness in different ways because their roles are different. The use of joint interviews allows for these different perspectives and voices to be heard (Bjørnholt and Farstad 2012), as illustrated by Gareth (person with MND) and his partner, Agnes:

Agnes (A): But the storytelling group, I think you are coming to a stage where it is harder and harder for you to go to the storytelling group, haven't you.
Gareth (G): No. I enjoy going to it, I just have to be careful. Can't go to any venues where there are steps.
A: Yes, it's getting more difficult. There will come a stage when you won't be able to go to the storytelling group.
G: As far as there are no steps.
A: Yes, I know that, but there will come a stage when you can't walk at all.
G: Yes, but I can sit in a chair, so I don't have to.
A: Yes, but I will still have to get you in and out of the car, Gareth.
G: Alright, yes.
A: It isn't going to be that straightforward, is it?
G: I don't know, I can't tell.
A: So, we don't know, but he does enjoy it.
G: Yes.

In the excerpt above, Agnes and Gareth are discussing Gareth's involvement in a storytelling group (a group of community members who gather together and narrate stories). Agnes anticipated future difficulties and was reluctant to make any plans, but Gareth focused more on his present experiences. They both expressed the different ways they made sense of living with an illness but, at the end, arrived at a shared understanding that they did not really know how the disease would progress and whether Gareth would be able to still participate in the storytelling group in the future.

Scene 3: Trying to Stand in Another's Shoes

Despite different roles and thus perception of the effects of illness of people living with illness compared to their family carers, what is central to these narratives are the shared themes of acceptance and collaboration. Daffyd's experience of the social act of consuming is enhanced through Siobhan's presence and more recent participation through eating; Agnes and Gareth similarly highlighted the shared enterprise of care. In both examples, practices of *giving* care were secondary to the affective practices of care, although the two types of care practices are almost impossible to separate in reality: these two cases illustrate the strong interrelationship between the instrumental acts 'caring for' another and the relational, agentic and emotive experience of 'caring about' a loved other (Manderson and Warren 2013). Indeed, it is because of the latter form of care that considerable compromises can be made in achieving the former and comments such as Gail's were common:

> Because [Stan, her husband, who had Parkinson's] is such a nice person, he wouldn't have an enemy in the world… He doesn't deserve what he's got.

Gail explained how she'd gone to considerable efforts in order to achieve their ideal of a good life. They'd moved into a residential community (for older people) so that Stan could still participate socially after the loss of driver's licence left him isolated in the suburbs. Ethnographic narratives can allow the elucidation of social aspects of illness, particularly the nuanced challenges that may present themselves when people go through such life changes:

> Gail: It is a big change, yeah, massive… And just things that I've had to learn to do around the house like change light globes and things like that. I've never have done that and now that we're in this new place, hanging pictures on the wall and yeah, things that, because I'm not good at heights either. Things that I would never have done… You know, he was always my rock. He did everything that I wanted done. It's just yeah, I relied on him for everything.
>
> Interviewer: So what impact has this had on your relationship then now that you kind of had to step up and do some of the jobs that he was doing?

> Gail: I don't think it's destroyed it in any way. He gets frustrated and he feels devalued because he can't do those things but I just cuddle him and tell him, "If it was the other way around you'd be doing things for me." That's what we promised when we got married, for better or worse. He accepts it but he doesn't like to watch me do it… I think he's proud that I've learned to do these things but he'd rather that I didn't have to.

Important within Gail's narrative was the idea of a shared goal, and this was reflected in the interview 'performance' itself: Stan was unable to contribute verbally due to dysarthria. Instead, he contributed to the interview non-verbally, nodding at Gail's comments or interjecting in his very weak voice when clarification was needed:

> Gail: As I said I don't begrudge it. I just don't think it's fair to him, because he's too nice a man to have that happen to him. He doesn't deserve it. I don't begrudge any time I spend with him, although I get cranky sometimes, don't I?
> Stan: Yep.

Through narrative ethnographies, ideas of a good life are not only performed, negotiated and conveyed, but also studied and become known. Language and its deployment between partners in the care relationship were central to this.

Scene 4: Negotiating Care

Study participants who were also carers sometimes had to accept loss of control, and the people with MND or Parkinson's sometimes had to exercise control. Despite her husband George's relatively advanced stage of Parkinson's, Marge found that their relationship, and her life, was much easier when she allowed him to make decisions about the structure of their everyday lives:

> [He] probably gets terribly frustrated, because there's a lot of things he can't do anymore. But if he makes up his mind, he can do what he wants to do.

For Marge, relinquishing control over the structure of their everyday lives and of her involvement in community groups—giving over a degree of control to George—was important to maintain a level of calm within the household. While she had understood care to be something that she *gave* to George, this was not possible given her own health problems (osteoarthritis) and the behavioural problems associated with his Parkinson's unless she was willing to accept a high level of conflict within the household. Practices of care for Marge thus involved managing the environment within and around the home, only providing sporadic hands-on personal care when George experienced a fall or forgot his medication.

As evident in Marge's example, the way people make sense of their life influences their needs, their choice of services and the way they negotiate their illness. Individuals, their families and friends and health care professionals have their own ideas of how life is to be lived, what needs to be done, how and why. They create what Kleinman (1988) called the different personal and interpersonal meanings of the disease and of life with it. These different perspectives are in constant negotiation in the context of daily life with everybody involved in a dynamic dialogue, trying to establish a common ground for understanding what is good and what has to be avoided. This is important for care practices as these are performed at home, often by a partner. As Karasaki and colleagues (2017) illustrate, such practices may be carefully orchestrated so as to achieve particular, and often strategic, goals. Reflecting on the example above, in actively choosing to step back from a hands-on type of care, Marge evoked an alternative suite of care practices, which required extensive interpersonal negotiation: with George, with their children, and with health professionals. Recognition of these and other similar practices are only accessible through the prolonged and intimate engagement with the lifeworlds of participants that is offered through ethnography.

The Heteroglossic Nature of Chronicity

Letiche (2008) referred to care as being in-between or being two. It cannot be defined by a single process but is always situation-bound and depends on who delivers it and who receives it; in effect, the meaning of care is co-constructed by the people who are involved in it. It is therefore *necessarily* intersubjective: care and acts of caring are not unidirectional; instead, they flow from people's understandings of reciprocity in kinship relationships (Manderson and Warren 2013) and are subject to fluctuations over time.

Practices of care also involve the enabling of processes through which the person not only survives, but also can move towards the construction of an inhabitable world. Making choices about what interventions to use, what technologies to allow into their life, the locus of care, and the kind of care they need can turn people into actors—active agents who have the power to make some changes to achieve a desired good outcome and thus move a little bit closer towards the construction of a good, or better, life. However, people living with ongoing illness or disability and people who engage in practices of care with them (e.g. partners, friends, paid carers) often focus on different issues when considering care and may use different systems of knowledge to make sense of the situation and thereby decisions for making things better.

Of consideration when discussing care, heteroglossia refers to the presence of 'another's speech in another's language' (Bakhtin 1995: 115). In the case of illness, the presence of multiple perspectives constitutes a heteroglossic world comprising the voices of people living with an illness and the voices of the health care providers, but also those of family, friends, work colleagues and other social actors. These multiple discourses are interconnected and are grounded in the diverse cultural discourses operative in every society. In an analogy with the textual construction of a novel in which heroes are situated in interactions initiated by the author and act within preset boundaries, social actors operate within an inescapable dominant cultural discourse. These multiple 'languages', the diverse perspectives of the various actors together with the scripts, beliefs and attitudes present in society comprise the social whole that frames human action. The different ways people talk and thereby represent the world around them is informative of their lived realities (Bakhtin 1995; Good 1994).

This presents a challenge for joint interviews: whose voice, and therefore, whose perspective is given priority? Is one person being silenced and, if so, who and in what ways? Joint interviews themselves allow for a real-time evidencing of intersubjectivity in action, as people (often spouses) work together to construct a shared account, while simultaneously preserving their own individual perspectives. Reflecting on the four scenes presented above, our contention is that while perspectives around what constitutes a good life vary to some degree between different people engaged in practices of care, what a good life looks like is negotiated through care relationships. While this is explicit in doctor–patient relationships, whereby the 'patient' uses biomedical language to explain their illness or status, it occurs in more subtle ways in care relationships. One partner draws upon the language of another to convey this shared understanding and, where the active contribution of the person with illness is not possible, they may act as an interlocutor, translating the unspoken into a form that can be conveyed to the ethnographer. Hydén (2011), for example, describes how caregivers provide the framework—which he terms 'scaffolding'—for people living with dementia to engage in activities of daily living and, sometimes, to communicate their own stories. A form of heteroglossia is central to this process of narrative scaffolding.

Towards a Dialectic Ethnography

The exploration of chronicity and how it is negotiated in people's own local worlds requires attention to a nexus of several, sometimes conflicting, stories. What, for example, can be seen as a good outcome, especially in the case of incurable or terminal conditions, can be very contested. Priorities, even within couples, can be diverging as the perspectives of people are different. The way the anticipated good is understood and mobilised in people's daily practices is directly related to practices of care and the intended, or desired, outcomes.

It is, therefore, important to develop methodologies that are sensitive to the heteroglossic nature of chronicity, allowing an exploration of diverging and conflicting perspectives. A dialectic ethnography seeks to include these multiple perspectives. Points of tension become the focus of critical analysis of the accounts, producing new understandings of life with illness. At the same time, these also act to elucidate the complexity of care practices, which themselves shape ideas of the good life.

For the participants in our studies, the constant negotiation between needs and desires produced a way of living in which subjectivity was not a given but had to be negotiated on a daily basis. Anthropological understandings on the emergence of subjectivity and on the importance of desires in the construction of a good life could be enriched by a closer examination of the interaction between different perspectives about the desired good outcomes in care practices. Such examination calls for an ethnography that is sensitive to the fluidity and contextual nature of people's desires and also sensitive to the inherent heteroglossic nature of illness.

The creation of an inhabitable world, one that a person can call home, is not an abstract process but one grounded in concrete acts of care. These, just like the every day in general, can often be taken for granted, remaining invisible. Knowledge of the every day is therefore also often implicit; we assume we know how people live behind closed doors, how they carry out activities such as eating or going to the bathroom and what these signify in their lives.

Das (2014) highlights the importance of acts that might often appear to be mundane for the creation of a way of living. What acts are important depends on the context. A focus on how people negotiate the creation of inhabitable worlds can enrich anthropological understandings of the enactment of subjectivity, and the ways people create a place of care and belonging to build a home in the world. Such focus can also help illuminate the different world views that people enact. Whether having a PEG, for example, is a good or a bad decision is ultimately a decision about what one's inhabitable world should look like.

The issue then is, how to explore the different care practices that people put together, often on an improvised and experimental way, to construct that elusive good life. Deleuze (1997) argued that we need to explore how people live, here and now, in their specific worlds. In other words, the strategies that people use to make sense of their life: their desires, needs and the means they have to pursue these. Such an approach makes space for alternatives, which focus not only on what is but also on what could be (Biehl and Locke 2010). This is especially relevant in ethnographies of disability and chronicity. Living with chronicity is shaped by different assemblages of economic, cultural, emotional and medical milieux, which make some potentialities possible and others beyond one's reach. Ethnography can highlight not only what can be, but also that which can no longer be; it can focus not only on care, but also on disregard (see Biehl 2012), or *un-care*, and on everything that comes in between the two.

Ethnographies focusing on how people living with ongoing illness or disability work towards the construction of a desired life provide valuable insights into several important anthropological questions, such as: What are the constitutive elements of a 'good' life and what practices contribute to this understanding? How can different world views best inform each other to construct a good life? What happens when 'the normative becomes subject to experiment' (Mattingly 2013: 322) and everyday previously taken-for-granted processes, such as eating or walking, need to be modified? And how can we, as researchers, be sensitive to what remains unspoken? Our case studies illustrate that a good life is created through people collaborating and negotiating actions and decisions towards an unknown and often unpredictable future. These negotiations are highly contextualised. Future research focused on how different perspectives interact to determine the desired good outcomes, and the means by which these can be achieved across structural, interpersonal and bodily contexts, would enrich understandings of the enactment of care. It is only through an ethnography sensitive to the fluidity of people's desires, while simultaneously responsive to the inherent heteroglossic nature of illness, that such an examination can meaningfully be achieved.

References

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science and Medicine, 48*(8), 977–988.

Bakhtin, M. (1995). The heteroglot novel. In P. Morris (Ed.), *The Bakhtin Reader; Selected Writings of Bakhtin, Medvedev, Voloshinov* (pp. 112–122). London, UK: Arnold.

Biehl, J. (2012). Care and disregard. In D. Fassin (Ed.), *A Companion to Moral Anthropology* (1st ed., pp. 242–263). Oxford: Wiley.

Biehl, J., & Locke, P. (2010). Deleuze and the anthropology of becoming. *Current Anthropology, 51*(3), 317–351.

Bjørnholt, M., & Farstad, G. (2012). 'Am I rambling?' on the advantages of interviewing couples together. *Qualitative Research* (early online). https://doi.org/10.1177/1468794112459671.

Block, P., Frank., G., & Zemke, R. (Eds.). (2008). Anthropology, occupational therapy, and disability studies: Collaborations and prospects, special theme issue. *Practicing Anthropology, 30*(3), 2–5.

Das, V. (2014). Action, expression, and everyday life: Recounting household events. In V. Das, M. Jackson, A. Kleinman, & B. Singh Durham (Eds.), *The Ground Between; Anthropologists Engage Philosophy* (pp. 279–306). Durham, NC: Duke University Press.

Deleuze, G. (1997). *Essays Critical and Clinical*. Minneapolis: University of Minnesota Press.

Frank, G., Baum, C., & Law, M. (2010). Chronic conditions, health, and well-being in global contexts: Occupational therapy in conversation with critical medical anthropology. In L. Manderson & C. Smith-Morris (Eds.), *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness* (pp. 230–246). New Brunswick, NJ: Rutgers University Press.

Friedner, M., & Cohen, E. (2015). Inhabitable worlds: Troubling disability, debility, and ability narratives. *Somatosphere, 4*. Accessed at http://somatosphere.net/2015/04/inhabitable-worlds-troubling-disability-debility-and-ability-narratives.html.

Good, B. (1994). *Medicine, Rationality and Experience*. Cambridge, UK: Cambridge University Press.

Hydén, L. C. (2011). Narrative collaboration and scaffolding in dementia. *Journal of Aging Studies, 25*, 339–347.

Karasaki, M., Warren, N., & Manderson, L. (2017). Orchestrating home: Experiences of spousal stroke care. *Medicine Anthropology Theory*. https://doi.org/10.17157/mat.4.1.366.

Kleinman, A. (1988). *The Illness Narratives*. New York: Basic Books.

Leibing, A. (2010). Looking over the neighbor's fence: Occupational therapy as an inspiration for (medical) anthropology. *Ethos, 38*(2), 1–8.

Letiche, H. (2008). *Making Healthcare Care*. Charlotte, NC: IAP.

Manderson, L. (2011). *Surface Tensions: Surgery, Bodily Boundaries, and the Social Self*. Walnut Creek, CA: Left Coast Press.

Manderson, L., & Warren, N. (2013). 'Caring for' and 'caring about': Embedded interdependence and quality of life. In N. Warren & L. Manderson (Eds.), *Reframing Disability and Quality of Life: A Global Perspective* (pp. 179–194). Dordrecht: Springer.

Marrtila, R. J., & Rinne, U. K. (1991). Progression and survival in Parkinson's disease. *Acta Neurologica Scandinavica. Supplementum, 136*, 24–28.

Mattingly, C. (1994). The concept of therapeutic 'emplotment'. *Social Science and Medicine, 38*(6), 811–822.

Mattingly, C. (2013). Moral selves and moral scenes: Narrative experiments in everyday life. *Ethnos, 78*, 301–327.

Mattingly, C. (2014). *Moral Laboratories: Family Peril and the Struggle for a Good Life*. Oakland: University of California Press.

Mol, A. (2008). *The Logic of Care; Health and the Problem of Patient Choice*. London: Routledge.

Pollard, N., & Sakellariou, D. (2012). *Politics of Occupation-Centred Practice*. London: Wiley-Blackwell.

Pols, J., & Limburg, S. (2016). A matter of taste? Quality of life in day-to-day living with ALS and a feeding tube. *Culture, Medicine and Psychiatry, 40*(3), 361–382.

Riessman, C. K. (2001). Analysis of personal narratives. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of Interview Research: Context and Method* (pp. 695–710). London: Sage.

Sakellariou, D. (2015a). Home modifications and ways of living well. *Medical Anthropology, 34*(5), 456–469.

Sakellariou, D. (2015b). Towards the construction of a nicer life: Subjectivity and the logic of choice. *Anthropology in Action, 22*(1), 46–53.

Sakellariou, D. (2015c). Creating in/abilities for eating. Retrieved October 3, 2015, from Somatosphere Web site: http://somatosphere.net/2015/06/creating-inabilities-for-eating.html.

Sakellariou, D. (2016). Enacting varieties of subjectivity through practices of care: A story of living with Motor Neuron Disease. *Qualitative Health Research, 26*(14), 1902–1910.

Sakellariou, D., & Pollard, N. (2016). *Occupational Therapies Without Borders: Integrating Justice with Practice*. Oxford: Elsevier.

Thomas, G., & Sakellariou, D. (2018). *Disability, Normalcy, and the Everyday*. Oxford: Routledge.

Warren, N., & Ayton, D. (2015). Loneliness as social suffering: Social participation, quality of life, and chronic stroke. In R. M. Anderson (Ed.), *World Suffering and Quality of Life* (pp. 159–170). Dordrecht: Springer.

Warren, N., & Ayton, D. (2018). (Re)negotiating normal every day: Phenomenological uncertainty in Parkinson's disease. In G. Thomas & D. Sakellariou (Eds.), *Disability, Normalcy, and the Everyday*. Oxford: Routledge.

Warren, N., & Manderson, L. (2008). Constructing hope: Dis/continuity and the narrative construction of recovery in the rehabilitation unit. *Journal of Contemporary Ethnography, 37*(2), 180–201.

Warren, N., & Manderson, L. (2013). Reframing disability and quality of life: Contextual nuances. In N. Warren & L. Manderson (Eds.), *Reframing Disability and Quality of Life: A Global Perspective* (pp. 1–16). Dordrecht: Springer.

Warren, N., & Manderson, L. (2015). Credibility and the inexplicable: Parkinson's disease and assumed diagnosis in contemporary Australia. In C. Smith-Morris (Ed.), *Diagnostic Controversy: Cultural Perspectives on Competing Knowledge in Healthcare* (pp. 127–146). New York: Routledge.

11

'What Sort of Jumper Is that, Your Wife Has Terrible Taste Mate'. Exploring the Importance of Positionality Within Ethnographic Research Conducted Alongside a Public Health Programme in Three Scottish Prisons

Matthew Maycock

Introduction

Ethnography has made important contributions to both public health (Bandyopadhyay 2011; Prentice 2010; Savage 2000) and prison focused research (Drake et al. 2015). In relation to prison-focused research, ethnographic methods are becoming increasingly utilised, despite context-specific limitations. The prison ethnography literature raises important questions relating to the extent to which ethnographic methods (and associated epistemological underpinnings) have the potential to illuminate what is often a hidden and difficult to access social context (Drake et al. 2015). Such questions as they relate to public health within prisons are reflected on in this chapter, describing a research project exploring the experience of a public health intervention delivered in a number of prison gyms.

M. Maycock (✉)
Scottish Prison Service, Edinburgh, Scotland, UK

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In this chapter, I explore the possible contribution that ethnography can make to public health research within prison contexts, an area not explored in any significant depth previously within the field of public health. There is an emerging body of literature that explores the negative health consequences for those who go to prison. This includes research that indicates limited opportunities for prisoners to eat healthily and participate in physical activity, resulting in a higher prevalence of overweight/obesity amongst male prisoners (Gates and Bradford 2015; Herbert et al. 2012). In order to explore these issues, I focus on the ways in which my positionality, as an ethnographic researcher,[1] evolved through, and influenced, the evaluation of a prison public health intervention, Fit for LIFE. Ethnographic methods were employed to understand participant and delivery staff experiences of the Fit for LIFE programme. This chapter will argue that ethnographic methods and analysis can create a context in which to consider the implications of positionality shaped by relationships developed within prison research. A number of challenges to undertaking research as an ethnographer in this context will be examined, including being viewed as part of the criminal justice system which prompted reflections on the implications of being a 'stranger' or 'outsider'. This chapter will explore the contribution that the reflections inherent to an ethnographic approach can make to prison ethnography and to wider debates on promoting public health within prisons.

Ethnographic methods and analysis were incorporated into a public health evaluation study to explore the development and early deliveries of Fit for LIFE, a healthy weight loss programme for male prisoners within three Scottish prisons. The aims of the ethnographic research as part of this study were to facilitate a deeper understanding of the prison context, in order to facilitate better insight into how the successes and

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[1] Prior to starting this post doc research, I undertook a year of ethnographic fieldwork as part of my Ph.D. in far-west Nepal. My Ph.D. research focused on performances of gender in a group of recently freed bonded-labourers. This period of research allowed me to hone my participant observation skills and reflect on the importance of positionality in influencing the sort of data I was able to collect (Maycock, M. (2018). *Masculinity and Modern Slavery in South Asia* (forthcoming). London: Routledge).

failures of the intervention were shaped by the context in which it was delivered. Undertaking ethnographic research as part of a multidisciplinary team of public health researchers posed a range of methodological, ethical implications. In particular, I consider the ways in which my positionality (Madison 2005) as an ethnographic researcher in this context determined the sorts of data I was able to collect to evaluate the Fit for LIFE programme.

For Madison, reflecting on positionality includes a focus on power and the way that power operates within and around the researcher's relationship with research subjects:

> Positionality is vital because it forces us to acknowledge our own power, privilege, and biases just as we are denouncing the power structures that surround our subjects. (Madison 2005: 7)

Within the context of this chapter, positionality will be considered in relation to the way power and authority functioned within the prison context, and the ways in which I was located as part of these power structures. I also consider the importance of clothing, posture and other embodied aspects of positionality. Prisons pose particular challenges as research contexts, given complex ethical issues, relating, for example, to the limits of informed consent (Schlosser 2008; Ward and Willis 2010) and the fact that many of those living in prisons have mental health and substance misuse issues (Singleton et al. 2003).

Methodological debates specifically relating to researcher and prisoner positionality have been considered within prison research (cf. Genders and Player 1995; Bosworth and Carrabine 2001; Liebling 2001; Phillips and Earle 2010) and ethnographic studies of prisons (cf. Crewe 2009; Drake et al. 2015). For example, Earle and Phillips (2012) consider the possible limitations of ethnographic prison research in terms of accounting for the aspects of prison life that are closed off and unavailable to ethnographic researchers. Such methodological and ethical issues raise questions about the boundaries of ethnographic enquiry and 'field' within prison contexts, and how the position of the ethnographer shapes the kinds of knowledge that can be produced about, for example, a prison-based public health programme.

The Fit for LIFE Programme

Fit for LIFE is a gender-sensitised public health programme, originally based on the Football Fans in Training (FFIT) intervention (Hunt et al. 2014), but substantially changed over a developmental period to take account of the prison context. Fit for LIFE is a ten-week, group-based, health promotion programme that utilises a range of behaviour change techniques to increase the use of prison sports/gymnasium facilities,[2] amongst men who were not previously using the sports facilities or interacting with the physical education instructors (PEIs) employed within the prison. The programme, which has been especially adapted for male prisoners, promotes increased physical activity, decreases in sedentary time and improvements in well-being and other aspects of lifestyle. Ethical approval was obtained from relevant Scottish Prison Service, NHS[3] and university ethics boards. In this chapter, names are not used to protect the anonymity of those who took part; participants are referred to only by a pseudonym. As issues of coercion and consent within prison research are particularly complex (cf. McDermott 2013; Moser et al. 2004), every effort was made to stress to participants that they should only take part in the research with full informed consent, and to ensure that they understood that they could withdraw at any time and only need to answer questions that they wished to respond to.

Ethnographic Approach and Positionality

The ethnographic underpinning of this research is informed by a focus on observing everyday life (Hammersley and Atkinson 1983), in this instance within prison (Drake et al. 2015). Given the specific power

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[2] The term 'gymnasium' is used throughout because it was the term which prisoners and staff used to describe multiple spaces, including the weights/cardio room, sports hall and changing room.

[3] This project was approved by the West of Scotland NHS Research Ethics Committee—13/WS/0218.

dynamics within prisons (cf. Crewe 2011; Foucault 1979), this chapter explores the ways in which power functions within the research process in prisons, through examining the importance of positionality. Ethnographic methods, specifically participant observation and interviews (cf. Madison 2005; Spradley 2016), were integrated into aspects of the evaluation research focused on the delivery and iterative development of the Fit for LIFE programme to understand the ways in which the prison context shaped outcomes of the programme. I undertook a range of participant observation activities that generated ethnographic knowledge relating not only to the programme, but also to the aspects of prison life more widely. During the fieldwork, I spent expensive periods of time with prisoners participating within the Fit for LIFE programme, working out and playing sport with them. I also spent time with staff in staff common rooms and in non-sport-specific spaces within the prison. Interviews exploring themes emerging from the observations were conducted with many of the prisoners and staff who took part in or delivered the programme.

Within the context of research on the delivery of the Fit for LIFE programme, the approach I adopted as the main fieldwork on the study was initially 'observer participant'. Participant observation is one of the preeminent methods utilised within ethnography (Atkinson and Hammersley 1994; Spradley 2016), but the term covers a variety of different types of relationship between the ethnographer and study context. For me, being an 'observer participant' reflected my being situated close to the group of participants[4] but not always actively participating within Fit for LIFE programme. Latterly, my position evolved and became closer to 'participant observer' because over time I began taking part in many of the sporting and exercise components of the programme. Yet, these methods were limited in terms of their level of immersion, due to the obvious constraints of a prison context and the

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[4] I refer to the men who took part in the Fit for LIFE programme as participants and not prisoners throughout this paper and the wider research project. This is due to the different underpinning in relation to agency that the term participant entails.

fact that the focus of the research was the gymnasium in each prison; a space where most prisoners spend relatively little of their time.

Through this transition to participant observation, I in some senses transitioned from an 'Outsider' to a 'Stranger' (following Simmel 1971). Initially, I was neither a participant nor a member of staff, although I was perceived by both prisoners and prison staff as being closer to the staff and this had profound implications for the sorts of insights and relationships I was able to develop with participants. Throughout these changes, the clothing I wore was a key influence determining my perceived position in a context in which uniforms (worn by both prisoners and staff) were the norm. These themes will be developed in more detail below as I discuss further my positioning as a part of the ethnographic research. I will highlight the implications for generating insights not only for the Fit for LIFE programme but also for understanding the wider currents of the 'everyday' within prisons and how to promote health in this context.

Multiple Perspectives on My Positionality

The sections below outline the evolution in the ways I was perceived by programme participants and my reflections on this. Firstly, I examine the implications of clothing within and how I was initially perceived, and then, I look at the connections and disconnections I had with programme participants. I consider the implications of being seen like a prison officer for the data I was able to collect about the programme. I draw on fieldnotes which were written for reflection on the context of the study, typically during and after session deliveries and various prison visits. I also draw on data generated through interviews with programme participants, which were conducted after the end of the programme. These usually took place in the prison gymnasia, although a number took place in participants' cells or in interview rooms in residential halls. Without the integration of the methods, as part of an ethnographic approach, the evaluation of the Fit for LIFE programme would not have been able to consider how my positionality as a researcher influenced the data collected, or how the prison context shaped the experiences of taking part in Fit for LIFE.

Entering the 'Field' and First Impressions

At the start of the deliveries of each of the various phases of the Fit for LIFE programme, I consistently tried to make it clear to participants that I was a researcher from Glasgow University. However, I found this more challenging over time, as it required going over the same ground when the group dynamics amongst participants—as a function of the behaviour change model of the health promotion programme—were evolving rapidly. I also stated, accurately at the time of conducting interviews as part of the Fit for LIFE evaluation and development, that I was not involved with the criminal justice system and had not been into prison prior to being employed on this research project. I consistently tried to make it clear that I was interested in participant and staff experiences of the programme. However, in post-programme interviews it became clear that these messages had not been *received* consistently. For, example, John[5] thought I was part of the prison coaching team delivering the programme:

> Aye, my first impressions, I thought you were coming tae [to] teach us as well, so I was like 'Oh, when's he going tae get in," like, ken [you know], tae, but no, I didnae realise that you were just, like, researching it.

Others referred to my position as 'the leader', despite my efforts to participate with the group and take part in the programme alongside the participants. Furthermore, I found that I was seen by participants at this point in the research as someone who was knowledgeable, in particular about health and exercise; I was someone to be approached and asked for clarification. This was captured in my fieldnotes reflecting on observations of the programme sessions:

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[5] All names and places have been changed to ensure the anonymity of all research participants.

> While many of the group are making really great changes as a consequence of the programme, many of the guys are really focused on bulking up. If I get asked about the best way of getting protein into their diet, I am going to go mad, it is like the only thing that I might know that might be useful to them sometimes. (Fieldnote extract, April 2016)

Cumulatively, this illustrates some of the ways I was initially viewed by some of the participants, with my positionality being constructed in relation to the focus of the Fit for LIFE programme. It also reveals certain manifestations of power within the ethnographic research process, indicating an imbalance and hierarchy inherent in my positioning, shaped particularly by perceptions of knowledge and expertise.

Clothing and the Materiality of Positionality

As a man with intersectional identities (such as class, gender, ethnicity), within an extremely hierarchical context, my positionality in relation to the hierarchies specific to the prison context[6] evolved over time. This was manifested particularly in increasing levels of 'banter',[7] including frequent ridicule of various jumpers I wore while in the prison. This served to establish my (outsider) position in relation to the Fit for LIFE participants and prison staff. This also illustrates the importance of clothing as an expression of agency within the prison context (cf. Ash 2010). In this sense, the materiality and physical embodiment of positionality in relation to clothing were consistently formative. In relation to the quotation in the title, one week I wore a red jumper, which I had not given much thought to previously. This provided a useful and unexpected insight into the importance of both clothing and colour within prison. Within the prison in question, the only people who wore red

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[6] Prison-specific hierarchies have been explored through multiple lenses, for example in relation to ethnicity (Phillips 2012), hierarchies relating to the crime committed (Crewe 2009) and performances of masculinity (Maycock and Hunt 2017).

[7] Banter is a term used quite widely within Scottish prisons that relates to playful or lighthearted interactions between people.

clothing were protection prisoners.[8] Therefore, that week I had a range of questions and banter aimed at me relating to the possibility that I was a sex offender, or that I was potentially a paedophile. This highlights my naivety in relation to prison life, the significance of specific clothing and colours within prison as well as illuminating the way these meanings were employed to construct and affirm my position as an 'outsider'.

In response to the positionalities relating to clothing explored here, I learned to strategically use different clothing, postures and embodiments to elicit responses from the participants that give me insights into how they viewed me. Through these changes, I made several quite obvious 'mistakes' that were the source of much ridicule. For example, one week I made the mistake of wearing muddy trainers, ridiculed significantly by participants as it is almost impossible for prisoners to get muddy footwear within prison:

> Today was quite a hard day, as I made the mistake of wearing muddy trainers. That were apparently shit anyway, basically anything less than the latest Air Max trainers and you are not seen to be keepin up with the lads and making an effort. Given they were covered with mud, according to quite a few of the participants this had to make a me a [colloquial term for gypsy]. (Fieldnote extract, March 2015)

Footwear more generally are sites of relatively uninhibited expressions of agency in prison. This is largely down to the contrast with prison uniforms, which undermine potential expressions of agency through clothing, while prisoners are allowed to wear their choice of trainers. This often resulted in some prisoners wearing the latest (and often quite expensive) Nike Air Max trainers.

A further material dimension to my positionality in relation to the prisoners and staff related to me not having a set of prison keys, unlike other prison ethnographers (Crewe 2009; Carr 2016). Having keys is

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[8] Protection prisoners are isolated from the mainstream prison population for a range of reasons; they might have committed a sexual offence, be high profile or feel vulnerable. Protection wings of prisons are often quite negatively viewed by other prisoners.

a physical embodiment of the prison officer role and a key difference between officers and prisoners, and without them I felt my positionality reflected my attempt to undermine an obvious expression of power and distinction between prison staff and prisoners. Through my ethnographic reflections, I was able to consider how my positionality was constructed in additional ways through the identities and meanings attached to materials, and which reflected particular hierarchies of power in the prison context.

Connections

The extent to which I was able to connect with participants taking part in the Fit for LIFE programme shaped my insight into the changes people were able to make during the programme. This helped me understand the ways in which the prison context was in some ways enabling of change to health-related behaviours and conversely restrictive of it. Building trust and rapport within the prison context is particularly challenging, particularly as prisoners are often very wary of 'officialdom' in any form it might take. Despite this, banter and certain types of speech can be means of building rapport. For some participants, me not being part of the criminal justice system was an advantage and the tone of the language I took when interacting with the participants was largely seen as positive. This was largely as a consequence of me fully embracing and foregrounding my relative lack of knowledge and insight into prison life, compared to the insights that the participants and staff had. That I spoke to the participants like a 'normal person' and was quite open about my personal circumstances (such as my marital status, Welsh heritage) was commented on by a number of participants. Derek discusses this below:

> I mean you spoke tae us like a normal person. You could've been apprehensive because you'd—and then but the thing is you were speaking, and ken [you know], you were asking questions, and that, and you made it an interesting. We were all learning. We were all learning. I was learning. You were learning.

There was a sense that many participants appreciated that I was making an effort to spend time in prison, trying to do something specific for prisoners which was valued by the participants. Adam discussed this in some detail:

> …you're taking the time an' [and] effort tae come in, actually do something for the prisoners. D'you know what I mean? So like people like yourself, prisoners actually appreciate like you're making an effort. Yous can do this anywhere.

Similar comments were made on a number of occasions; it seemed relatively rare that people from the 'outside' would come into prison to get the views of prisoners on programmes such as Fit for LIFE or other aspects of prison life. That prisoners would engage with me at all about a range of aspects of their prison and pre-prison lives was, to an extent, shaped by my position as non-staff. However, despite me making some connections with the participants, there were instances in which it was possible to observe the limitations of my relationships with them, limitations that emerge from the specifics of my positionality in relation to the Fit for LIFE programme. These are explored in more detail below.

Disconnections

The quotes below indicate some of the implications of my position in relation to the participants in Fit for LIFE. As stated earlier, I was neither a participant nor a member of staff (although positioned closer to staff), during the time that I conducted the interviews below. How I was viewed by participants in relation to prison staff had profound implications for the sorts of conversations I was able to have within prison, both about the programme and prison life more widely. Kevin illustrates this below:

> They [other participants] look at you as just like part o' the jail, because there's things that they know that they cannae speak to you aboot, like

> the last few questions on this consent form.[9] Aye, even although they'll tell you things, they know there's still that barrier there.

This quote also points towards some of the issues which emerged throughout the research. There was a sense that while at times I was accepted as a participant in the Fit for LIFE group (particularly when working out or playing sport), there were important limitations and barriers to this. For example, Keith indicates that I will never understand prison and the conversations amongst prisoners as a consequence of me being a 'stranger' within this context:

> Even though you're coming fae [from a] university, they find it easy tae talk tae a con. I think is better because it's a con talking tae a con so a con'll listen mair [more] fae [from] a con and it's easier for them tae talk to the con and you understaun better fae a con I think.

Yet, a further complication to my positioning, which constructed a different type of disconnection, arose through relationships with prison staff outside the delivery of the main programme sessions. When not in the gym or sports hall with the participants and prisoners, I spent a lot of time while in prison with gym staff in their office which overlooked the main gym hall. This meant that when I was not playing sport with participants and prisoners I was able to have more detailed conversations with staff, on a range of topics:

> I spent the day at HMP A today, while the session was only 2 hours long. In the time before and after the session was delivered, I spent a lot of time talking about football, women and the state of the prison service with the guys in the office in the gym. The guys working in the gym are uniformly and passionately in favour of Scottish Independence, which resulted in some interested and challenging conversations about Wales. (Fieldnote extract, July 2014)

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[9] The second to last question in all consent forms read: "I understand if I disclose any information about any intention to harm myself or other people, or otherwise pose a threat to security, the research team have to pass this information to the prison authorities."

On reflection, these conversations and the time I spent in the prison office had positive implications for my relationships with prison officers (POs), and for navigating the context of my ethnographic research, but resulted in me being more distant from participants and prisoners more widely in all three prisons. This reflected the common mistrust and dislike of POs—or 'screws'—by participants, though this relationship was nuanced with POs working in the gym viewed differently from the POs on the halls where the prisoners live. John reflects on these nuances below:

> I don't talk to the hall staff. PTIs [gym staff] definitely 'cause obviously you're talking tae them, they're telling you what, best way tae dae your training is. They are helping you a lot more 'cause you are doing this course.

As such, my positionality as an ethnographer was multiple, reflecting developing relationships with participants and prison staff and a shifting range of connections and disconnections arising out of the prison context. These various positionings also highlighted the limitations of the insights I was able to generate from these contexts, both about the evolution of the Fit for LIFE programme and the every day of prison life.

Conclusions

Reflecting on my ethnographic research practice within three Scottish prisons, through examining how I was viewed and positioned by the Fit for LIFE participants, illustrates the ways in which my multiple positionalities highlighted the specific relationships and hierarchies arising around the delivery of the health promotion programme in a prison context. This chapter illustrates the potential for ethnography to contribute insights into both prison contexts and public health interventions delivered within them. Through using ethnographic methods, I have illustrated that the prison context shapes meaning (of clothing and colour, for example), identity and status in particular ways. Having greater insight into these aspects of prison life enabled a more nuanced and richer evaluation of the Fit for LIFE programme. For example, my engagement with the participants of the programme through participation in physical activities gave rise to better understanding of the sorts of bodies the participants inspired to have through the programme and their interests in techniques for 'bulking' up. This contributed to interpretations of how and why participants engaged with the Fit for LIFE programme and the potential dynamics of its behaviour change mechanisms in the prison context.

My positionality through the various identities I brought to the research—my clothing, gender, education, race, class—influenced both how I collected data and its interpretation (Mullings 1999). That I am not a former prisoner or was not associated with the criminal justice system is also a critical factor. In relation to the Fit for LIFE programme, participant observation during programme deliveries through playing sport and working out with the participants had two advantages. In the first instance, this facilitated a context in which to gain trust and generate rapport with participants. Secondly, participant observation gave me insights into the lived experience of the Fit for LIFE intervention, which illuminated some of the barriers and opportunities inherent in the prison context to making and sustaining positive lifestyle choices in relation to health. Without the insights into these wider aspects of prison life relating to bodies, appearance and consumption facilitated by the ethnographic methods used in this study, the changes that the participants made and the setbacks they faced in relation to their personal goals would not have been contextualised or understood.

Ethnographic methods enabled me to illuminate some of the challenges associated with a designing and delivering a behaviour change intervention within a context in which both behaviours and performances of identity are constrained at multiple levels. Therefore, ethnograpy applied within the context of public health interventions such as Fit for LIFE have a vital role to play in understanding the dynamics of relationships and hierarchies of knowledge and power unique to prison contexts, which undoubtedly shape the mechanisms and outcomes of attempts to improve prisoners' health.

References

Ash, J. (2010). *Dress Behind Bars: Prison Clothing as Criminality*. London: I. B. Tauris.

Atkinson, P., & Hammersley, M. (1994). Ethnography and participant observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 248–261, Xii, 643 pp). Thousand Oaks, CA: Sage.

Bandyopadhyay, M. (2011). Tackling complexities in understanding the social determinants of health: The contribution of ethnographic research. *BMC Public Health, 11*(Suppl. 5), S6.

Bosworth, M., & Carrabine, E. (2001). Reassessing resistance: Race, gender and sexuality in prison. *Punishment & Society, 3,* 501–515.

Carr, L. (2016). Re-entry to prison: Transition from HMP researcher to 'independent' researcher. In D. H. Drake et al. (2015) (Eds.), *The Palgrave Handbook of Prison Ethnography*. Basingstoke: Palgrave.

Crewe, B. (2009). *The Prisoner Society: Power, Adaptation and Social Life in an English Prison*. Oxford: Oxford University Press.

Crewe, B. (2011). Soft power in prison: Implications for staff-prisoner relationships, liberty and legitimacy. *European Journal of Criminology, 8*(6), 455–468.

Drake, D. H., Earle, R., & Sloan, J. (Eds.). (2015). *The Palgrave Handbook of Prison Ethnography*. Basingstoke: Palgrave Macmillan.

Earle, R., & Phillips, C. (2012). Digesting men? Ethnicity, gender and food: Perspectives from a 'prison ethnography'. *Theoretical Criminology, 16*(2), 141–156. https://doi.org/10.1177/1362480612441121.

Foucault, M. (1979). *Discipline and Punish: The Birth of the Prison*. Harmondsworth: Penguin Books.

Gates, M. L., & Bradford, R. K. (2015). The impact of incarceration on obesity: Are prisoners with chronic diseases becoming overweight and obese during their confinement? *Journal of Obesity*. http://dx.doi.org/10.1155/2015/532468.

Genders, E., & Player, E. (1995). *Grendon: A Study of a Therapeutic Prison*. Oxford: Clarendon Press.

Hammersley, M., & Atkinson, P. (1983). *Ethnography: Principles in Practice*. London: Tavistock.

Herbert, K., Plugge, E., Foster, C., & Doll, H. (2012, May 26). Prevalence of risk factors for non-communicable diseases in prison populations worldwide: A systematic review. *The Lancet, 379*(9830), 1975–1982. https://doi.org/10.1016/s0140-6736(12)60319-5.

Hunt, K., Wyke, S., Gray, C. M., Anderson, A. S., Brady, A., Bunn, C., et al. (2014). A gender-sensitised weight loss and healthy living programme for overweight and obese men delivered by Scottish Premier League football clubs (FFIT): A pragmatic randomised controlled trial. *The Lancet, 383,* 1211–1221.

Liebling, A. (2001). Whose side are we on? Theory, practice and allegiances in prison research. *British Journal of Criminology, 41,* 472–484.

Madison, D. (2005). *Critical Ethnography: Method, Ethics, and Performance*. London: Sage.

Maycock, M., & Hunt, K. (2017). *New Perspectives on Prison Masculinities*. London: Palgrave.

McDermott, B. E. (2013). Coercion in research: Are prisoners the only vulnerable population? *Journal of the American Academy of Psychiatry and the Law Online, 41,* 8–13.

Moser, D. J., Arndt, S., Kanz, J. E., Benjamin, M. L., Bayless, J. D., Reese, R. L., et al. (2004). Coercion and informed consent in research involving prisoners. *Comparative Psychiatry, 45,* 1–9.

Mullings, B. (1999). Insider or outsider, both or neither: Some dilemmas of interviewing in a cross-cultural setting. *Geoforum, 30,* 337–350.

Phillips, C. (2012). *The Multicultural Prison: Ethnicity, Masculinity, and Social Relations Among Prisoners*. Oxford: Oxford University Press.

Phillips, C., & Earle, R. (2010). Reading difference differently?: Identity, epistemology and prison ethnography. *British Journal of Criminology, 50,* 360–378.

Prentice, R. (2010). Ethnographic approaches to health and development research: The contributions of anthropology. In I. Bourgeault, R. Dingwall, & R. De Vries (Eds.), *The Sage Handbook of Qualitative Methods in Health Research*. London: Sage.

Savage, J. (2000, December 2). Ethnography and health care. *BMJ, 321*(7273), 1400–1402.

Schlosser, J. A. (2008). Issues in interviewing inmates: Navigating the methodological landmines of prison research. *Qualitative Inquiry, 14*(8), 1500–1525.

Simmel, G. (1971). The stranger. In D. Levine (Ed.), *Georg Simmel: On Individuality and Social Forms* (pp. 143–150). Chicago: University of Chicago Press.

Singleton, N., et al. (2003). Substance misuse among prisoners in England and Wales. *International Review of Psychiatry, 15*(1–2), 150–152.

Spradley, J. P. (2016). *Participant Observation*. Long Grove, IL: Waveland Press.

Ward, T., & Willis, G. (2010, November–December). Ethical issues in forensic and correctional research. *Aggression and Violent Behaviour, 15*(6), 399–409.

12

Ethnographic Encounters with the ‘Community’: Implications for Considering Scale in Public Health Evaluation

Joanna Reynolds

Introduction

Public health evaluation research is a multidisciplinary endeavour that seeks to inform decision-making for the promotion and protection of health at the population level. The aim of public health evaluation research is to build an evidence base of ‘what works’ to inform practitioner and policymaker decisions (at local and national levels) about what programmes and policies to implement to improve the health of the population. The kinds of interventions evaluated for their public health impact range from individual behaviour-change programmes, such as to promote exercise or healthy eating, to interventions targeting more social or structural determinants of health, such as housing or education. Relating particularly to the latter, recent developments in public health evaluation research in both academic and practice settings have seen increased focus on how to evaluate ‘complex interventions’.

J. Reynolds (✉)
Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London, UK
e-mail: joanna.reynolds@lshtm.ac.uk

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These are typically defined as interventions with multiple, intersecting components which interact dynamically with the context in which they are delivered (Medical Research Council 2008). Complex interventions are thought to bring about change to health through multiple, complicated pathways and as such, their effects cannot easily be assessed through the experimental methodologies traditionally associated with (biomedical) evaluation research, such as the randomised controlled trial. Furthermore, the rise of attention on 'complex interventions' has also seen a shift in the expressed aims of evaluation. No longer is it considered useful to say simply whether or not an intervention works to improve health outcomes. Increasingly, evaluators seek to understand how, for whom and under what circumstances changes to health occur through an intervention (Bonell et al. 2012). This kind of knowledge is framed as valuable for informing how an intervention might be successfully delivered elsewhere or 'scaled up' to be delivered at a population level. As a result, different methodological approaches are increasingly being brought into the design of public health evaluation studies, including qualitative methods that can attend to the processes and dynamics of an intervention in context, such as ethnography (Cohn et al. 2013).

In this chapter, I seek to explore how ethnography can be used as part of public health evaluation research to explore dynamics of complex interventions and how changes to health might occur and be assessed. I focus particularly on the concept of 'scale' as a dimension of understanding how complex interventions bring about change, and I describe the way in which ethnographic research enabled me to explore dynamics of scale in an unfolding community empowerment intervention.

Conceptualising Scale in Evaluation of Complex Interventions

The concept of 'scale', I suggest, is embedded within the contemporary literature on the evaluation of complex interventions for health, but is rarely explicitly interrogated or explored. Complex interventions are frequently framed in evaluation research using 'systems' perspectives, influenced by theories of complex adaptive systems from various disciplines including biology and computing (Hummelbrunner 2011).

A typical systems perspective used in evaluation research sees interventions as unfolding within, and interacting dynamically with, a broader contextual system. This system is thought to comprise complex, dynamic structures and relationships between its constituent (social, political, economic, environmental, physical) elements (Hummelbrunner 2011). When a complex intervention, such as a community empowerment initiative, is delivered, it will prompt multiple mechanisms of change which occur at different 'levels' or scales of the system (Mowles 2014). This is in contrast to, for example, the simple delivery of a drug for which the mechanisms of change are thought to be confined to the individual body. Therefore, the framing of evaluating complex interventions rests on an assumption that change occurs through interactions happening across different scales of the system in which the intervention is delivered. Not only will changes to health occur because of actions taken by a few individuals, such as a programme's implementers or its participants. Instead, due to the multiple components of the complex intervention interacting with the context in which it is delivered, rippling interactions will occur across the system as a whole (Diez Roux 2011), both closer to and more distant from the site(s) in which the intervention is actually delivered. The purpose of evaluation from this perspective is to try to identify these mechanisms of change, to provide information or evidence on how an intervention influences health and to help inform decision-making by policymakers as to whether (and how) to implement an intervention in another context.

The concept of scale, then, also relates to this purpose of public health evaluation: to produce evidence of an intervention's effectiveness that can be transferred or 'scaled-up' to inform decision-making to improve health at a population level (Hanson et al. 2003). This denotes an assumption that there is a comparability of scales between different settings or contexts which enables the meaningful transference of knowledge—as 'evidence'—between them (Cartwright 2013). A further conceptualisation of scale inherent in public health evaluation research, and arguably at the heart of public health as a field, concerns the (assumed) predictability of the scalar relationship between the individual—the level at which health outcomes are typically measured—and the population—the level at which public health decisions are made. This relationship is typically assumed to be linear and stable, such that knowledge produced at the individual level about how to improve health can be extrapolated, or scaled up, unproblematically as 'evidence' to the population level (Krieger 2012). Critical consideration of the different dynamics of scale at play in the delivery and evaluation of complex interventions is required for public health evaluation research to contribute productively to the improvement of population health.

Conceptualising Scale Within an Ethnographic Approach

In this chapter, I draw primarily on perspectives from anthropology in my consideration of what ethnography might offer to public health evaluation research seeking to inform policy and practise decision-making to improve population health. My interpretation of ethnography reflects its anthropological roots in traditional 'fieldwork', whereby the understanding of relationships, structures and processes within (and beyond) the field of interest arises through 'being there' (Lewis and Russell 2011), via the researcher's engagement with and embeddedness within these relationships (Hannerz 2003). From this perspective, ethnographic knowledge can be taken as '*consisting of, and steeped in, social relations*' (Hastrup 2005: 141), and through the researcher-as-instrument, it enables (critical) interpretation of being and knowing in the world (Ingold 2008). In this chapter, I seek to demonstrate that these forms of positioning and interpretation unique to ethnographic research can help shed light on dimensions of scale inherent in the delivery of complex interventions, and which must therefore be acknowledged and explored through public health evaluation research.

Critical reflections on scale have emerged in applications of and debates around ethnography. Contemporary anthropological topics of interest, such as globalisation and mobilities of people, ideas and resources, have prompted reflections on how ethnography can be applied across territories to examine flows of relations (Marcus 1995; Gupta and Ferguson 1997). This contributes to disruptions of any assumed fixed scalar hierarchy between the 'local' and the 'global' (Massey 2004; Hastrup 2013), and of how the 'field' of inquiry might be defined in scalar terms relative to the dynamic systems in which it is situated. There have also long been debates on the process of producing ethnographic knowledge, and the inevitable scalar relationship between 'anecdotes' or observations from fieldwork (detailed, particular) and the interpretation of a broader social system conveyed through the ethnographic narrative (abstracted, often comparative) (Strathern 2004; Candea 2007). Hence, contemporary approaches to ethnography promote reflexive attention on relations of scale, in terms of both how the 'object' and field of study can be understood, and how knowledge on that object is produced and represented. As such, these perspectives hold much potential for exploring and considering scale within public health evaluation, and the role ethnography might play in interpreting how complex interventions unfold, to inform decisions on improving population health.

Ethnographic Explorations of the Enactment of 'Community'

Overview of Ethnographic Research

To illustrate these arguments further, I draw on ethnographic research conducted around the delivery of a complex, community empowerment intervention in the UK, the *Big Local* (*BL*). The research was undertaken alongside a public health evaluation of the intervention, and here I describe ethnographic interpretations which illustrate some of the dynamics of scales and scalar relations occurring through the delivery of the intervention. The *BL* is a long-term empowerment intervention which was developed and funded by a third-sector organisation, BIG Lottery. Its design reflects recent policy movements in the UK (and elsewhere) to address spatially patterned determinants of health and social inequalities through local, area-based interventions (Bridgen 2004). The *BL* also reflects increasing shifts in public health and social policy towards engaging communities to empower citizens to identify and address local factors influencing their health and well-being (Popay et al. 2007; Reynolds et al. 2015). The *BL* began in 2010 and is underway (at the time of writing) in 150 areas across England, with populations ranging from 5000 to 12000 residents. Residents are given control over identifying and addressing priorities for improving their local areas to make '*a massive difference to their communities*' (Local Trust 2015: 5). Residents are facilitated to form a committee, then conduct consultation with the wider community to develop and deliver a plan to address local priorities using allocated funding (one million pounds per area) over a period of 10 or more years.

Though not an explicitly health-oriented intervention, the *BL* has been identified as holding potential to improve the health of participating communities and to reduce health inequalities within and between populations. This reflects theorised pathways between increased collective control within participating communities via the empowerment mechanisms of the *BL*, and improved health outcomes (Whitehead et al. 2016). An evaluation study has been developed by a team from multiple universities to identify the mechanisms of the intervention which might lead to improved health and reduced inequalities. This evaluation study frames the *BL* as a complex intervention in a dynamic system (Orton et al. 2017).

My ethnographic research focused on how 'community' was enacted through the delivery of the intervention, alongside the first phase of the evaluation study (2014–2015). I conducted fieldwork in two of the participating *BL* areas and I spent 13 months in and between the two areas, following the tempo of activities unfolding in each area (Reynolds 2017). I observed a range of activities occurring as the *BL* was delivered in each area including: regular meetings of the residents' committees leading the planning and delivery of the intervention; events organised by the committees such as consultation activities; and the roll-out of projects funded through the intervention, such as a sports programme for young people. I also engaged in informal conversations and interactions and more formal in-depth interviews with local residents, workers and other 'stakeholders' closely, and less closely, involved with the intervention.

'Craybourne' (all places and names are pseudonyms) is an area of 6000 residents in a coastal town, formerly a popular holiday destination, but now facing relatively high levels of deprivation, unemployment and health inequalities. At the time of fieldwork, the residents' committee in Craybourne was beginning consultation with the wider community to identify priorities for the local area and develop a plan to address these. The second area, 'Westin Hill', is an urban site on the outskirts of a large city with around 11000 residents, with high levels of socio-economic inequality. The committee in Westin Hill had already conducted a year of community consultation prior to my arrival and were beginning to implement their plan to address issues of promoting intergenerational relations and improving community spaces and the local economy.

Scalar Relations Emerging Through the Enactment of Community

What did and did not enter my ethnographic 'gaze' while exploring enactments of community around the *BL* intervention is a first example of the different dimensions of scale at play in this context. My gaze was particularly small-scale, given the possible scope of the *BL*. I selected only two out of 150 participating areas in which to conduct fieldwork, my fieldwork lasted for only around one-tenth of the expected time span of the intervention, and I considered enactments of community occurring only *within* my two areas, rather than at the national level at which the *BL* was administered. Following the premise of 'being there', with my interactions constituting the mechanism through which ethnographic knowledge was generated, I was necessarily restricted in my ethnographic engagements. My interactions typically involved only a small minority of the residents in each area (rarely more than the 20–30 people actively involved in delivering the *BL* at any one time) and a limited number of spaces (typically community centres, residential homes and leisure spaces). Yet, through my ethnographic perspective, I was able to slide between different explanatory scales. The individual interactions and activities I identified through my presence were '*not 'small-scale' at all in terms of the…insights they afford[ed]*' (Strathern 2000: 66) for interpreting how community is enacted through a complex intervention and the implications of this for public health evaluation.

Furthermore, my ethnographic research enabled me to identify a diverse range of ways in which scale and scalar dynamics were being produced, in often unpredictable ways, through the enactment of community as the *BL* unfolded. This included practices of representation undertaken by the residents' committees acting on behalf of the wider community; the ongoing work of asserting and negotiating boundaries around eligibility to contribute to or benefit from the intervention; and the shifting positioning of the individual relative to the collective, through the delivery of the *BL*. I will describe ideas of scale in relation to each of these and highlight their implications for considering the role of scale in evaluations of complex interventions for health.

The Scalar Dynamics of Representation

The practice or representation, whereby a small group of people speak and act for or on behalf of a larger group, reflects a 'folding together' (Hastrup 2013) of different scales. This could be seen in much of the work of delivering the *BL* as a community intervention in both areas. Representation was performed by the small number of committee members in each area who consulted residents on local priorities for improvement, synthesised and reformulated these opinions into a plan and then took steps to put this plan into action. These representative practices reflect negotiations of the scalar disparity between the small numbers of active residents and the broader community for, and as whom, they were acting. The tensions of this process were captured in particular in my ethnographic observations in Craybourne, as the residents' committee commenced the phase of community consultation.

The work of planning and doing consultation—of identifying groups of people, spaces, events and mechanisms to elicit residents' opinions on the local area—involved a continuous interplay between scales. A range of discrete and targeted consultation activities was carried out that constructed the community as segmented and localised, but also as a broader, holistic 'picture' that was being painted through the collation of different views. There was constant movement between the community as a 'whole' and as a series of socially and spatially demarcated segments or groups, performed through the different types of consultation activities undertaken in Craybourne. Shortly after I began my fieldwork in Craybourne, the residents' committee appointed a part-time 'community worker', Katy, to manage the consultation process.

Katy identified her role and workload to me in terms of the need to 'get round' as many groups in the community as possible. She arranged weekly drop-in sessions at a couple of centres in Craybourne, as a mode of connecting directly with different types of people, and would feedback on her progress to the rest of the committee at meetings, illustrated in my notes from one such meeting:

> Katy said she'd been holding her drop-in sessions and although they'd been slow to start with they'd picked up and she now has a queue of people… She also talked about a few groups of people who wanted to talk to her, but in a group setting and in a 'safe' place. She said there's a rehab group who meet at Craybourne Action who'd like to have a session with her, and there's a group of older women who meet at the Aroma café who would like to meet with her, but in an environment they feel comfortable in…. (Craybourne, observation, July 2014)

My ethnographic notes highlight the processes of segmentation of the community occurring through Katy's accounts of her consultation work, into different groups and spaces defined by particular characteristics and needs.

However, later on, the limitations of this approach to 'covering' the whole community were identified, as Katy expressed frustration that her sessions were not '*bringing in enough people*' and were too '*ad hoc*'. This exemplified a disruption to the assumed scalar flow between the series of small-scale engagements with discrete groups and spaces, and mapping the community as a 'whole' through the consultation process, thus indicating the unpredictable scalar dynamics of doing representation.

My ethnographic work highlighted a further example of the dynamic relation between community as a whole and a series of discrete segments which occurred towards the end of my time in Craybourne, when the committee were coming to the end of their year's worth of consultation activities. I observed efforts in committee meetings to gather together all the information they had produced through the various activities to feed into the development of the plan to guide the delivery of the next stage of the *BL*. These conversations involved attempts to identify where different pieces of information were held and the format they were in, including data on various personal computers and copies of completed questionnaires stored in homes and local workplaces. This process of locating and amalgamating the fragmented outputs of consultation indicated how representation, as a core mechanism of the unfolding *BL* intervention, engaged, traversed and sometimes disrupted flows between the partial and the whole, as different scales at which the community was enacted. This suggests that evaluations must attend closely to how specific mechanisms of interventions shape and produce the scales at which interactions occur, which may disrupt expected notions of how groups of people, spaces and structures are positioned relative to one another and the wider system in which they are situated.

Shifting and Negotiated Boundaries

Another dimension of the enactment of community that I identified through my ethnographic fieldwork was the processes of asserting and negotiating boundaries around who and what was eligible to contribute to and benefit from the *BL* intervention in each area (Reynolds 2018). The shifting of boundaries (spatial, social, conceptual) indicated an ongoing fluidity of the scale(s) at which the intervention was being delivered and at which its impacts might be experienced. An example of this can be seen in Westin Hill, where my fieldwork began as the residents' committee were preparing to deliver activities to meet the priorities specified in the plan they had developed, following a period of consultation. Yet, while this plan had been agreed, the steps needed to begin delivering against priorities of improving the local economy, community spaces and intergenerational relations appeared unclear to the committee. In the first few months of my fieldwork, I observed the committee develop a pilot process for commissioning projects to help meet the priorities. They decided to focus first on improving intergenerational relations and, within that, invited proposals for projects to improve resources for young people in Westin Hill. As such, this pilot process served to assert a boundary around the community that was very focused in its scale, funding a few activities that targeted only a specific group of the population.

Yet, even within this small-scale enactment of the community intervention, other negotiations of boundaries were performed, indicating the dynamic flow of the mechanisms of the *BL* across and between different sites, groups and levels of activity. One of the first projects chosen to be funded by the Westin Hill residents’ committee was a weekly youth sports programme located at the communal sports pitch on the Palmer Grove housing estate in Westin Hill. In some ways, situating the sports programme at Palmer Grove appeared to assert a rather limited spatial boundary, wherein the community focus of the *BL* was enacted only within the confines of the sports pitch and through the intended beneficiaries of the programme (young people). Yet, the activities unfolding here also carried connections that extended beyond the scalar limitations of this small space. The programme itself had been run successfully before at Palmer Grove and elsewhere in the wider borough over the previous couple of years, and a range of flyers and posters arranged on the registration desk at the entrance to the sports pitch publicised a number of similar upcoming events beyond Westin Hill.

I also identified dimensions of scale playing out through the registration procedure for the sports programme which involved giving an address and postcode to identify whether participants were residents of Westin Hill or not. This had been a point of contention and negotiation during the earlier residents’ committee meetings where members of the committee were concerned that programmes they chose to fund as part of the *BL* should be for the benefit of residents of Westin Hill only. However, the sports programme organisers had pointed out the challenges of managing this and their reluctance to turn away anybody who was not a resident. Alex, the organiser of the sports programme, conveyed to me during an interview some uncertainty around managing the ‘official’ Westin Hill boundary:

> … and they can maybe dot, maybe have a map for a project, so when people come, can you put a dot or a pin on your road or something? … Just so we can see and we can build a picture of the [sports] project within Westin Hill… Where everyone’s come from… And did we get anybody outside? Because I know there was like priority is Westin Hill but I don’t want to turn away anybody, you know, that sort of … and then that’s ways for people to kind of say, look

> [the programme's] here from Westin Hill, look this is what we're doing to encourage building of knowledge … Because we've, obviously we've got the register and we can kind of allocate the roads and the postcode to where they are. Because when we asked them, are you Westin Hill? they didn't know.

This example illustrates how the asserting and negotiation of boundaries through the delivery of the *BL* performed the intervention, and the community, at multiple scales. Asserting a boundary through the narrow social and spatial focus of the sports programme was a mechanism through which the residents' committee felt they could take steps to begin delivering against their plan for the whole community. Yet, the enactment of this programme revealed connections with broader spatial contexts, and the negotiation of eligibility to participate revealed the porous nature of boundaries that undermine their apparent fixed scale. This ongoing boundary work (Reynolds 2018), identified through my ethnographic interpretations, indicates that the levels at which an intervention's mechanisms of effect occur are not neatly bounded, but porous and negotiated, and that the scale of the target population 'receiving' the intervention is not fixed, but constantly in production.

Disrupting Aggregation from the Individual to the Collective

A third example of the kinds of scalar dynamics at play in the enactment of community through the *BL* was the positioning of the individual relative to the collective. My ethnographic observations and reflections identified the shifting positions of individuals relative to the collective, challenging assumptions from a public health evaluation perspective that community reflects a neat scalar hierarchy of individuals aggregated into a collective. During my fieldwork, I found myself following in detail the shifting positions and pathways taken by several individual residents that diverged from and intersected with the collective activity and spaces of the delivery of the *BL*. This indicated the limitations of interpreting community as an entity of greater scalar magnitude than the individual for understanding the plurality of ways in which the mechanisms of the intervention unfolded and prompted interactions.

An example of one such trajectory involved Magda, a long-time local resident and very active member of the residents' committee in Craybourne, and someone I came to spend quite a lot of time with during my fieldwork. During my time in Craybourne, Magda became involved in 'Star People', a social enterprise scheme offered alongside the *BL* to participating areas, to enable individual residents to develop social entrepreneurship ideas. Shortly after I first met Magda, she began to tell me about her desire to find a new source of income and to get back into catering, something she had trained in some years before. As I got to know her better, chatting before and after committee meetings and at other events, Magda told me about her plan to apply for a small fund from the scheme, to develop a lunch club that she would host in local venues around Craybourne.

My presence in Craybourne and developing connection with Magda enabled me to follow her progress with applying for—and receiving—the funding and setting up her first lunch club, and to identify this as a trajectory that at times distanced Magda from her continuing involvement with the (collective) work of delivering the *BL*. Much of the preparation work for Magda's new venture was located in her private home (in the kitchen), and her interactions with other people and spaces to facilitate setting up the venture tended to involve those unconnected with the *BL*, for example the local council environmental health officer. Furthermore, Magda's discursive construction and narration of her trajectory to me served to highlight its distinction from the collective nature of the main intervention, despite the Star People funding only being available to residents of *BL* areas. Our conversations about her venture tended to occur on the spatial and temporal 'fringes' of the ongoing *BL* activity, for example as we were leaving committee meeting venues, or at a local café when Magda and I had arranged to meet socially. Following a rather difficult few meetings of the *BL* residents' committee a few months into my fieldwork, Magda emphasised firmly to me that the lunch club was, in her mind, '*completely separate*' from the *BL*.

Yet, despite this conceptual and spatial separation of Magda's venture, and of her narration of it to me (as someone ostensibly *not* part of the *BL* or the community it represented), her trajectory intersected the collective nature and practices of the *BL*. On several occasions, Magda brought to committee meetings samples of new recipes she was trying out for the lunch club for feedback from attendees, and once invited me and several committee members back to her house after a meeting to try her food and see her kitchen, newly renovated in anticipation of her catering venture. Furthermore, people with whom Magda had become friendly through being involved in the *BL* were among those who attended her first lunch club event. Thus, Magda's pursuit of a personal, occupational goal was individual but also collective, such that it emerged from, and at times was performed through the collective endeavour of the *BL* as a community intervention.

Thus, these ethnographic encounters serve to disrupt assumptions of simple aggregation of scale from the individual to the collective (or population) level, which underpin much evaluation research and its methods of measuring and interpreting the health impacts of an intervention. Instead, my ethnographic practice highlights the need to attend to the more dynamic and unpredictable flows between scales, and how they constitute each other through an unfolding complex intervention.

Discussion

Through this chapter, I have sought to highlight some of the ways the concept of 'scale' and scalar relations are embedded in current public health framings of the evaluation of complex interventions. Drawing on empirical examples from fieldwork exploring the enactment of 'community' through a complex, community empowerment intervention, I highlighted how ethnographic approaches enable the identification of flows of relations and interactions across scales as the intervention is delivered within a dynamic contextual system (Mowles 2014). Ethnographic research showed that enactment of community through the *BL* intervention engaged and occurred across different social, spatial and conceptual scales that were not distinct from one another, but instead frequently '*enfolded in each other*' (Hastrup 2013: 148).

These ethnographic interpretations, produced through engaging in situated relations in two areas participating in the intervention, indicate the need for evaluation approaches to pursue a more nuanced understanding of how interventions unfold within a series of contextual structures and relations. While ethnography has been upheld as valuable for evaluation research in terms of the 'holistic' perspective it offers (Cohn et al. 2013) and for its attention to 'context' (Morgan-Trimmer and Wood 2016), recent debate has pushed for recognising further and potentially more critical roles for ethnography in public health evaluation (Reynolds 2017). The example described here shows a valuable role for ethnography in illuminating flows of relations across the different scales at which an intervention might bring about change, and how the processes of the intervention itself might disrupt those very scales and scalar relations, illustrated, for example, through the practices of representation within the *BL*. As such, ethnography may facilitate interpretation of the complex, dynamic pathways of interaction between intervention and context that existing evaluation approaches have failed to capture fully (Shoveller et al. 2015).

The ethnographic process in itself is also an example of the dynamic scalar complexities of producing more abstracted and generalised accounts from personal, situated interactions. In switching between levels of focus, from following individual trajectories to interpreting collective processes, my ethnographic approach highlights the potentially problematic basis of traditional analytical approaches within evaluation which rest on aggregating information from the individual to the population level. The fluidity of the ethnographic perspective across these scales creates an opportunity to consider the 'incommensurability' (Lambert 2013) of the analytical basis of public health evaluation, where health is measured (and felt) at an individual level but extrapolated to function as 'evidence' for decision-making at the population level. Rather than taking the target population of a complex intervention as a stable, aggregate unit of analysis, an ethnographic approach enables greater reflection on how the scales of the categories employed in an intervention and evaluation are varyingly performed, shaping and shaped by the mechanisms of effect that bring about change to health. Therefore, ethnographic approaches offer much to the field of public health evaluation: highlighting the dynamic scalar relations in the processes through which complex interventions bring about change to health, and prompting reflection on how knowledge produced through evaluation might usefully inform public health evidence and decision-making at a population level.

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References

Bonell, C., Fletcher, A., Morton, M., Lorenc, T., & Moore, L. (2012). Realist randomised controlled trials: A new approach to evaluating complex public health interventions. *Social Science & Medicine, 75*(12), 2299–2306.

Bridgen, P. (2004). Evaluating the empowering potential of community-based health schemes: The case of community health policies in the UK since 1997. *Community Development Journal, 39*(3), 289–302.

Candea, M. (2007). Arbitrary locations: In defence of the bounded field-site. *Journal of the Royal Anthropological Institute, 13*(1), 167–184.

Cartwright, N. (2013). Knowing what we are talking about: Why evidence doesn't always travel. *Evidence & Policy, 9*(1), 97–112.

Cohn, S., Clinch, M., Bunn, C., & Stronge, P. (2013). Entangled complexity: Why complex interventions are just not complicated enough. *Journal of Health Services Research & Policy, 18*(1), 40–43.

Diez Roux, A. V. (2011). Complex systems thinking and current impasses in health disparities research. *American Journal of Public Health, 101*(9), 1627–1634.

Gupta, A., & Ferguson, J. (Eds.). (1997). Culture, power, place: Ethnography at the end of an era. In *Culture, Power, Place: Explorations in Critical Anthropology* (pp. 1–29). Durham, NC: Duke University Press.

Hannerz, U. (2003). Being there… and there… and there! Reflections on multi-site ethnography. *Ethnography, 4*(2), 201–216.

Hanson, K., Ranson, M. K., Oliveira-Cruz, V., & Mills, A. (2003). Expanding access to priority health interventions: A framework for understanding the constraints to scaling-up. *Journal of International Development, 15*(1), 1–14.

Hastrup, K. (2005). Social anthropology. Towards pragmatic enlightenment? *Social Anthropology, 13*(2), 133–149.

Hastrup, K. (2013). Scales of attention in fieldwork: Global connections and local concerns in the Arctic. *Ethnography, 14*(2), 145–164.

Hummelbrunner, R. (2011). Systems thinking and evaluation. *Evaluation, 17*(4), 395–403.

Ingold, T. (2008). Anthropology is not ethnography. Radcliffe-Brown lecture in social anthropology, 2007. *Proceedings of the British Academy, 154*, 69–92.

Krieger, N. (2012). Who and what is a "population"? Historical debates, current controversies, and implications for understanding "population health" and rectifying health inequities. *Milbank Quarterly, 90*(4), 634–681.

Lambert, H. (2013). Plural forms of evidence in public health: Tolerating epistemological and methodological diversity. *Evidence & Policy, 9*(1), 43–48.

Lewis, S., & Russell, A. (2011). Being embedded: A way forward for ethnographic research. *Ethnography, 12*(3), 398–416.

Local Trust. (2015). *What is Big Local?* London, UK: Local Trust.

Marcus, G. E. (1995). Ethnography in/of the world system: The emergence of multi-sited ethnography. *Annual Review of Anthropology, 24,* 95–117.

Massey, D. (2004). The responsibilities of place. *Local Economy, 19*(2), 97–101.

Medical Research Council. (2008). *Developing and Evaluating Complex Interventions: New Guidance*. London, UK, Medical Research Council. Available from http://www.mrc.ac.uk/documents/pdf/complex-interventions-guidance/. Accessed November 12, 2017.

Morgan-Trimmer, S., & Wood, F. (2016). Ethnographic methods for process evaluations of complex health behaviour interventions. *Trials, 17,* 232.

Mowles, C. (2014). Complex, but not quite complex enough: The turn to the complexity sciences in evaluation scholarship. *Evaluation, 20*(2), 160–175.

Orton, L., Halliday, E., Collins, M., Egan, M., Lewis, S., Ponsford, R., et al. (2017). Putting context centre stage: Evidence from a systems evaluation of an area based empowerment initiative in England. *Critical Public Health, 27*(4), 477–489.

Popay, J., Attree, P., Hornby, D., Milton, B., Whitehead, M., French, B., et al. (2007). *Community Engagement in Initiatives Addressing the Wider Social*

Determinants of Health. A Rapid Review of Evidence on Impact, Experience and Process. Lancaster, UK: Lancaster University.

Reynolds, J. (2017). 'Missing out': Reflections on the positioning of ethnographic research within an evaluative framing. *Ethnography, 18*(3), 345–365.

Reynolds, J. (2018). Boundary work: Understanding enactments of 'community' in an area-based, empowerment initiative. *Critical Public Health, 28*(2), 201–212.

Reynolds, J., Egan, M., Renedo, A., & Petticrew, M. (2015). Conceptualising the 'community' as a recipient of money—A critical literature review, and implications for health and inequalities. *Social Science & Medicine, 143*, 88–97.

Shoveller, J., Viehbeck, S., Di Ruggiero, E., Greyson, D., Thomson, K., & Knight, R. (2015). A critical examination of representations of context within research on population health interventions. *Critical Public Health, 26*(5), 487–500.

Strathern, M. (2000). Environments within. An ethnographic commentary on scale. In K. Flint & H. Morphy (Eds.), *Culture, Landscape and the Environment. The Lincare Lectures 1997* (pp. 44–71). Oxford: Oxford University Press.

Strathern, M. (2004). *Partial Connections*. Walnut Creek, CA: Alta Mira Press.

Whitehead, M., Pennington, A., Orton, L., Nayak, S., Petticrew, M., Sowden, A., et al. (2016). How could differences in 'control over destiny' lead to socio-economic inequalities in health? A synthesis of theories and pathways in the living environment. *Health & Place, 39*, 51–61.

13

'To Uninstall Oneself': Ethnographizing Immunostimulants for Autoimmunity in Brazil

Márcio Vilar

Introduction

Where do I go and where am I taken to when I follow non-authorised immunostimulants used for the treatment of autoimmune diseases in Brazil, diseases that are conventionally treated with immunosuppressive pharmaceuticals worldwide? What does it mean when I follow these drugs, not only as ethnographer but also as a user? In this chapter, I present aspects of my strategy to 'ethnographize' the use of immunostimulant therapies as biotechnological innovations to treat autoimmunity in contemporary Brazil. I understand 'ethnography' as a descriptive account of other people's realities and ways of life based on a serious consideration of their world views and on first-hand learning of their knowledge as conducted during prolonged fieldwork. With 'ethnographizing', I mean two interlinked actions. The first concerns a predisposition to wonder that the ethnographer exercises *during* the fieldwork, towards an attempt to learn how people reproduce and reinvent

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M. Vilar (✉)
University of Leipzig, Leipzig, Germany
e-mail: m.vilar@uni-leipzig.de

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themselves as they live and, consequently, as constitutive parts of their distinct realities. The second may be understood as the ulterior reflective efforts to systematise a multiplicity of research material (artefacts, interviews and life stories, fieldwork notes, genealogies, 'data', etc.) to produce ethnography (Ingold 2014: 386).

Although appearing as successive, these interlinked actions take place cyclically. Even during fieldwork, the ethnographer always finds moments and places of relative isolation and uses them as opportunities to reflect and systematise available findings before resuming participant observation. Likewise, though on another scale, one may conduct several fieldwork stays in intercalated periods, as is the case of my research since 2009, when I began to attempt to understand the world of immunostimulant users, both patients and physicians. Underlying my ethnographizing attempt is my personal experience of becoming sick and recovering from an autoimmune disease by unconventional means. Autoimmune diseases are considered by biomedical authorities as one of the greatest causes of disability in the world (WHO 2017; Policy Department of European Parliament 2017). An autoimmune disorder is characterised as the immune system's loss of capacity to distinguish between healthy tissue and antigens, and, consequently, it mistakenly destroys the body's own healthy tissue (NIH 2016). The cause remains unknown, and autoimmunity does not officially have a cure. Despite their unpredictability, autoimmune diseases are considered by global biomedical authorities as 'chronic': patients are normally informed by physicians that they 'have to learn to live with it' (Greenhalgh 2001; Anderson and MacKay 2014; Andrews 2011).

In Brazil, however, thousands of patients and some medical professionals have informally adopted immunostimulant therapies and respective drugs to treat autoimmunity. This is in contrast to the long-standing global biomedical approach that generally treats autoimmunity with immunosuppressive drugs. Immunosuppressants palliatively slow down the activity of the immune system by artificially damaging it to prevent immune reactions, for example, when the immune system 'attacks itself' because it can no longer distinguish between its own and strange cells. By contrast, immunostimulant drugs seek to enhance the immune system's activity to help it to restore its proficiency in making vital distinctions between self and non-self. Given that global biomedicine for autoimmunity based on immunosuppression plays a dominant regulatory role also in Brazil, immunostimulant drugs hold a much more precarious status than immunosuppressants in terms of legal and medical recognition of their effects and authorisation of their use.

Taking my personal experience of autoimmune disease as a starting point, I show how my strategy to ethnographize what I have encountered during my research consists of a combination of autoethnography and the act of 'following' non-authorised drugs as complementary methods. While both are constitutive of my participant observation, I use the concepts of 'life assemblages' and of 'self-uninstallation' to articulate and frame the research materials produced through my fieldwork. Life assemblages refer to the set of provisionally interconnected networks or associations of people, including scientists and non-scientists, who share common ideas and moralities concerning the development, adoption and cross-boarding implications of scientific innovation as a way to alter life (Sleeboom-Faulkner 2014: 2). The practices of life assemblage members converge to promote marginalised scientific innovation on the one hand. On the other, their practices might incur medico-legal deviations that many life assemblage members see as necessary.

Self-uninstallation, a term introduced to me by Dr. Rosa, a Brazilian medical scientist and co-producer of now authorised immunostimulant drugs to treat autoimmunity, refers to one's abandonment of one's own medical premises as a basic condition to embrace new scientific truths, premises, knowledge and medical practices. Specifically, Dr. Rosa used this term to refer to a condition for the process of inclusion of new members into his laboratory team. '*In order to make part of the team*', he explained (personal communication in March, 2017), '*the new member has to uninstall oneself*' (in Portuguese: '*desinstalar-se*').[1] I find this expression can also be extended to the processes of discontinuing or diminishing therapies based on immunosuppression as a treatment approach, to embrace other ones based on the opposite principle

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[1] This and all further translation within this chapter from Portuguese into English were done by the author.

of immunostimulation as carried out by thousands of patients with autoimmunity and some physicians in Brazil despite the associated risks.

Although I here focus on a single case study, I adopt this same strategy to approach other immunostimulant therapies which meet difficulties to be accepted by Brazilian regulatory institutions, like the *National Sanitary Surveillance Agency* (ANVISA), as part of my broader anthropological research on their development, circulation and regulation. This combination of methods and concepts allows me to experience and apprehend displacements and the crossing of regulatory borders within the contemporary biomedical world of immunology, and between biomedical and non-biomedical worlds. These translational movements, as I have been learning, are important for the re-creation and regeneration of established biomedicine itself. By accompanying the struggles for legitimacy and linked regulatory processes involving the adoption and use of contrary immunotherapies within a Brazilian context, it became possible for me to locate the global (Latour 1987) and to initiate the production of ethnography of immunostimulant therapies as innovations for autoimmunity from a Global South perspective (Medina et al. 2014).

In what follows, I first present basic premises on which my anthropological study on scientific innovation within immunology is based, and I emphasise key aspects of ethnographizing immunology and biopolitical materials. I then posit myself as a kind of first ethnographic location where my research began. I describe how, through my own crossing of boundaries, I was able to become an interstitial point between different biomedical therapeutic models. Next, I highlight some implications of exploring my individual experience as part of a collective enterprise by delineating aspects of life assemblages for the promotion of immunostimulants to treat autoimmunity. I will then show how members of these life assemblages informally seek to confer legitimacy to immunostimulant drugs for autoimmunity by publicly producing forms of medical evidence more acceptable to patients than those produced through biomedically authorised clinical trials. Finally, I resume my argument about how my strategy to weave ethnography of immunostimulant therapies and respective drugs helps to retrace associations and map relations that have constituted immunostimulants as travelling biotechnological innovations and, simultaneously, as objects of medico-legal dispute.

Ethnography of Non-authorised Immunological Materials

As some studies have shown, it is not only possible but crucial to research immunity from an anthropological perspective as a way to understand contemporary societies (e.g. Moulin 1996; Haraway 1991; Napier 2012; Davis et al. 2016). If particular interpretations and conceptualisations of immunity are produced under specific cultural settings, which are in turn expressed and reproduced by their conceptualisations of immunity, then to apprehend changing perceptions and attitudes related to the immune system may be useful to understand social change at various levels. For instance, the very notions of autoimmunity and of immunity as 'defence system' as based on the idea of the body as nation state, and the acceptance of immunosuppressants, became hegemonic only after the Second World War (see, particularly, Martin 1990). Among other factors, this change related to changing perceptions on the causality of the diseases associated with autoimmunity, to the persistence of the Western Christian idea of human nature and of this as inherently evil (e.g. through the 'original sin') within science, and to the oblivion of concurrent conceptualisations of the body, such as the so-called principle of 'horror autotoxicus', i.e. '*[…] the unwillingness of the organism to endanger itself by the formation of toxic autoantibodies*' (Silverstein 2001: 279).[2]

One may speak of immunology but also of *immunologies* within life sciences (Moulin 1989, 1996). Likewise, one can also refer to immunologies found 'outside' biomedicine, in a more symmetrising sense, as far as there are multiple non-biomedical actors engaged in conceptualising, organising and manipulating immunity. From an anthropological

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[2] For a social history of the development, controversy, acceptance and establishment of the idea of autoimmunity, see also Anderson and MacKay (2014).

perspective, a central issue concerns the ways in which different people in specific places and times differently conceive what can be understood or recognised as immunity, including related notions of person and moralities that inform how one should deal with it.[3] It has further political implications. Because drugs that alter the immunity and, therefore, people's bodies are biopolitical materials, they should be formally sanctioned by institutionally recognised authorities and their corresponding systems to move along legally established pharmaceutical paths (see, e.g., Lezaun 2012). Lakoff (2007), for instance, claims that researchers should look at the connections that pharmaceuticals need to circulate as authorised substances among multiple social spheres. Building on that, my research inversely complements Lakoff's claim. For example, I ask: Where do drugs go when they are impeded from moving along a legally predefined path?

By focusing on non-authorised immunological therapies as sets of practices that co-constitute biomedicine and persons, and by taking their associated drugs as vehicles, it is possible to move through the institutional entanglements in which these practices are embedded. I observe how other people, physicians and patients do the same and use immunological drugs to navigate between official and unofficial health care paths. Through this, I identify a further set of actors who co-regulate immunity through *other* biomedical ways of understanding and dealing with it that counter established biomedicine. While immunosuppressants as conventional pharmaceuticals appear to most people as non-controversial biotechnologies—or, as Latour (1987) would say, 'blackboxed'—I begin to follow immunostimulant therapies used to treat autoimmunity in Brazil as 'science in the making', that is, as biotechnological innovations whose medico-legal controversies are still open (ibid.). I consider which marks these therapies carry in their

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[3] The current established discourse on autoimmunity addresses the question 'how to live with it'. But there is a trap there in the sense that the idea of chronicity (e.g. to refer to the unavoidability's character of autoimmunity) is already embedded ('installed', so to say). And that is exactly what immunostimulant users challenge: the very idea of 'having to' live with it. Because of that I think that when I use 'deal with', I do not automatically take for grant the premise that autoimmunity is necessarily uncurable.

movements through Brazilian society; what these therapies leave behind them; and how they affect people, institutions and environments, and vice versa.

Of Two Initiations, or When the Experience Comes Before the Ethnographic

In early 2009, shortly before I travelled to Brazil to spend one year as part of the fieldwork for my doctoral study, I was diagnosed with psoriasis arthritis in Germany. Like lupus, diabetes and Sjögren's syndrome, psoriasis arthritis belongs to those hundreds of conditions that comprise what medical specialists call autoimmune diseases (Cooper et al. 2009). My diagnosis was a one-way entry ticket to the immunosuppressing biomedical world of autoimmunity, to which physicians, immunosuppressants and immunocompromised persons belong. In this world, the discourse of chronic disease poses inevitability to the condition, such that all one can do is to try to decelerate one's premature process of self-decomposition. Immediately after being informed of my diagnosis, I started taking a cortisone-based drug at the hospital and then, following a visit to a rheumatologist doctor, I began treatment using methotrexate (MTX).

As any other rheumatic patient, I was instructed by my rheumatologist to learn about my condition, to seek what may be good for my health and to monitor myself so as to avoid things that could cause immune reactions. This could include the food I eat and the liquids I drink, among other everyday things. The rheumatologist prescribed 15 mg of MTX per week to be taken for six months initially. This initiation into the world of chronic diseases as a patient only took a couple of days. When I left Leipzig, after having passed through biomedical environments such as the clinic, the medical office and the drugstore, I arrived in my home country, Brazil, to carry out fieldwork as an immunocompromised person. However, it was by following the medical instruction of seeking what might be good for my health independently of my use of MTX that I would paradoxically reach a position contrary to that stated by the established immunological reality, which had only so recently comprised my entire education about autoimmunity.

During my stay in Brazil, mainly in the southern state of Bahia, I learned as much I could about *my* disease, and also about how other people deal with it. I used the Internet a lot and encountered several blogs by people reporting their therapeutic experiences, the progression or remission of symptoms, the use of immunosuppressants and people's comments on these. I began to notice a few individual commentaries left by forum participants on different Internet sites recommending an 'anti-brucellic vaccine' (*vacina anti-brucélica*, VAB) to 'cure' arthritis. At first, I thought someone wanted to cheat the other participants. But then I saw a post by a man who briefly reported his own experience with this vaccine, and who left his contact details for information. Provoked by this story, I phoned him and, from Brasília, where he lives, he confirmed what he had posted, complementing it further, while also mentioning other people with a similar perspective. He then provided me with the contact details of the scientist who was producing and commercialising the vaccine, Dr. Veiga. I also contacted other people who wrote about their experiences with the vaccine on the Internet and paid attention to their comparisons with the conventional treatment for autoimmunity, immunosuppressants.

By this time, I was already following the VAB by searching for information about it on the Internet and by phone. In a certain sense, by doing this I was being inoculated by the VAB into networks of people engaged in promoting the *vacina* through the exchange of non-authorised or unforeseen therapeutic practices, knowledge and experiences. These networks were partially closed and partially opened in the sense that most of participants were VAB users and used to exchange experiences among themselves, and, simultaneously, their goal was also to disseminate the use of the VAB. Everyone could accompany discussions without having to be a member of these networks.

During my movements through these networks, I also found out that this vaccine had been forbidden by ANVISA in October 2005 because it was not officially registered as a pharmaceutical. At the same time, the stories and explanations that I heard, and the texts on the vaccine and its effects that I read, offered me a completely new view about immunity and how to treat my immune system, which was supposedly 'wrong' or 'crazy' because it was attacking itself. I found the arguments of the vaccine users more convincing. The official discourse on autoimmunity began to appear to me as a sort of non-explanation on autoimmunity mechanically repeated by established biomedical authorities who apparently associate fatalism and pessimism (e.g. through the chronicity of autoimmunity) with realism. For instance, the current biomedical strategy of, through immunosuppressants, damaging the sick body as a way to avoid the body damaging itself was—in the words of Dr. Veiga—'*an act of desperation*' of biomedicine, given that, '*they don't know what to do; they don't see another option*' (personal communication in July, 2012). Not having much expectation regarding the palliative treatment, and instead feeling myself very harmed through the MTX's side effects, I decided to shift my therapy, despite the medico-legal controversy around the VAB and other immunostimulant therapies.

As part of my initiation into the unofficial biomedical world of immunostimulants, I stopped taking MTX and, two weeks later, started taking the VAB. Rather than living as an immunocompromised person, I began to live as an immunostimulated one. In the face of the improvements I experienced following the use of the VAB, I decided to start to conduct research about it as a controversial scientific innovation. Among several questions which I encountered on my way, I wanted to know what it meant to shift my therapy: What does this apparent incommensurability between these two therapeutic models of immunosuppression and immunostimulation imply?

The methodological challenge that emerged was how to use my own individual experience as a primary translational resource and instrument to apprehend changing biomedical cultures 'from within' and, with that, to turn my personal therapy into ethnographic research by integrating it into new biotechnological settings as one among several other therapeutic narratives. By focusing on the collective significance of my individual experience (an auto-ethno-graphic becoming by then), I began to convert the knowledge that I have been developing on the effects of the VAB on my immunity into relevant materials for an anthropological study, while being mindful to avoid self-absorption and solipsism (Greenhalgh 2001). Ever since, this posture has been helping me to balance and use the tensions between auto (self) and ethnos (people) within my fieldwork settings as to weave ethnography of immunostimulants to treat autoimmunity in Brazil in a symmetric way.

Delineating Life Assemblages from Within

I began to research immunology as situated in the intersections between scientific innovation, informal markets and drug regulation as a participant of a non-official pharmaceutical circuit, as well as a doctoral student. I became one among other immunostimulant users who were exchanging non-authorised therapeutic knowledge and practices on the Internet and personally. I maintained phone contact with Dr. Veiga, until recently the main VAB manufacturer, from 2009 onwards, and had the opportunity to meet him personally and conduct long talks with him in 2011 and 2017. In keeping with this spirit, I met other people engaged in promoting the VAB and other immunostimulants that encounter difficulties in achieving acceptance among established biomedical authorities. I also communicated my experience with the VAB to three physicians in Brazil (a homoeopath, a nutritionist and an allergologist), and to further two in Germany (my rheumatologist at that time and a general practitioner who is a personal friend). I also met other physicians in Brazil. However, by seeing how sceptical or afraid some of them were of immunostimulants, I became aware of further difficulties in considering immunostimulation as a possibility to treat autoimmunity. These difficulties encompass not only the general distrust in the pharmaceutical industry, which I found among immunostimulant promoters and further physicians in Brazil, but also concerns, e.g. the established medical knowledge as taught in medical schools and the fears associated with becoming tabooised with medical communities, i.e. professionally contaminated through contact with a non-approved drug.

As a member of an Internet group organised to promote the VAB and while exchanging information about the application of the VAB with other members, I learned about the common interests of people experiencing the same therapeutic shift that I went through and about other people in changing conventional therapies and about the risks implied. The networks formed by these members who rarely knew each other personally seemed to be apprehensible through the concept of life assemblages as heuristically formulated by Sleeboom-Faulkner '[…] *to define communities that share questions related to the definition of what is "a life worth living"*' (2014: 2). According to Sleeboom-Faulkner,

> A life assemblage develops under particular socio-economic conditions, shifting boundaries of knowledge, changing conceptualisations of the body, and forms of political organisation that underlie activities of assembling and reassembling life through technological interventions. (Sleeboom-Faulkner 2014: 2)

Following the VAB was therefore a way to help delineate life assemblages engaged in its promotion.

Sparsely but systematically, from 2009 until the present day, I have been accumulating different kinds of research materials. I have done this through complementary means of participant observation, such as open interviews and conversations, digital methods and/or virtual ethnography, and archive research. I have been including in my set of research materials: descriptions of clinical procedures, prescribing data, conversations and debates on VAB sites, homepages and channels; conversations and life stories; documents at local and global institutions, including on their websites; media reports; and other scientific literature. Throughout the production and accumulation of these materials, I have also organised and interpreted them across three co-extensive analytical axes.

The first axis concerns the development and production of the VAB. Through a historical reconstitution of the VAB, I seek to reveal traces and elements through which the VAB becomes a form of scientific innovation, tracing how this is achieved, and the actors and networks involved in its composition and its successive re-appropriations. This method of analysis helps me understand at first seemingly unrelated historical processes, which are formative to the trajectory of innovation and future potentiality, including the discovery of the Brucella during the Crimean War; the models of teaching about brucellosis in medical schools during the first half of the twentieth century; the development of a vaccine against Brucella; the national and global politics of eradication of brucellosis; and the consequent reworking of Brucella-based materials in the beginning of the 2000s, for example as an immunostimulant (Vilar 2018).

The second axis covers the VAB's circulation and constraints: I here examine medico-legal discontinuities, negotiations and re-appropriations of the VAB. This encompasses: the recognition and acceptance of an effective vaccine against brucellosis as one among multiple possibilities; the use of Brucella itself as raw material to manufacture an innovative drug and thereby the eventual relations between Brucella and autoimmune diseases; the question of whether the VAB is or not a vaccine[4]; and the clinical tests that are required by regulation to be registered.

The third axis regards the perceptions and attitudes of VAB users: I have been apprehending how VAB users respond to the regulatory acts of established authorities, calling particular attention to their uses of the Internet as a means of sharing knowledge, contesting legitimate regulatory agencies and referencing other immunostimulating therapies. Likewise, this analytical axis also refers to the physicians' activities, for example, to deal with legal constraints. In the case of the VAB, seeing that ANVISA would never approve any drug containing Brucella, Dr. Rosa and Dr. Pacheco reformulated it in such fashion that no Brucella can be found in its new composition. Instead, they are now offering the so-called Complex of Essential Amino Acids (CAE, *Complexo de Amino-Ácidos Essenciais*) which imitates the immunological properties of the VAB and, therefore, may be seen as an evolution of it and, simultaneously, as another drug. For these reasons, and to capture the dynamic tensions of its ambiguity, from this point onwards I will refer to it as VAB/CAE.

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[4] There was controversy around whether the VAB is a vaccine or not because the definition of vaccine depends not only on its composition but also on its use: one extracts and inoculates material of a specific antigen to immunise the body against this specific agent. But if one takes a vaccine developed for a specific disease and uses it against another one whose aetiologic agent has nothing to do with its composition, then it is not a vaccine. That is also the understanding of ANVISA (2005).

Immunostimulant Users as Co-producers of Medical Evidence

Because my research project is essentially an anthropological one, I pay more attention to the third analytical axis that I use to articulate the other two subanalyses. That is, I subsume historical reconstitution and regulatory constraints of the VAB/CAE to the VAB/CAE users' perceptions and attitudes towards (including their narratives on) their medico-legal experiences as an expression of a particular biotechnological and immunological culture. For instance, the following statement, posted by Débora in July 2016 in a Facebook group for the VAB/CAE publicly accessible on the Internet, plunges us into the core of what my research topic became:

> I have lupus and arthritis. I found out about that three years ago.
> I took corticoids. It was horrible. I had several side effects.
> I was afraid to keep taking medication that do more harm than good.
> I started taking the vaccine only 20 days ago. But it is natural and I've read reports of so many people who have cured themselves [with it].
> As one takes it twice a week, I took only a few. But I felt that my knee hurts a little more; my toes are less swollen.
> I think, it is not very normal to not try something [a therapy, a new drug] that may cure you. When doctors give us this pile of medicines, sometimes we do not question them, even if we know that they do not cure [us]. Why [then do] some [people] question so much the medicine that cures [us]?
> Of course, it may not work for everyone. However, how many drugs do the rheumatologists give us that do not solve the problem?

Débora's questioning seems to resonate the longing of many other patients with autoimmunity and who are potential immunostimulant users: What sense does it make 'to have to learn to live with' chronic pain and suffering, with all the severe consequences for their lives and dignity, if there may be one or more therapeutic possibilities 'to cure' or relieve it? At least for her, there was not much to lose, as she continues the dilemma by asking: '[…] *how many drugs do the rheumatologists give us that do not solve the problem?*'.

Like Débora, despite contrary professional advice, thousands of people with autoimmune diseases and also some physicians in Brazil have stopped using immunosuppressants and have begun to speak from 'cure'—a word profoundly tabooed within established biomedicine in relation to autoimmune 'chronic' diseases. This shift becomes clearer when one pays attention to the responses that Débora received to her Facebook post, which became a dialogue involving five people. Margarida, the first commentator, described how, despite her experience of using VAB/CAE as sometimes painful, she recovered within a few months because of persisting with the VAB/CAE. Noteworthy is her comparison between her health state before and after her use of it: '[…] *Of course I still feel some pain and insecurity when I walk, but nothing that compares to what I experienced before the anti-brucellic vaccine* […]'. Suzana identified her and her mother as arthritis patients who were '*victims of cortisone*'. In contrast to her mother, Suzana '*was fortunate enough to meet the vaccine*' and became '*cured*'.

Thaísa, a lupus patient who was taking the VAB/CAE, reported her improvements with the vaccine. She did this by comparing the amount of drugs for pain that she used to take before and after the new treatment. As a VAB/CAE user, she significantly diminished her consumption of drugs for pain, which now she only takes '*to sleep quiet*', while before that she used to take '*beyond the prescribed amount*' without the expected results: '*I followed the conventional treatment for more than 5 years and* [during this time] *it only got worse; just more side effects have appeared*'. Sometimes, she also experienced pain when changing the dosage of the VAB/CAE. However, as she puts it, '*as time passes there are more good days than bad days*'.

Débora went on to explain that she wanted to help others to overcome their doubts and insecurities concerning the VAB/CAE. She felt disappointed and found it difficult to understand how people still could cope with conventional treatment that is so harmful instead of trying something new. She expressed this by means of a metaphor: '*it seems that the person opens a hole* [and then] *enters into it and do not want to come out of it!*'. In the Facebook chat, Thaísa agreed with Débora and restated how her health was compared to how it is now, after the VAB/CAE. She explained that '*nothing is magic, nothing is spontaneous*' indicating how the VAB/CAE is a therapy that requires time to be effective. Finally, Tanya gave her testimony by telling the therapeutic experience of her mother with the VAB/CAE. She affirmed that after eight months of treatment, her mother '*rarely feels any pain*'. As others had done in this dialogue, she referred to the health state of her mother before and after the VAB/CAE as a radical turning of the tide. In all their posts, the participants encouraged each other to keep using the VAB/CAE.

As further dialogues that I observe on Internet fora demonstrate, the participants' accounts show how the individual suffering and perspectives of recovering from VAB/CAE users—as different as their realities may be and despite not knowing each other personally—are transformed into interpersonal experiences of getting sick and recovering. Likewise, their statements express strategies developed to deal with biotechnological innovations, while they evaluate their therapeutic options independently of physicians but as sharers of a common (auto) immunological destiny. Moreover, the therapeutic knowledge generated among the immunostimulating users may be understood in those terms in which Ingold refers to the knowledge of practitioners. That is, it

> … *comes from a lifetime's experience of working* with *the material* [for example, immunological drugs]. *This is a knowledge born of sensory perception and practical engagement, not of the mind with the material world* […] *but of the skilled practitioner participating in a world of materials.* (Ingold 2010: 30)

Immunostimulant users are, thus, engaged in reshape themselves as immunologically capable persons.

To include my own experience into this set of narratives, I now recall that I first left the world of healthy people when I was diagnosed with psoriasis arthritis and automatically began the use of immunosuppressants. I was initiated a second time into a new biomedical world when I began to take and follow the VAB/CAE as a non-approved immunostimulating therapy for a couple of years. After having used the VAB/CAE, I considered myself to be back in the world of healthy people, although not under the same circumstances, which prompted me to ask myself whether I was properly ‘re-installed’ and which displacements did these initiations allow me to experience.

Conclusion

Taking and following immunological drugs are the primary instruments I use to weave an ethnography of non-authorised immunostimulants to treat autoimmunity. The following and, consequently, *moving with* immunostimulants as materials, enabled me to learn how the emergence of new and changing perceptions about established biomedicine may coincide with the experience of moving between different therapeutic models. This became clearer when I took into account my own therapeutic case as part of a broader set of therapeutic narratives of people who share the experience of ‘uninstalling themselves’ and of compounding life assemblages for immunostimulant treatments.

To uninstall oneself appears, on the one hand, as a condition to stop being an immunocompromised person and to become an immunostimulated one. On the other, it consists of a process which requires considerable research, deep reflection and careful decision-making. Thus, it stands in opposition to the medical practices through which patients with autoimmunity are rapidly and almost mechanically absorbed into a system of palliative care that uses immunosuppressants supported by the belief in the inevitability, or chronicity, of autoimmunity. In this sense, the trajectories of immunostimulants in Brazil reveal aspects of how people who engage with non-authorised knowledge about immunostimulants and adopt them to treat their autoimmunity seek to re-assume and reorganise the destiny of their lives, taking it at least partially back from established biomedicine by moving along marginalised regenerative biomedical circuits. Through this, immunostimulant users reposition themselves and others around them, including biomedical, regulatory authorities and the set of diseases and substances associated with autoimmunity.

By sharing their experiences of illnesses and recovery, VAB/CAE users are co-producing evidence that, in my opinion, is often considered more valuable by immunostimulant users and potential users than the clinical evidence produced to keep immunosuppressants legitimate in biomedical terms. The dialogues between immunostimulant users that I have presented in this chapter show how the participants, as members of life assemblages that overlap each other, may argue for the legitimacy of immunostimulant therapies as effective biomedical innovation to treat autoimmunity. At the same time, these dialogues which promote immunostimulants to treat autoimmunity tend to disqualify established immunosuppressants by reopening them as controversial biotechnologies.

While following immunostimulants for autoimmunity, I discovered a set of non-authorised or invisible 'others' who are differently integrated and committed to dealing with the issue of how immunocompromised bodies should be treated. These others may be seen as co-regulatory actors who move through multiple channels and coinhabit places such as local clinics, medical offices and drugstores, Internet sites, post offices and private spheres. To follow the VAB/CAE means to align my attention during my participant observation to the attentions and association with which the VAB/CAE has gained in its struggle for regulation. Thus, following immunostimulants in this way enables me to have a view on how medical knowledge, evidence and practices can be co-produced and co-regulated at the same time as I come to know about other conceptions of illness and health and respective biopolitical agendas and artefacts.

The fact that I started using the VAB/ACE as my main case study opened the possibility for me to begin to forge a critical understanding of how scientific innovation, established biomedicine and informal health care coexist and interface in contemporary Brazil, and how their relations are mediated by sometimes contrary regulatory institutions and respective co-regulatory actors. The ethnographic methodological strategy of following these drugs as travelling biotechnological artefacts enabled me to apprehend current ideas of person and moralities that were expressed through different understandings of (auto) immunity, body and medico-legal institutions.

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References

Anderson, W., & Mackay, I. (2014). *Intolerant Bodies. A Short History of Autoimmunity*. Baltimore: John Hopkins University Press.

Andrews, A. (2011). *Autoimmunity: Deconstructing Fictions of iIlness and the Terrible Future to Come*. PhD thesis, Goldsmiths, University of London. Available from http://eprints.gold.ac.uk/6920/. Accessed December 2, 2017.

ANVISA. (2005). Anexo: Regulamento técnico dos procedimentos de registro, de alteração pós-registro e revalidação de registro dos produtos biológicos terminados. *Diário Oficial da União, 209*(31/10), 58–62. Available from https://www.jusbrasil.com.br/diarios/6009658/pg-59-suplemento-secao-1-diario-oficial-da-uniao-dou-de-31-10-2005. Accessed December 2, 2017.

Cooper, G., Bynum, M., & Somers, E. (2009). Recent insights in the epidemiology of autoimmune diseases: Improved prevalence estimates and understanding of clustering of diseases. *Journal of Autoimmunity, 33*(3–4), 197–207. Available from https://doi.org/10.1016/j.jaut.2009.09.008. Accessed December 2, 2017.

Davis, M., Flowers, P., Lohm, D., Waller, E., & Stephenson, N. (2016). Immunity, biopolitics and pandemics: Public and individual responses to the threat to life. *Body & Society, 22*(4), 130–154. Available from http://journals.sagepub.com/doi/pdf/10.1177/1357034X14556155. Accessed December 2, 2017.

Greenhalgh, S. (2001). *Under the Medical Gaze. Facts and Fictions of Chronic Pain*. Berkeley: University of California Press.

Haraway, D. (1991). The biopolitics of postmodern bodies: Determinations of self in immune system discourse. In *Simians Cyborgs and Women: The Reinvention of Nature* (pp. 203–230). New York: Routledge.

Ingold, T. (2010). *Being Alive: Essays on Movement, Knowledge and Description*. London and New York: Routledge.

Ingold, T. (2014). That's enough about ethnography!. *Hau: Journal of Ethnographic Theory, 4*(1), 383–395. Available from https://www.journals.uchicago.edu/doi/pdfplus/10.14318/hau4.1.021. Accessed April 9, 2018.

Lakoff, A. (2007). The right patients for the drug: Pharmaceutical circuits and the codification of illness. In E. Hackett, O. Amsterdamska, M. Lynch, & J. Wajcman (Eds.), *The Handbook of Science and Technology* (pp. 741–759). Cambridge, MA: MIT Press.

Latour, B. (1987). *Science in Action: How to Follow Scientists and Engineers Through Society*. Cambridge: Harvard University Press.

Lezaun, J. (2012). The pragmatic sanction of materials: Notes for an ethnography of legal substances. *Journal of Law and Society, 39*(1), 20–38. Available from http://onlinelibrary.wiley.com/doi/10.1111/j.1467-6478.2012.00568.x/epdf. Accessed December 2, 2017.

Martin, E. (1990). Toward an anthropology of immunology: The body as nation state. *Medical Anthropology Quarterly, 4*(4), 410–426. Available from http://onlinelibrary.wiley.com/doi/10.1525/maq.1990.4.4.02a00030/pdf. Accessed December 2, 2017.

Medina, E., da Costa, I. M., & Holmes, C. (Eds.). (2014). *Beyond Imported Magic: Essays on Science, Technology, and Society in Latin America*. Cambridge, MA: The MIT Press.

Moulin, A. (1989). The immune system: A key concept for the history of immunology. *History & Philosophy of the Life Sciences, 11*, 221–236.

Moulin, A. M. (1996). Un objet scientifique à la charnière des sciences biologiques et sociales : le système immunitaire. *História, Ciências, Saúde—Manguinhos, 3*(2), 300–318. Available from http://www.scielo.br/pdf/hcsm/v3n2/v3n2a06.pdf. Accessed December 2, 2017.

Napier, D. (2012). Nonself help: How immunology might reframe the enlightenment. *Cultural Anthropology, 27*(1), 122–137. Available from http://onlinelibrary.wiley.com/doi/10.1111/j.1548-1360.2012.01130.x/epdf. Accessed December 2, 2017.

NIH (National Institute of Health). (2016). *Understanding autoimmune diseases*. National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Department of Health & Human Services—USA. NIH Publication No. 16–7582. Available from https://www.niams.nih.gov/sites/default/files/catalog/files/understanding_autoimmune.pdf. Accessed November 28, 2017.

Policy Department of European Parliament (Ed.). (2017). *Autoimmune Diseases—Modern Diseases*. Directorate General For Internal Policies. Policy Department A: Economic And Scientific Policy. Study for the European Parliament's Committee on Environment, Public Health, and Food Safety. Brussels: European Union. Available from http://www.europarl.europa.eu/cmsdata/133620/ENVI%202017-09%20WS%20Autoimmune%20diseases%20%20PE%20614.174%20(Publication).pdf. Accessed April 9, 2018.

Silverstein, A. (2001). Autoimmunity versus horror autotoxicus: The struggle for recognition. *Nature, Immunology, 2*(4), 279–281. Available from https://www.nature.com/articles/ni0401_279.pdf. Accessed December 2, 2017.

Sleeboom-Faulkner, M. (2014). *Global Moralities and Life Science Practices in Asia—Assemblages of Life*. London and New York: Palgrave Macmillan.

Vilar, M. (2018, in press). Moving between 'chronic diseases' and 'secret cures': Bionetworking in the context of autoimmunity in Brazil. *Curare – Journal of Medical Anthropology, 41*(1+2).

WHO (World Health Organization). (2017). *Noncommunicable Diseases Progress Monitor 2017*. Geneva: World Health Organization. Available from http://apps.who.int/iris/bitstream/handle/10665/258940/9789241513029-eng.pdf?sequence=1. Accessed April 9, 2018.

14

Knowledge Infrastructures of Air Pollution: Tracing the In-Between Spaces of Interdisciplinary Science in Action

Emma Garnett

Introduction

This chapter draws on findings from ethnographic research conducted as part of an interdisciplinary scientific project studying the relationship between air pollution and health. I focus on data practices and how the informational and material capacities of data made visible the process of interdisciplinary knowledge making. From there, I reflect on my ethnographic methods and how these unfolded in relation and in response to my interdisciplinary co-collaborators. Rather than stable identities, I consider disciplines in terms of how they are performed. Interdisciplinary research characterises contemporary science and the conduct of public health research. Social scientists are often key contributors to these epistemic milieus. I was embedded in the interdisciplinary project as a Ph.D. student, whilst ethnographically

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E. Garnett (✉)
Faculty of Life Sciences and Medicine,
King's College London, London, UK
e-mail: emma.garnett@kcl.ac.uk

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studying the knowledge production process. Learning to adapt, attune and respond to the practices and processes of research meant I observed and experienced the organisational, social, epistemic and material reconfigurations of interdisciplinary relations. Key to the continuation of research was informal technologies of collaboration. Ultimately, these became relational sites for examining interdisciplinary science in action. I came to understand these sociotechnical configurations as 'informal infrastructures' that enabled data sharing and thereby the construction of joint knowledge about health.

Ethnographies of Science

Ethnographic studies of knowledge often come under the rubric of science and technology studies (STS). In the 1980s and early 1990s, laboratory ethnographies demonstrated the myriad ways in which science is entangled with its social, cultural, economic and political contexts (Latour and Woolgar 1986). Unlike previous philosophical and historical studies of science that emphasised the unique status of science in the western world (Merton 1973), critical social scientists have shown that science is constructed much like any other social or cultural form. Ethnographic methods enable exploration of the everyday work of science, so that objects of knowledge, such as model organisms or randomised control trials, become things that are processual and relational rather than fixed and abstract. What ethnographies of science have shown is that seemingly mundane, pragmatic concerns are very much entangled with epistemic issues and ontological concerns around the status of 'the real' and 'the natural'.

Attending to material practices therefore opens up the social, cultural and political dynamics of science for further investigation. As Mol's (2002) well-cited dictum the 'multiplicity of practices' makes so apparent, sociological and anthropological research must be attentive to the situated contingencies and material relationalities of knowing *and* doing (Law 2004). Significantly, this has expanded the remit of 'the social' to include non-human actors, materialities and more-than-human processes. Taking seriously living things like cells, plants and microbes (Landecker 2007; Kirksey and Helmreich 2010; Myers 2015), or technical objects like scientific instruments and data (Burri and Dumit 2007; Edwards 2010) as agential actors, demonstrates the distributed potentialities of human and non-human formations. Indeed, starting from a point of multiplicity means that rather than different ways of knowing health we are dealing with other ways of doing health. This has theoretical and methodological implications because prevailing ways of framing issues (e.g. by approaching air pollution as a human concern rather than a chemical process), and the normative assumptions embedded in these, can also be challenged. Ethnographic engagements with science can also be enacted through interdisciplinary research and experimental projects. For example, social scientists have contributed to the framing of policies (e.g. anthropologist Marilyn Starthern is member of the Nuffield Council on Bioethics) and designing of health and care (Rodríguez Giralt and Sanchez Criado 2016). Ethnographic methods, then, are not just ways to study science but critical opportunities to intervene in the conduct of science and contribute to its unfolding.

Examining Interdisciplinary Knowledge Making of Air Pollution

Air pollution is a ‘matter of concern’ (Latour 2004); a gathering together of different fields of expertise, policymakers and publics. Rather than matters of fact, Latour attempts to de-objectify scientific things by foregrounding the ways in which they are presented as concerns: affectively charged, complex and historically situated. By making visible the thinking and presentation of data, and their association with care for human health, this chapter attempts to foreground the collective ways in which researchers and data compose air pollution (Puig de la Bellacasa 2011). The status of something as polluting results from its considered harmful effects. Expertise in atmospheric and environmental chemistry can help model and measure what is in the air. However, without epidemiological methods it is not possible to work out what these numbers mean for human health. Thus, rather than approaching disciplines as ways of seeing one world, and interdisciplinary research the combining of different perspectives, data practices are contingent, practical and messy sites where interdisciplinary knowledge emerges and matters of concern take form.

Our methods for studying science in action need to be able to traverse these divides, gaps and tensions. Generating more data, and sharing these data between disciplinary fields of expertise, are often proposed as novel and effective ways to advance knowledge of air pollution and health (a funding call by the Natural Environment Research Council in 2016 was dedicated to exploring these opportunities). Yet, as Edwards et al. have pointed out, if '*datasets become increasingly commoditized, mined, and exchanged among distant disciplines, this area needs much closer scrutiny*' (2011: 669). Concepts such as boundary objects (Star and Griesemer 1989), immutable mobiles (Latour 1990) and the technologically mediated spaces of trading zones (Galison 1996) have been used to understand and make sense of the translation work that takes place between different fields of practice. The argument goes that objects take on the shapes they do because they act as boundaries or crossing points between different social groups with different cultures (Law and Singleton 2004). If scientific objects can be interpreted differently through situated epistemic practice then they must be relatively flexible in character. These kinds of emergent formations have been described by Latour as immutable because they hold their shape despite being mobile (Latour 1990).

Nonetheless, boundary-crossing practices are inherently fluid and unstable formations and processes. Indeed, every movement of data across an interface, such as between epidemiologists and social scientists, represents a point of resistance where data may be garbled or misinterpreted. In social systems, '*data friction*' creates disagreement in ways that make them sites of inexact, unruly processes (Edwards et al. 2011: 670). Unlike the conceptual tenor of boundary objects or trading zones, data friction leads to the construction of analytical, material formations that participate in scientific research. Edwards et al. (2011) talk about '*meta-data*'—the data that describes data—as the social and material work that enables data to travel between different social and disciplinary groups. In a similar vein, Leonelli's (2010) term '*packaging*' captures the role of labels, vehicles and expertise in aiding the movement and translation of data between epistemic cultures. The material form of data highlights the significance of the ways in which data are presented and how these can potentially help researchers use data generated by others. These kinds of packaging processes temporarily liberate data from its context of production, transforming data into non-local entities that can be recruited for use in new and different contexts (Leonelli 2008, 2009).

Although part of, or arguably essential to, research, friction between different epistemic practices requires ongoing maintenance and repair. Such work is often invisible, however. To try and understand this, Star's critical analysis of the concept of infrastructures, developed through her research on invisible labour has sought to foreground the taken for granted and/or undervalued dimensions of knowledge making (Star and Ruedhler 1997; Star 1999). Building on Star's work, Bowker et al. define infrastructure as '*a broad category referring to pervasive enabling resources in network form*' (2009). In accounting for the material, social and organisational dimensions of infrastructure, infrastructures can be approached via their human-technological components and the ways in which these interrelate. From a starting point of infrastructure, the generation of metadata and the process of packing both illustrate the instrumental role of less visible kinds of work and material forms that support the mobility of data and knowledge (Graham and Thrift 2007). I suggest that it is in the breakdown and repair of the '*practical equilibrium*' (Graham and Thrift 2007) required for achieving interdisciplinary research that new insights into research objects and processes, and their social relations, can emerge. Indeed, Graham and Thrift's work on repair and maintenance suggests that it is in 'the visible' (e.g. data friction) and 'the concealed' (e.g. packing practices) practices of research that the invisible labour of scientific knowledge is made perceptible.

For an ethnographer studying multisited, interdisciplinary research, data were a way to explore this dynamic of visibility and concealment. Rather than combining data to make new inferences about air pollution, the opening up of data in the work of repair and maintenance was an opportunity to trace the products of science, its inclusions and exclusions, and thereby the social and material configuration of public health knowledge and its material discursive formations.

The WHAP Project

The WHAP project (2011–2015) involved a range of disciplinary expertise, including atmospheric chemists, environmental chemists, building physicists, epidemiologists, statisticians and sociologists. Funded by a UK environmental research council, the project was claimed as novel in its bringing together of environmental and health concerns under one research remit: developing interdisciplinary methods for measuring the short-term health effects of air pollution. The aim of my ethnographic research was to examine the ways in which interdisciplinary science of air pollution is constructed, mobilised and made meaningful. The geographic configuration of the project meant that as an ethnographer I travelled between institutions and the two major cities in the UK where team members were based. This involved carrying out research in the interdisciplinary space of the weekly liaison meeting and the particular disciplinary sites of data production, including research groups with expertise in statistics, chemistry and epidemiology. These spaces were practical sites for doing research, which ranged from observing a chemistry laboratory to participating in the running of a computer model, and from sitting in on a meeting to tracing an email thread. I also visited the different research groups on WHAP and attended specific disciplinary research discussions. Much of my research, however, was conducted in one city and I used web-conferencing tools and other digital communication technologies to follow and trace the research process. Thus, I harnessed the project's methods of collaboration to develop my own ethnographic research practices.

Both principal investigators (PIs) on WHAP acknowledged the work involved to achieve good collaborative relations and research practices. The weekly liaison meetings were understood as a key space to ensure this was maintained and achieved and became a central space for conducting my ethnography. It was in attending these meetings that I came to appreciate the central role data played in everyday work. Meetings focused on the time frames of completing data sets, cleaning and curating data, accessing government data, the analysis of preliminary results and how to share these data among the team. It was the practices and processes tied up with sharing data that were informative of interdisciplinary relations. It was not simply how to share data that was interesting, but the negotiation of their meaning and material form that seemed to 'socialise' data and make them transportable.

Work on data to mobilise and socialise them, then, influenced how knowledge about air pollution and health was made. The epidemiologists planned to use the air pollution data to make health claims. To do so required input from the data producers and users, which in this case involved the environmental chemists, atmospheric chemists and epidemiologists coordinating to build a shared understanding of the nature of data: the way it is made and what it can do and say. Air pollution data include measurements of the concentration of different pollutant species in atmospheric time and space. The main species of concern generated by the UK Automatic Urban Rural Network (AURN) of monitors include ozone, particulate matter, oxides of nitrogen and sulphur dioxide. Monitors generate real-time measurements of air pollution at locations across the UK to achieve a multitude of aims: from informing environmental and health policy to providing the public with information on air quality and associated health risks.

In WHAP, there was ongoing debate around the use of a further kind of air pollution data: modelled data. Modelled data are produced by atmospheric chemistry models that work forwards and backwards in time to produce measurements of chemical species in volumetric space. The model can also be used to simulate alternative air pollution policy scenarios and to speculate how they could influence future atmospheric toxicity. Access to health data at the level of granularity that did not disclose sensitive information whilst remaining informative to the study of the health effects of exposure to air pollution also fed into discussions around the sharing and bringing together of different data in WHAP. Negotiating the shape and form of data meant interdisciplinary data practices were emergent sites for considering the wider aims and impact of research and thereby data's potential meaning and use.

Constructing Data in Multiple Ways

During my ethnographic fieldwork, I observed that it was scientific data practices rather than epistemic framings of 'air pollution' or 'health' that informed everyday work. Data were the material stuff of meetings and verbal discussions, which simultaneously transgressed disciplinary expertise and sites of practice; they were social forms as well as informational ones (Walford 2013). One of the key movements of data in WHAP was the transfer of air pollution data from the atmospheric and environmental chemists to the epidemiologists and statisticians. It was the chemists who made the data ready for the epidemiologists to use and combine with health data. Moving data between different disciplinary practices and working on multiple kinds of data were points of friction. At the same time, working on data enacted sociotechnical spaces and relations for existing and future collaboration. They were amicable as well as risky spaces. Drawing on two examples of data friction, I highlight how the organisational arrangements of scientific research relate to data practices and the research object air pollution.

Formatting Data (The Wiki Space)

> I think we should still meet on 13th June. I'm not suggesting we delay that [the bi-annual team meeting]. We will come on to the details of this in today's meeting [the weekly liaison meeting]. Umm we could use that to go through further analyses. But I think also there are some questions, err, I had a brief telephone conversation and email exchange with Elizabeth [co- principal investigator on WHAP] last week, who was clearly slightly worried following our Monday meeting [the previous weekly liaison meeting] about what we were requesting with regard to sources [air pollution emission sources] and whether they [atmospheric chemists based in city 2] could actually deliver this; the distinction between the source [of air pollutants] identity within the main epidemiology bit [of research] and the empirical data we are going to work with, as opposed to the scenario runs, which fall under [their] work package are different. (Tim, Team liaison meeting, 22 April 2013)

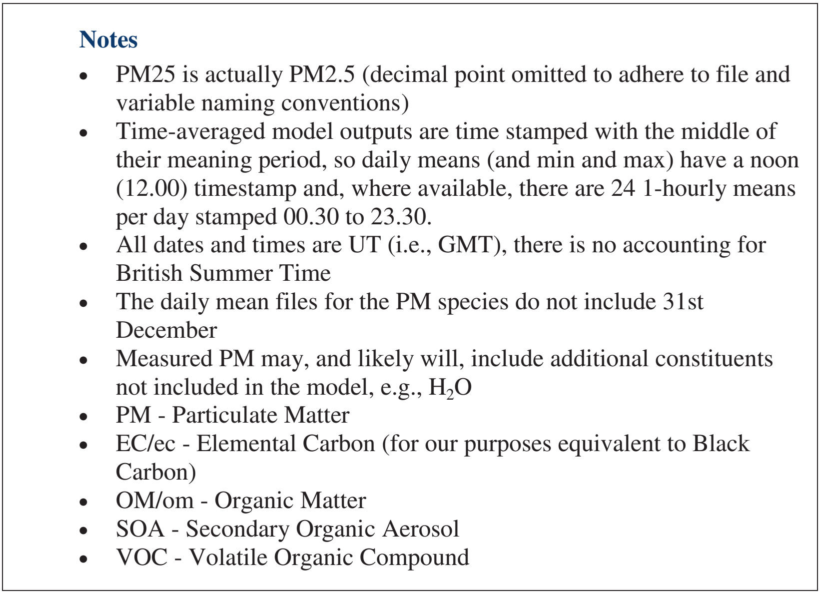
The extract above was recorded during my attendance of a weekly liaison meeting and illustrates several ways in which connections and relations were established between team members. Various modes of communication used in the project are highlighted. A phone call on one topic becomes interlaced with the weekly web-meeting and the forthcoming physical team meeting. Emails were another communication technology that tacked between shared spaces. Team meetings often ended with ‘can you pop that in an email?’ as a cue for a concern that may require further discussion and input from a selected few. A team meeting may also be initiated with reference to an email previously sent by one team member, as the opening quote shows. What these different modes of communicating across the team demonstrate are the ways in which the organisation of scientific work is fluid and the arrangements of people and data always shifting.

These different modes of communication were also used instrumentally to control information flow. On one occasion, being copied into an ongoing email thread allowed me to unpack some of the tensions involved in sharing data. I joined an email discussion between the atmospheric chemists and the epidemiologists on WHAP. The epidemiologists were concerned with the metrics of modelled data and how these compare to data generated by monitoring stations. The sources or emissions of a pollutant were understood differently by team members. The atmospheric chemists include meteorology and chemical changes in their understanding of where air pollution comes from. For the epidemiologists, pollutant sources were categorised as either traffic, agriculture, fossil fuel use and so on. Sources of air pollution were the assumed emitters of a pollutant. This is significant given that the causes of toxicity determine how research is interpreted for future policy responses. Understanding the sources of air pollution influences the kinds of health claims that are made. For example, the atmospheric chemistry modellers argued that reducing traffic is only one part of understanding a pollutant, and that there is not a direct correlation between increased emissions and increased levels of pollutants in the atmosphere. In this case, negotiating data seemed to raise questions around what toxicity and health are, both empirically and conceptually.

These more overarching queries were managed in rather mundane, pragmatic ways. One proposed option was to standardise metrics. The epidemiologists wanted to check whether the atmospheric chemistry model measured daily maximum or minimum concentrations or produced an average. Since the model simulated atmospheric processes continuously in time and space, measurements of air pollution could be manipulated and formatted to requirement. Yet this was not simple. The theoretical assumptions underpinning the atmospheric chemistry model also constrained what the data meant and how it could be used (Garnett 2017). Indeed, even though the model could generate data in any of the metrics required by the epidemiologists, the chemists were uneasy with what was being asked of them, as illustrated in the fieldnotes quoted above. This wariness led to further deliberation around what the standard metric for the project *should* be, becoming a theoretical question about the object of research as well as a rather more practical one.

Ultimately, attempts to communicate across different kinds of data of air pollution were materialised through a wiki space (Fig. 14.1). A wiki space is built through an open-source web hosting service for sharing information. One of the atmospheric chemists on WHAP managed this resource for the project. Researchers contributed to the online space so that it was continually updated with a range of disciplinary inputs. Responding to discussions that took place at the weekly liaison meetings, on the phone, or over email, the online wiki made interdisciplinary data practices 'live'. As a result, the wiki became an emergent spatial and temporal configuration for studying decisions on metrics and the formation of air pollution as a research object. As Fig. 14.1 shows, there are different ways of defining air pollution in time and space. Air pollution is either measured continually and concentrations averaged, or the mean measure produced by using the minimum and maximum concentrations over a 12- or 24-hour period. These temporal metrics were significant because air pollution is not a stable phenomenon but continually in flux and process. Researchers had to account and manage for these instabilities in their data practices. Mean measurements rather than daily averages or maximum/minimum measurements were decided upon and the negotiation around metrics concretised through its documentation in the wiki space. The wiki space therefore made the expansion and manipulation of the spatio-temporal contours of air pollution possible.

The online wiki space was live and responsive to verbal and textual discussions. The information shared and collated in the wiki functioned



Notes

- PM25 is actually PM2.5 (decimal point omitted to adhere to file and variable naming conventions)
- Time-averaged model outputs are time stamped with the middle of their meaning period, so daily means (and min and max) have a noon (12.00) timestamp and, where available, there are 24 1-hourly means per day stamped 00.30 to 23.30.
- All dates and times are UT (i.e., GMT), there is no accounting for British Summer Time
- The daily mean files for the PM species do not include 31st December
- Measured PM may, and likely will, include additional constituents not included in the model, e.g., H_2O
- PM - Particulate Matter
- EC/ec - Elemental Carbon (for our purposes equivalent to Black Carbon)
- OM/om - Organic Matter
- SOA - Secondary Organic Aerosol
- VOC - Volatile Organic Compound

Fig. 14.1 Extract from wiki page detailing shared standards

as internal *metadata* descriptives that granted air pollution data the capacity to travel and circulate among the team (Leonelli 2009). From the information provided, data could be worked on in ways that made it meaningful and relevant to other researchers. Information on how these data can be presented in different data practices was also shared in this space. For example, in the computer model the decimal point in $PM_{2.5}$ must be omitted for the file to be processed. The online and visual space of the wiki established a dynamic two-way connection between the research process and the various material outputs. As an ‘informal infrastructure’, the wiki mobilised interdisciplinary relations and managed differences *within* data. The repair and maintenance work of building and updating a shared space of research generated consensus and strengthened relations. At the same time, the material and informational contours of air pollution were delineated through the wiki, demonstrating its role in assembling socio-material, epistemic and ontological research concerns.

Linking Data

> I meet Ann in her office to learn about the data linkage process. She collects some papers and a small folder before we move to a small, private meeting room on the same floor. I had, prior to the meeting, asked if she could go through the process of using the Geographic Information System (GIS) tool to link data. I was slightly disappointed as I had ideally wanted to observe the practice and process of 'over-laying' at a computer interface. However, Ann explains that she has decided to show me more literally what the tool does by bringing print-outs to represent the various data-sets which are going to be linked computationally. She was acutely aware of how the computer interface leaves the work black-boxed and was keen to explicate it visually and in a tangible way. Sitting round a small table, Ann spreads different sheets of papers with tables of data and diagrams of grid squares explaining that there is a lot of data on the WHAP project and it is her job to ensure that these data are transformed into a format that the epidemiologists can use. Ann demonstrates the process of over-laying by placing the different pieces of paper representing data sets on top of each other, asking me to imagine the grid squares [the computational arrangement of data] as a process of layering the different data on top of each other. She does this for the pollutant, temperature, chemistry and weather data. (Fieldnotes, 9 December 2013)

Ann is an environmental epidemiologist with expertise in Geographic Information Systems (GIS). Her role in WHAP was to link the finalised air pollution data (post-wiki space discussions) with the health data and prepare them for epidemiological analysis. The work of linking data was initially considered technical rather than scientific, unlike the data cleaning or validation work which were acknowledged as crucial to data's meaning and potential reuse (Garnett 2016). Although not counted as an academic output, linking data was essential if the different data sets on the project were going to be brought together and health effects and relative risks of exposure to air pollution produce. Like the wiki space, data linkage was a kind of work on data that contributed to the informal infrastructure of interdisciplinary knowledge on WHAP.

Ann described her work as '*the last link in the chain*' of the project. The GIS tool, which enabled Ann to overlay the different data within one digital space, was referred to in the Project Protocol with a simple statement: '*each [health data set] will be linked by day and location to the air pollution and weather data […] using Geographical Information Systems methods*' (WHAP Project Protocol). The brevity of this explanation of data linkage certainly contrasted with the amount of time and energy the team members seemed to put into this process. Indeed, Ann was a key contact for all data producers on the project. Ann's responsibility to link all the different data and to produce a complete data set which everyone could access (Meeting with Ann, 9 December 2013) was a huge task considering the inevitable friction involved in sharing and de-localising data.

The health data sets used by the WHAP project include the hospital episode statistics (HES) and the Myocardial Ischaemia National Audit Project (MINAP). HES is a data warehouse containing information on admissions, outpatient appointments and A&E attendance at NHS hospitals in England. These administrative data are designed for secondary, non-clinical purposes. MINAP is a national clinical audit of the management of heart attack providing participating hospitals across the UK records of their management. Their data are made public in annual reports but can also be accessed (upon request) for research purposes. For the epidemiologists on WHAP, the HES and MINAP provided data of the geographic and temporal distribution of air pollution-associated cardiovascular health harms. The focus of WHAP was short-term health effects. Key to the data-linkage process was generating measurements of the temporal correlation between a specific air pollution concentration and its associated health effect.

One of the first stumbling blocks, Ann reflected when we met, was the size of the data files generated by the atmospheric chemists. Sending these via email or downloading them through special software was impractical, and even if it had been possible it would have likely crashed the system. The second issue with data, after size, was format. Ann explained that before the data can be overlayed they must be made '*all the same*'. For example, Ann converted the three-dimensional modelled data in Network Common Data Form (NetCDF), a two-dimensional text format that was legible and usable by the epidemiologists. The third way in which data were made the same was by standardising metrics. The range of measurements shaping data's meaning and form had to be equivocal, so that the air pollution data sets and health data sets could be used together. Building on the work of the wiki space, Ann regularly communicated with other researchers responsible for sending the final data sets to check metrics and format were consistent.

If the air pollution data spatially and temporally corresponded with the mortality and morbidity data, then the health risks of exposure could be explored. Through statistical methods, the relationship between air pollution concentrations and health effects was analysed: the higher the statistical correlation, the stronger the association between exposure and negative health effects. So, someone suffering from a heart attack on a day of high air pollution connects an individual with their local environment and therefore population health to geographic differences. Linking air pollution to human health was not this simple and a number of nonlinearities and uncertainties emerged. In terms of the mortality data, there was the challenge of harvesting, a concept that refers to the deaths that would have happened on those days anyway, even in the absence of high levels of air pollution. This meant linking air pollution concentrations with number of deaths within a given period could not reliably demonstrate short-term health effects or statistically significant relationships.

Here, defining the temporal relations of air pollution was essential repair and maintenance work that helped to shape the meaning of data and their capacity to be linked in effective ways. Patterns and relationships between phenomena are lively sociotechnical processes. The interdisciplinary work performed by Ann illustrates the ways in which data linkage performs correlations of air pollution and health through the arrangement of data. By focusing on the work of data linkage, my ethnographic methods were able to study interdisciplinary research in action and explore how health gets objectified, measured and known through data practices.

Practices of Repair and Maintenance

In-between data and practices of repair and maintenance are productive sites for studying knowledge making. This is particularly so for air pollution because the relationship between public health and air pollution is difficult to measure in any direct, causal way. Generating and combining multiple and expansive data sets are increasingly being proposed as innovative and efficient ways of generating insight into air pollution that can help improve our understanding of exposure and its associated health risks. Yet my research shows that additional data and the combining of multiple data sets do not always easily or neatly fit together to solve such puzzles. More data does not mean a more clearly defined health problem. Despite this, large funding bodies increasingly call for interdisciplinary research and the sharing of large or 'big data'.[1]

The first empirical example I discussed in this chapter was an online space that configured the boundaries between what was shared within the interdisciplinary team or restricted to bounded disciplinary spaces. Through the spreadsheet software the air pollution and health data could be described and differences clarified before being physically linked together. These moments of epistemic tension and explication shifted everyday work and produced certain kinds of '*collaborative efficiency*' (cf. Star and Ruedhler 1997; Ribes and Jackson 2013: 10). In this way, data became objects of scientific work but also the formations around which it was practised and achieved.

Rather than focusing on networks of relations and the circulation of facts, attending to the sharing or not sharing of documents, information and data through online and digital platforms permitted a more dynamic and nuanced understanding of research routines, movement and sociality (Postill and Pink 2012). Approaching social relations as

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[1] For example, NERC's recent call (http://www.nerc.ac.uk/innovation/activities/environmental-data/health-call/) invited projects for identifying and filling knowledge gaps around the potential of environmental data to improve health outcomes in the UK.

practical and material processes, the various contingencies and partial nature of knowledge making were made visible. Starting out from the concept of friction, the technical practices of repair and maintenance (Graham and Thrift 2007) showed that interdisciplinarity is actively performed through data. Indeed, data friction includes epistemic concerns and the technical demands of different working environments (Edwards et al. 2011), whilst also having implications for the mobility of information and data and more reflexive modes of sharing. By focusing on the discontinuities of data, their vital contribution in maintaining and enabling social and technical relations is also emphasised (Graham and Thrift 2007). In doing so, my ethnographic account of knowledge making expands to include sociotechnical forms that not only assist in the making of stable data, but also shaped how relations between air pollution and health were enacted.

Concluding Summary

This chapter offers an ethnographic approach to understanding knowledge production that expands and multiplies the different kinds of socialities making up scientific work and how they unfold. I argue that, although the sharing and mobilisation of different data create social, material and epistemic friction, the data practices that emerge as a result are sites for research innovation. By recognising the often invisible work of interdisciplinary research and data practices, we can connect the diverse and intricate mechanisms of how we know with the informal infrastructures that support these processes. Studying the in-between processes of knowledge making is increasingly relevant for ethnographers (and other social and non-social science researchers) working in health research settings that frequently demand the dual role of generating data and knowledge whilst facilitating collaborative exchange (Fitzgerald and Callard 2014). Infrastructure is an encompassing conceptual tool that can simultaneously account for tension, difference and maintenance. It also highlights the value of ethnographic research for disentangling and making visible the work that builds and transforms these infrastructures and wider knowledge-enabling processes.

Since practices construct knowledge, ethnographic analyses of data practices can also contribute to the process of interdisciplinary knowledge making, as well as support understanding of the health implications of its material outputs. This may mean moving beyond attempts to construct correlations between air pollution data and mortality statistics, and instead explore the ways in which ‘health’ can also overflow such reductive practices. Based on ethnographic descriptions of repair and maintenance, critical accounts of data practices are opportunities to map out creative ways in which air pollution is a phenomenon defined by its differences. If different metrics generate different findings about air pollution and health, then perhaps future collaborations should be targeting these multiple temporalities of air pollution exposure and harm, research of which is already emerging (e.g. the prevalence of personal sensors in public health and global health scientific research projects). The ethnographic examples drawn upon in this chapter highlight the potential of emergent, live and digital spaces for engaging with the process of interdisciplinary research. It was in these spaces that data became objects around which shared concerns could rally: collaborative ways of working were developed, new lines of inquiry opened up and novel questions posed. Rather than simply describing data, this chapter focuses on the performative capacities of data, interrogating the transient, in-between processes of data making, sharing and linking. In doing so, it maps out the ways in which the social relations of science can be harnessed in future research to develop creative and collaborative insights on health and health problems more broadly.

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References

Bowker, G. C., Baker, K., Millerand, F., & Ribes, D. (2009). Toward information infrastructure studies: Ways of knowing in a networked environment. In J. Hunsinger, L. Klastrup, & M. Allen (Eds.), *International Handbook of Internet Research* (pp. 97–117). Dordrecht: Springer.

Burri, V., & Dumit, J. (Eds.). (2007). *Biomedicine as Culture: Instrumental Practices, Technoscientific Knowledge, and New Modes of Life*. London, UK: Routledge.

Edwards, P. (2010). *A Vast Machine: Computer Models, Climate Data, and the Politics of Global Warming*. Cambridge, MA: MIT Press.

Edwards, P., Mayernik, S. M., Batcheller, L. A., Bowker, C. G., & Borgman, L. C. (2011). Science friction: Data, metadata, and collaboration. *Social Studies of Science, 41*(5), 667–690.

Fitzgerald, D., & Callard, F. (2014). Social science and neuroscience beyond interdisciplinarity: Experimental entanglements. *Theory, Culture & Society, 32*(1), 3–32.

Galison, P. (1996). Computer simulations and the trading zone. In P. Galison & J. D. Stump (Eds.), *The Disunity of Science: Boundaries, Contexts, and Power*. Stanford, CA: Stanford University Press.

Garnett, E. (2016). Developing a feeling for error: Practices of monitoring and modelling air pollution data. *Big Data & Society, 3*(2). https://doi.org/10.1177/2053951716658061.

Garnett, E. (2017). Air pollution in the making: Multiplicity and difference in interdisciplinary data practices. *Science, Technology and Human Values, 42*(5), 901–924.

Graham, S., & Thrift, N. (2007). Out of order: Understanding repair and maintenance. *Theory, Culture & Society, 24*(3), 1–25.

Kirksey, E. S., & Helmreich, S. (2010). The emergence of multispecies ethnography. *Cultural Anthropology, 25*(4), 545–576.

Landecker, H. (2007). *Culturing Life: How Cells Became Technologies*. Cambridge, MA: Harvard University Press.

Latour, B. (1990). Visualisation and cognition: Drawing things together. In M. Lynch & S. Woolgar (Eds.), *Representation in Scientific Activity* (pp. 619–668). Cambridge, MA: MIT Press.

Latour, B. (2004). Why has critique run out of steam? From matters of fact to matters of concern. *Critical Inquiry, 30*(2), 225–249.

Latour, B., & Woolgar, S. (1986). *Laboratory Life: The Construction of Scientific Facts*. Princeton, NJ: Princeton University Press.

Law, J. (2004). *After Method: Mess in Social Science Research*. London: Routledge.

Law, J., & Singleton, V. (2004). Object Lessons. Published by the Centre for Science Studies, Lancaster University, Lancaster LA1 4YN, UK, at http://www.comp.lancs.ac.uk/sociology/papers/Law-Singleton-Object-Lessons.pdf.

Leonelli, S. (2008). Classificatory theory in data-intensive science: The case of open biomedical ontologies. *International Studies in the Philosophy of Science, 26*(1), 47–65.

Leonelli, S. (2009). On the locality of data and claims about phenomena. *Philosophy of Science, 76*(5), 737–749.

Leonelli, S. (2010). Circulating evidence across research contexts: The locality of data and claims in model organism research. *Working Papers on The Nature of Evidence: How Well Do 'Facts' Travel? No. 25/08*. London School of Economics: 1–44.

Merton, R. K. (1973). *The Sociology of Science: Theoretical and Empirical Investigations*. London: University of Chicago Press.

Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham and London: Duke University Press.

Myers, N. (2015). Conversations on plant sensing: Notes from the field. *NatureCulture, 3,* 35–66.

Postill, J., & Pink, S. (2012). Social media ethnography: The digital researcher in a messy web. *Media International Australia, 145*(1), 123–134.

Puig de la Bellacasa, M. (2011). Matters of care in technoscience: Assembling neglected things. *Social Studies of Science, 41*(1), 85–106.

Ribes, D., & Jackson, S. J. (2013). Data bite man: The work of sustaining a long-term study. *"Raw Data" Is an Oxymoron* (pp. 147–167). London, UK: The MIT Press.

Rodríguez Giralt, I., & Sanchez Criado, T. (2016). Caring through design? En torno a la silla and the 'joint problem-making' of technical aids. In C. Bates, R. Imrie, & K. Kulman (Eds.), *Care and Design: Bodies, Buildings, Cities* (pp. 198–218). Oxford: Wiley.

Star, S., & Griesemer, J. (1989). Institutional ecology, 'translations' and boundary objects: Amateurs and professionals in Berkeley's Museum of Vertebrate Zoology 1907–39. *Social Studies of Science, 19*(3), 387–420.

Star, S. L. (1999). The ethnography of infrastructure. *American Behavioral Scientist, 43*(3), 377–391.

Star, S. L., & Ruedhler, K. (1997). Steps towards an ecology of infrastructure: Design and access for large information spaces. *Information Systems Research, 7*(1), 111–134.

Walford, A. (2013). *Transforming data: An Ethnography of Scientific Data from the Brazilian Amazon*. Ph.D., Copenhagen University, Copenhagen.

15

Towards a Pragmatics of Health

Tiago Moreira

Health: Between Ethnography and Praxiography

What does ethnography have to do with health? What can ethnography contribute to health? This is, in essence, the question this book tries to address (see Chapter 1). The question is a timely one for a combined set of reasons. While the use of the ethnographic method in health care settings can be traced back at least seven decades (e.g. Fox 1959), the deployment of the ethnographic imagination to health as an everyday, ordinary practice is much more recent. Such deployment was facilitated by parallel movements in ethnographic practice and the conceptualisation of health.

The first has to do with the methodological status of ethnography. At least since the 1980s, ethnographic techniques of data production and analysis—immersed observation, field notes, etc.—have been problematised, and their ability to represent 'culture' or society questioned.

T. Moreira (✉)
Durham University, Durham, UK
e-mail: tiago.moreira@durham.ac.uk

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Ethnography's status as a provider of objective, scientific facts about people's beliefs or ways of living was in trouble. Interestingly, around the same time, ethnographers were themselves opening up the culture of science, exploring the ordinary ways in which facts were put together in the laboratory, and, importantly, how they too relied on writing and inscription—on 'inscriptions devices'—to establish those facts (Latour and Woolgar 1986). This approach has underpinned a fundamental conceptual redescription of science as a complex, multiple practice, a description which itself has motivated a re-engagement with key questions in the methodology of the social sciences (Law 2004). From this perspective, ethnography can no longer be understood as just another utensil in the social research toolkit, able to address both fundamental and applied disciplinary questions, but rather should itself be seen as a set of specific social and material arrangements intrinsically linked to the practice of fieldwork (e.g. Law and Ruppert 2013).

This methodological shift has consequences for the promise—often articulated in health research (e.g. Savage 2000)—that ethnography is capable of delivering a more detailed, accurate understanding of the complexities of health and healthcare. My argument is that this positivist investment in ethnography is both misplaced and counterproductive. It is misplaced because, as argued above, and any brief experience in fieldwork will soon reveal, ethnography is an excellent practice for generating data but is also, or perhaps more importantly, a device for generating questions (e.g. Katz 2002). It is counterproductive because it requires ethnography to produce 'arrangements' underpinned by general, rather than specific standards of knowledge production.

The second movement has been the increased focus on health as a practice. In this, it is of particular interest how work in critical public health has been increasingly challenging prevailing conceptions of health behaviour that underlie much public health research, policy and intervention. This work calls for a paradigmatic shift from a public health that is focussed on the health behaviours of individuals and their 'social contexts' to one that is concerned with everyday practices that are situated, composite and contingent, and not solely '*a direct result or outcome of mental processes but emerge out of the actions and interactions of individuals*' (Cohn 2014: 160). Such a shift calls for public health research that emphasises and investigates the material and symbolic elements of such practices, of the times and spaces involved in this kind of situated activity (e.g. Blue et al. 2016), and of how such features emerge and permit the co-evolution of practices, and hence more and less healthy ways of living and consuming.

One important consequence of what are sometimes labelled 'praxiological' studies of health is that they challenge and shift dominant models of health. Whereas governing approaches to health are concerned with its mechanisms of production, a focus on practices directly queries the applicability of simple fabrication metaphors or models. From the perspective of everyday practice, health is experienced, lived through, reflected upon and experimented with in a situated and evolving relationship with other elements of people's lives. Even practices that can be seen as solely focused on health monitoring, maintenance and enhancement, such as self-tracking, are significantly underpinned by identity work and belonging, as well as particular technoscientific imaginaries. This means that health cannot be simply linked to discrete forms of action or behaviours, such as running, physical locations or social positions, but is complexly entangled with patterns of institutional life, cultural practices, innovation processes and the like.

From this perspective, the appropriate metaphor for health is not that of the production machine but rather that of the assemblage, of the coming together of disparate sets of resources and elements. This coming together, however, is not the result of some planned organisation, a strategic overseeing of preparing and formatting the fitting of the elements. It is indeed one of the key aims of the concept of assemblage to point towards the contingency of its gathering (Deleuze and Guattari 1988). This is not to say that the specific composition of elements is totally haphazardous, but more importantly that ethnographic studies of health practice focus on how the relations between elements are engendered, maintained and transformed in everyday life.

As the chapters in this book demonstrate, ethnography is uniquely adequate to investigate situated and emergent constituents of health and well-being, and to identify and understand their fragile and contingent character. However, while ethnographic studies of health practices are able to question psychologising and individualising assumptions of research on health, they have been less engaged in exploring what exactly counts as health and well-being. There are good reasons for this. By focusing their attention on reconceptualising how health becomes embodied in actual practices, studies of health practice have had to accept, sometimes tacitly, dominant concepts of health. In effect, the power of such research to challenge public health models relies on accepting to work on features or versions of health and well-being that those models focus on. This is a price worth paying, to be able to open up health 'from below', showing how everyday practices transform and reconfigure concepts and models of health.

My suggestion is that this more established approach should be combined with a novel programme of research that opens health 'from above', that is to say, one that specifically explores the collective production of formal definitions, measures and forms of valuing health. This programme brings together a focus on the knowledge practices deployed in health and biomedical research with a particular interest in mensuration and standards themselves. This interest in measures draws significantly on the intermediary role Actor-Network Theory assigns to standards in the making of social relations (Callon and Latour 1981; Latour 2005). As intermediaries, measures and standards do not only provide stability and composure to institutions but also, and importantly, spark moral conflict and violence, often entering in tension with other standards and their own, respective 'worlds'. This programme of research is attentive to the *complex ecology* of standards and measurements: How they interact in practice, how they might assemble different moral and technological worlds, how they generate difference and spark the moral imagination.

By bringing to the fore the rich processes that engender routinely used measures or definitions of health, and the work such measures do in facilitating specific organisational formats and normative orientations in health care and everyday life, this approach should provide a useful handle on what Star and Bowker once termed 'infrastructure reversion': making visible and evident, what normally lies in the background. For this reason, studies of health mensuration are perhaps more suitably pursued by adopting a praxiographic methodology to '*stubbornly take notice of the [often overlooked] techniques that make things visible, audible, tangible, knowable*' (Mol 2002: 33). This should, in my view, encompass both fieldwork observation and archival work, tracing the genealogy of the standards encountered in the present. This is for practical purposes, as it enables an analytical attention to the 'technical', often boring, aspects of fieldwork that are related to health as an object of enquiry and measurement. This, in turn, supports following the transformation and reconfiguration of concepts and measures of health across 'local' contexts, time and space.

The aim of combining the ethnography and praxiography of health is to bring forth a pragmatics of health. As suggested above, one of the key defining features of dominant, contemporary health assemblages is its emphasis on productivity, on how health is produced and what it produces. While ethnographic studies of health practice go some way into deflating this *productivist* orientation in health research and public health policy, such studies leave the question of the politics of formalised health untouched. What are the practical, normative consequences of measuring health in a particular way? To what extent are everyday life, 'lay' enactments of health implicitly indebted to long-established biomedical ways of knowing and measuring health, such as or absence of disease (morbidity)? To what extent do everyday practices question or transform such 'standards of living'? A pragmatics of health is intended to empirically investigate and explore those questions.

Below I explore how the pragmatics of health can be used to understand the dynamics of healthy ageing, a specific health assemblage that has gained increasing institutional and policy leverage in the past two decades.

Healthy Ageing: From Policy Device to Laboratory Assemblage

The Promise of 'Healthy Ageing'

Policy responses to demographic ageing have, in the last two decades, emphasised the need to create an age-integrated society, moving from a focus on age-stratified policies towards initiatives that promote what is often labelled 'active and healthy ageing'. These are conceived as strategies that promote the extension of 'healthy life expectancy' and remove institutional barriers to older people's economic and social participation (Fernández-Ballesteros et al. 2013). A central policy concept in the EU (Lassen and Moreira 2014), it is aimed at '*adjusting our life practices to the fact that we live longer*', which '*in practice, means adopting healthy life styles, working longer, retiring later and being active after retirement*' (European Commission 1999: 2).

As I have suggested elsewhere (Moreira 2017: 31–49), healthy ageing is best understood as a policy device to tackle epistemic and political uncertainties stemming from the 'social security crises' of the early 1980s. Those 'crises', usually portrayed as a result of demographic ageing and/or neoliberal policy, can be more directly linked to emerging public reservations about the quality of actuarial projections of life expectancy. Rather than a 'technical detail' in the functioning of the system of modern old age pensions, calculations of life expectancy—based on life tables—are key components in the financial determination of present and future insurance contributions and payments. For this reason, they formed a central component of what Ewald (1991) labelled 'the insurance society' that emerged with the Liberal Welfare State at the turn of the twentieth century. Such questioning of the quality and purpose of the actuarial apparatus of life expectancy calculations was particularly evident in the USA, where possible miscalculations of '*the growth of the elderly and oldest-old population*' (Manton 1991: 310) had consequences not only for social security but also for Medicare programmes.

In this context, it entailed a difficult recognition by the Office of the Actuary that their 1977 life expectancy projections relied on erroneous 'assumptions' about the limits of human longevity and the likely effect of future health technologies on mortality. To correct those mistakes, critics argued, it was necessary to embrace not only a more 'optimistic' view of the human lifespan, but also of the possible effects of biomedical innovation on health. This, in turn, required a shift from a sole reliance on life tables to combining these with the production and monitoring of morbidity/disability data. Indeed, it had been to address the bluntness of life expectancy calculations to assist decision-making when '*public health programmes compete with each other and with other government activities for budget allocations*', that Sullivan had first proposed a measure of 'health expectancy' (Sullivan 1966: 1).

From its inception, the concept of 'healthy life expectancy'—years lived free from disability—was entangled then with a set of technoscientific promises that had justified and propelled biomedical innovations programmes such as the 'War on Cancer', or later, the NIH Alzheimer's Disease programme. Thus, when, following the 'social security crisis', the Committee on an Aging Society was formed, its aim was '*not to propose national policy but to explore areas of research that might contribute usefully to the weighting of national choices*' (Committee on an Aging Society 1985: vi). Significantly, the Committee focused on exploring economic scenarios that would stem from rising 'healthy life expectancy': how this would impact on the productivity, working and post-retirement lives of older people, and how could 'assistive' technologies and tools support and enhance older people's daily activities.

These, I suggest, set the template for the knowledge-focused response to the 'ageing society' for the decades to come, such that when, in 2007, the UN Programme on Ageing and the International Association of Gerontology and Geriatrics (IAGG) proposed a 'Research Agenda on Ageing for the Twenty-First Century' their concerns largely overlapped those of the US Committee on an Aging Society more than twenty years earlier. In 2007, as in 1983–1985, the priorities continued to be to understand how 'healthy and active ageing' was responsive to biomedical intervention and public health measures, to relate such health responses to the 'productive contribution of older persons' (UN/IAGG 2007: 3), and to explore the role of 'enabling and supportive environments' for active and healthy ageing. Healthy ageing—or healthy life expectancy, on a population level—can be conceptualised as the articulation between technology (biomedical, assistive) and the economy (productivity, innovation) in the 'ageing society' (Moreira 2017).

Assembling Healthy Ageing in the Laboratory

The relevance of this analysis of healthy ageing was brought to bear during ethnographic fieldwork conducted by my collaborator, Marie Otto, within a randomised trial of diet and exercise to prevent age-related muscular loss. The trial—Counteracting Age-related Loss of

Skeletal Muscle Mass (CALM)—focuses specifically on sarcopenia, a degenerative loss of skeletal muscle mass, which is seen as having significant impact on mobility, independence, activities of daily living and quality of life. The aim of CALM is to understand the role of increased protein intake combined with physical activity in older populations at risk of developing sarcopenia. The trial consists of two interdependent clusters. Cluster 1 is a classic randomised clinical trial (RCT), wherein dieticians, exercise physiologists and microbiologists intervene on, observe, monitor and measure the health, functioning and digestive bioactivity of participants. Cluster 2 is a design-driven innovation project based on the emerging results from cluster 1, leading to food product design and public health innovation.

During ethnographic fieldwork, we increasingly became aware of the centrality of the exercise physiology laboratory in the assemblage of the trial. This was not only the main centre of coordination of the trial, but also the site where both diet and exercise interventions were conducted and baseline and outcome measures collected. In particular, standard exercise instruments, such as the treadmill, assumed a critical place in the flow of activities of the trial, being in themselves both part of the exercise intervention and key components of the apparatus to measure physiological responses to physical activity. Indeed, we came to realise that the exercise physiology laboratory was, to use Actor-Network Theory language, the 'obligatory passage point' (Callon 1986) for the translation between technological innovation and the economic renewal invested in the concept healthy ageing.

In practice, however, achieving such intermediary role was a complicated and fragile affair. As we have suggested (Otto and Moreira 2017), the main challenge presented to researchers and participants in the trial was to adapt the exercise physiology laboratory to the 'needs and wants' of ageing bodies. Designed to understand the physiology of the competitive athlete's body-in-stress (see below), making the trial work entailed training bodies to adjust to the requirements of the gym technologies but also adjusting exercise devices to the existing embodied habits and conditions of the participants, i.e., instruments and protocols had to be adjusted to a specific group of people. This work was continuous and contingent.

So, for example, one of the key baseline data collected in the trial concerned insulin processing. For this, according to the protocol, the research participants should fast before a two-hour glucose tolerance test, followed by physical training on the treadmill. The test subject then should have a blood sample done, followed taking a glucose drink, another blood sample being taken two hours later. The glucose test checks for insulin resistance (type 1, type 2 and prediabetes). However, to most participants in the trial, this test presented a challenging schedule by requiring physical exercise to be carried out with a low blood-sugar level. One of the research participants, whom we called Anders, fell ill during pretesting. When getting up from the test machine, he felt dizzy and swayed, causing concern among the researchers. At another time, a woman fainted during the treadmill exercise part of the test. This presented a practical problem for the researchers because it both prevented them from obtaining data and undermined their ability to be seen to care for their participants. In the subsequent pretesting, the research participants were therefore given food such as energy bars and bananas prior to exercise on the treadmill. Later, after some research on age-related change in glucose processing, a decision was made to perform the glucose tolerance test and the physical test over two days. This meant that the research participants would not endure physical tests on an empty stomach, but also that data were obtained according to a new protocol.

To make the trial work, researchers and participants had to learn from each other; they had to fine-tune, to tinker with the trial protocols and procedures. The trial, and in particular the exercise protocols, can be seen as a practical articulation—or, the interactive, co-productive, learning process—between enactments of physiological, measured bodies, on the one hand, and lived, inhabited bodies, on the other (Otto and Moreira 2017). It brings together or assembles complex forms of practising health in everyday life with the equally ordinary ways of measuring health, health in informal and formal enactments. As such the CALM trial is an excellent case to pursue a pragmatics of health, as I described it in the previous section. This would entail deepening the ethnographic exploration of participants' everyday lives, which has been the main concern of Marie's research, and a praxiographic exploration of the measurements of health used in the trial, which I will pursue for the rest of this section.

Of particular interest here, given what was argued above, are the measurements performed using the exercise physiology equipment. On a surface level, these appeared to be peculiarly linked to CALM as a trial of different exercise protocols to maintain muscular strength. Fieldwork data collected through participant observation and interviews with researchers and participants in the trial, however, suggested that while the novelty of using modern gym equipment to build muscular strength in older individuals justified funding the trial, its epistemic value build on a long history of physiological research based on the athlete as a 'model organism' (Johnson 2013). Indeed, tracing the history of some of these exercise devices enabled a fuller understanding of the epistemological layers enacted in the specific health measurement used in the CALM trial, making us realise that some of the modern gym equipment, such as the treadmill, were originally used as a physiology research instrument.

Such realisation provided a solution to a question we had stumbled upon after recognising the pivotal, articulation role the exercise physiology laboratory had in aligning the trial with what I called the healthy ageing assemblage. Our problem was the following: How can an instrument such as the treadmill, used as it is for individual measurement of responses to physical stress, translate a concept of health—healthy life expectancy—that is essentially related to populations? The easy, unproblematic way in which researchers in the trial took these two measurements to be corresponding and equivalent indicated that there was a sedimented, stable circuit of translation upon which the trial researchers' could rely. To open up and understand how such equivalence was established involved, however, tracing praxiographically how the treadmill came to occupy such intermediary role.

The Treadmill: Tracing the Intermediary

Following this trace led us to focus on the exercise physiology experiments conducted in the Harvard Fatigue Laboratory in the 1930s. Established as collaboration between Lawrence J. Henderson, a physiologist, and Elton Mayo, a psychologist of labour relations, the laboratory's work hinged on the promise of translating Henderson's views on physiological internal equilibrium (Henderson 1917) to one of the key labour problems of the interwar years: that of fatigue. Aiming explicitly to challenge the then dominant, thermodynamic-based, progressive view on human labour, Henderson envisaged the Fatigue Laboratory as a new departure in this field of research by '*studying the mutual dependence of quantitatively large physiological activities in different normal men [….] to make trustworthy quantitative distinctions and discriminations between individuals*' (Henderson in Scheffler 2015: 405).

This vision buttressed them in a series of experiments that attempted to measure physiological responses to controlled amounts of physical activities in different individuals, from which the exercise treadmill apparatus emerged as an instrument for research in industrial physiology, and exercise science more generally, until the present day. Comparing responses of competitive athletes—as a model organisms—such as the then famous Marathon runner Clarence de Mar, with those of 'normal men', Henderson and his colleagues established a relationship between training—adaptation to stress—and performance showing that 'internal equilibrium' was a function of previous training in running rather than age (Mayo 1933: 14). Bringing this insight more closely into the politics of the emerging 'problem of ageing' of the 1940s, McFarland proposed that, '*changes with age do not necessarily mean decline. […] In athletic performance there is a positive correlation between maturity and success in competition requiring endurance*' (McFarland 1943: 507).

Drawing on the treadmill laboratory experiments—and the figure of Clarence de Mar—McFarland was able to propose the concept of 'functional age', a measurement that is still used today (Moreira 2017). As he saw it, functional age, by using '*refined methods of evaluating [the worker's] ability to respond to fixed stresses*' was able to provide '*trustworthy quantitative distinctions and discriminations between individuals*' (McFarland 1943: 509) in a manner that chronological age was not able to do. It is my suggestion that it is through this capacity to 'discriminate between individuals' that the treadmill is able to articulate between individual and population concepts of health, by sorting individuals according to their capacity to respond to fixed, calibrated stresses.

Articulating the Paradox of 'Healthy Ageing'

As we saw in the exercise laboratory seven decades later, the treadmill continued to operate this translation, through laborious work of adjustment within the trial, to produce similar differentiating effects on a specific population. This capacity was, we came to realise, what provided the treadmill and similar apparatuses another agentic capacity within the trial: that of bringing together and assembling the technoscientific promises of expertly designed exercise techniques and protein-rich diet products, and the vision of a stronger, fitter, more active, productive older population. The data it produced, through careful attention of researchers and participants to adapt and fine-tune the protocols of the trial, were interdependent on this assemblage, this peculiar set of elements. The data it produced tell a story about 'healthy ageing' and how health can be produced through diet and exercise, mostly through data plots, variables, correlations, linear regressions, etc.

As we know, however, from the ethnographic descriptions provided above, the process of adjusting participants' everyday practices to the trial's protocols sometimes required stepping aside, or erasing complicated details, such as whether walking or cycling to the shops every day constituted 'exercise'. Often this erasing took a more definite form, through enforcing exclusion criteria on potential participants. As we argued, the trial required a specific population—healthy older individuals that do not engage in regular exercise—that was not only hard to find, but also, once enrolled, to be 'disciplined' to the trial's demands and schedules. This is a crucial point to emphasise: that the effects of the trial assemblage encompassed both clear, powerful data, and unclear stories about lived, embodied health, stories that could not be made present, included in the trial assemblage (Otto and Moreira 2017).

In the light of the ethnography undertaken, we are able to understand how the protocols and instruments used in the trial, while aligned with robust knowledge-making procedures, *close off* (often unintentionally) a variety of health practices, affects and bodies. That is to say that the dynamic interface between embodied and measured health, as enacted in the CALM trial, was not necessarily a wholly harmonious affair. In order to produce—again, through laborious, everyday adjustment—data on the relationship between diet, exercise and 'healthy ageing', researchers and participants ignored, downplayed and sometimes silenced details, versions of health that were not relevant for the trial. This was not an act of deception; rather, it was due to a practical commitment to making the trial work, and understanding the conditions under which meaningful data could be produced. As Law (2004) would put it, the trial produced both presences and overflows, or absences.

Noting this dual dynamic is important because it clarifies the paradox at the heart of the trial: that while wanting to clarify the relationship between diet, exercise and muscular frailty, and to guide public health programmes on how to extend such interventions to the wider population, in practice, the trial demonstrated exactly why such extension would be difficult to implement. This is not a critique of the researchers and participants in the trial. It is a recognition that by using instruments designed to produce 'trustworthy quantitative distinctions and discriminations between individuals', and measurements that can be precisely plotted and correlated, the trial cannot produce *uniform, collective* devices for 'health ageing'. It is a recognition that by articulating healthy ageing assemblages, its focus will be necessarily on the young-old, and the deployment of forms of knowledge that individuals produce in the maintenance of their own health (Moreira and Palladino 2008). It is recognition that its enactment of healthy ageing is reliant on a politics of technoscientific promises that omits modes of engagement with health that are not linked to consumption and self-monitoring.

Towards a Pragmatics of Health

In the previous section, I have provided an exploration of how the pragmatics of health could be used to understand the dynamics of healthy ageing. My argument was that a parallel examination of health practices and health mensuration enables an understanding of interactive processes whereby measures or definitions of health transform and are transformed by everyday practice. My analysis was particularly concerned with what, after Mol, I labelled the praxiography of health, only exploring health practices, when it entered in contact with the protocols of the trial. Nevertheless, the suggestion was that pre-existing practices of health became complexly interweaved, in that they were sometimes transformed by the protocols of the trial, but that these too had to be adapted to fit with people's lives, social obligations, aspirations, etc.

Further, I was particularly interested in the central intermediary role played by the exercise physiology laboratory, and how it could bring together and articulate a complex ecology of standards and measurements of health. I emphasised how this was pragmatically accomplished through researchers' and participants' tinkering with machines, protocols and their own lives, making, for example, small concessions about how much exercise to do in one week. Here, my argument was that this enabled instruments such as the treadmill not only to link individual and populations measures of health but also articulate between technoscientific promises and economic scenarios for the 'ageing society'. In turn, I suggested that this was possible because the trial assemblage enacted both clear, present data effects and overflows or absences. A pragmatics of health should not only explore how health practices are shored up and made visible by specific metrics, but also how those standards and practices produce other, less visible realities, realities which might contain the possibilities for further exploring and recomposing what counts as health.

As I have argued above, such recomposition can only be achieved by a parallel exploration of health practices and health mensuration. In this regard, the chapters in this book can, on one level, be seen as highlighting the contribution of ethnography for deepening our understanding of practice-based accounts of health. From the perspective presented in this chapter, however, they should also be read as detailed examples of a pragmatic analysis of health, particularly in how they perform other possible realities and ways of doing health. To fully realise this recomposition, it is now necessary to extend our interpretations and uses of ethnography to develop the *praxiography* of health, to extend our understanding of how formal definitions, measures and forms of valuing health are crafted, sustained and transformed.

References

Blue, S., Shove, E., Carmona, C., & Kelly, M. P. (2016). Theories of practice and public health: Understanding (un)healthy practices. *Critical Public Health, 26*(1), 36–50.

Callon, M. (1986). Some elements of a sociology of translation: Domestication of the scallops and the fishermen. In J. Law (Ed.), *Power, Action and Belief: A New Sociology of Knowledge*. London: Routledge & Kegan.

Callon, M., & Latour, B. (1981). Unscrewing the big Leviathan: How actors macro-structure reality and how sociologists help them to do so. In K. Knorr-Cetina & A. Cicourel (Eds.), *Advances in Social Theory and Methodology: Toward an Integration of Micro- and Macro-sociologies*. London: Routledge.

Cohn, S. (2014). From health behaviours to health practices: An introduction. *Sociology of Health & Illness, 36*(2), 157–162.

Committee on an Aging Society. (1985). *Health in an Older Society*. Washington, DC: National Academy Press.

Deleuze, G., & Guattari, F. (1988). *A Thousand Plateaus: Capitalism and Schizophrenia*. London: Bloomsbury Publishing.

European Commission. (1999). *Towards a Europe for All Ages*. Brussels: EC.

Ewald, F. (1991). Insurance and risk. In M. Foucault, G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault Effect: Studies in Governmentality*. Chicago: University of Chicago Press.

Fernández-Ballesteros, R., Robine, J. M., Walker, A., & Kalache, A. (2013). Active aging: A global goal. *Current Gerontology and Geriatrics Research* (Article ID 298012).

Fox, R. C. (1959). *Experiment Perilous: Physicians and Patients Facing the Unknown*. San Francisco: Transaction Publishers.

Henderson, L. J. (1917). *The Order of Nature: An Essay*. Harvard, MA: Harvard University Press.

Johnson, A. (2013). The athlete as model organism: The everyday practice of the science of human performance. *Social Studies of Science, 43*(6), 878–904.

Katz, J. (2002). From how to why: On luminous description and causal inference in ethnography (Part 2). *Ethnography, 3*(1), 63–90.

Lassen, A. J., & Moreira, T. (2014). Unmaking old age: Political and cognitive formats of active ageing. *Journal of Aging Studies, 30*, 33–46.

Latour, B. (2005). *Reassembling the Social: An Introduction to Actor-Network-Theory*. New York: Oxford University Press.

Latour, B., & Woolgar, S. (1986). *Laboratory Life: The Construction of Scientific Facts*. Princeton, NJ: Princeton University Press.

Law, J. (2004). *After Method: Mess in Social Science Research*. London: Routledge.

Law, J., & Ruppert, E. (2013). The social life of methods: Devices. *Journal of Cultural Economy, 6*(3), 229–240.

Manton, K. G. (1991). The dynamics of population aging: Demography and policy analysis. *The Milbank Quarterly, 69*(2), 309–338.

Mayo, E. (1933). *The Human Problems of an Industrial Organization*. New York: McMillan.

McFarland, R. A. (1943). The older worker in industry. *Harvard Business Review, 21*, 34–35.

Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Chapel Hill: Duke University Press.

Moreira, T. (2017). *Science, Technology and the Ageing Society*. London and New York: Routledge.

Moreira, T., & Palladino, P. (2008). Squaring the curve: The anatomo-politics of ageing, life and death. *Body & Society, 14*, 21–47.

Otto, M., & Moreira, T. (2017). *Ageing Bodies on Trial*. Copenhagen and Durham: Centre for Healthy Ageing.

Savage, J. (2000). Ethnography and health care. *British Medical Journal, 321*(7273), 1400.

Scheffler, R. W. (2015). The power of exercise and the exercise of power: The Harvard fatigue laboratory, distance running, and the disappearance of work, 1919–1947. *Journal of the History of Biology, 48*(3), 391–423.

Sullivan, D. F. (1966). Conceptual problems in developing an index of health. USPHS Publ. No. 1000, -Ser. 2-No. 17.

United Nations Programme on Ageing/International Association Gerontology and Geriatrics. (2007). *Research Agenda on Ageing for the Twenty-First Century*. New York: United Nations.

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