Relational chronicities: kinship, care and ethics of responsibility

Emilija Zabiliūtė (Durham University)

Hannah McNeilly (University of Edinburgh)

Short abstract

This introduction to the special issue outlines how living with, treating, caring for, and experiencing chronicity are entangled with kinship and its underlining ethics of responsibility. It introduces papers that explore how relational caring responsibilities are contested, generated, (re)distributed and defined in clinical, everyday and institutional

settings.

Abstract

Care for chronic illness in clinical and everyday settings is relational, and underpinned underscored by ethical dilemmas about kinship care responsibilities as much as it is about self-care practices and technologically aided living. Such is the central argument of this special issue, which explores kin care and ethics of responsibilities in the everyday lives of persons and families with chronic illness across different locations globally. Rather than outlining the importance of kin care in times and spaces where clinical attention and healthcare are absent, or examining kin care as a modality of care that is separate to, contradictory, and incompatible to the clinical one, we examine how clinical modes of attention dovetail with the ethics of kin care relational knowledge. We explore redistributions of care responsibilities between the family and the clinic by paying attention to kinship

1

dynamics and argue that chronicity and kinship co-constitute each other in everyday life and

clinical settings.

Keywords: Chronicity, care, kinship, responsibility

Ethics statement

We declare no conflict of interests. Ethical approval for the author's projects that inspired this

introduction were obtained from the ethics committee at the University of Edinburgh.

Acknowledgements

The initial discussions and ideas outlined in this introduction were discussed in a workshop

'Chronic Illness, Kinship and Responsibility of Care', organised by Emilija Zabiliūtė at the

Edinburgh Centre for Medical Anthropology, University of Edinburgh, in 2019. The authors

would like to thank the discussants for the rich discussion and comments: Lotte Buch-Segal,

Letizia Bonanno, Janet Carsten, Ian Harper, and Alice Street; workshop participants as well

as the contributors to this special issue. We are grateful Ayo Wahlberg for the comments on

a draft of this introduction. The editorial work for this special issue was funded by Zabiliūtė's

Marie Skłodowska-Curie fellowship of The European Commission Research Fund (H2020-

MSCA-IF-2017), grant number 798706, and Edinburgh Centre for Medical Anthropology.

We declare no conflict of interests.

Introduction

Chronic care responsibilities are distributed across the affected individuals, their families, and

other social networks, clinics, and the state, and this distribution is continuously contested,

2

negotiated and in flux. Chronicity overflows individual bodily boundaries and takes shape within the fabric of social networks of care, particularly within families. Managing chronic illness in families challenges kin dynamics, continually modifies relationships, and exposes the limitations of caring work and affects. This happens when chronic condition challenges, reverses and adjusts caring roles, and conflicts arise in everyday life. At the same time, kin relations also spill over into other care settings and influence the care provided in clinical or religious institutions, where family support and neglect are taken into account by healthcare providers, or where new forms of families and homes are created.

This special issue, *Relational Chronicities*, offers an anthropological account of how chronicity in everyday life and clinical encounters is shaped by ethics of kinship and relational ordering of care responsibilities. We explore redistributions of care responsibilities between the family and the clinic by paying attention to kinship dynamics, and argue that chronicity and kinship co-constitute each other in everyday life and clinical settings. By placing relationships and kinship at the fore of our inquiry into chronicity, we seek to move away from accounts of chronic illness that emphasise autonomous, individual subjects, and care as an individualised practice, directed solely at individual selves or at singular, bounded bodies. We show how, among those who suffer, receive, and provide care in the face of chronicity, ethical deliberations about relational care-giving and receiving, and obligations to significant others, come to the fore in everyday clinical and institutional settings.

The central questions that the special issue addresses are: How do chronic conditions contest, generate, call into question, and make visible the responsibilities of kin care and its underlying ethics? How are responsibilities of care distributed across the familial, non-clinical, and medical-institutional realms in the face of chronic suffering? What do these (re)arrangements of responsibilities tell us about kinship, medical practice, and chronicity? Which forms of kin relations, modes of exchange, and temporalities come to the fore in the

face of chronic illness? We engage with these questions by bringing anthropological inquiry into kinship in dialogue with critical debates about the distribution of care and management of chronicity in the everyday.

The distribution of care across familial and institutional settings is embedded in the history of public health. As shown by Foucault (2009), seventeenth-century Europe saw a shift in in how family figured in techniques of government. Whereas previously the family had served as a model for governance and authority with caring connotations, a reconfiguration of government subsumed the family as an instrument in the governance and care of the population to achieve specific public health goals, with little interest in the dynamics of family care itself. In their modern shape, states exercise both power and care responsibility over citizens and their familial units. However, the historically established contract of care between state and citizens is not uniform, and is refracted through inequalities and categorisations of those who deserve state care and those who do not (Montesi and Calestani 2021). This is particularly apparent in the wake of neoliberalism and its effects on health systems, however heterogenous these political economic shifts are. On the one hand, then, family can be seen as a governance unit. Simultaneously, the state's absence or withdrawal is often used to explain why family is important in healthcare, particularly for chronic care. Where public healthcare systems are weak, whether due to historical structural violence or austerity, families often take up most of the care (Das 2015; Han 2012; Moran-Thomas 2019).

Through an exploration of kinship dynamics – or, to use Strathern's (2005; 2020) term, the *knowledge of relationships* that constitutes chronicity – we highlight a different logic to that of the absence of the state of how relations come to matter in chronicity experience and chronic care. Even in strong healthcare systems, chronic care is linked to deliberations about the role of families and their caring responsibilities (Heinsen et. al. 2022; Montesi and

Calestani 2021). Increasingly, states and medical institutions incorporate kin and relational care into their protocols, blurring the boundaries between professionalised and everyday forms of care (Chase, this issue; Diodati, this issue; Takashi 2021; Zabiliūtė 2021).

Chronic care informed by relational ethics and responsibility is parallel to self-care, underlining the ethos of chronic conditions. In recent years, the governance of health, healthcare's neoliberal turn, and their analyses by social scientists, have all focused on autonomous individuals, particularly in the context of chronic conditions. Self-care has emerged as both an emic and an analytical category to understand how individuals care for themselves as they extend and support their lives and make them as good and liveable as possible in the face of a chronic condition (Wahlberg 2014; 2009). Self-care is enabled by neoliberal governance as an individualising force, where citizens have an obligation to care for themselves in tandem with public health goals (Rose 2001). Responsibility of care is placed on the individual. Patients with chronic conditions are expected to attend to their bodies through self-care and self-surveillance practices and embodied techniques, calibrated by biomedical knowledge, such as specific diets, therapies, weight loss, or exercise (Mol 2008, Rose 2001, Ward 2015). Self-care practices, such as taking medications, adhering to therapies, pricking one's finger to measure blood sugar – structure patients' daily lives under the supervision and monitoring of biomedical practitioners (Mol 2008). These clinical care imperatives often reinstate the self at the centre of the illness experience. Self-care practices entail rearrangements of care, restructure peoples' everyday lives, and redefine their notions of self (Guell 2012; Seligman 2010).

Social studies of chronic conditions have explored the imperatives and limits of selfcare, which particularly surface in neoliberal clinical settings and medical encounters. Selfcare that attends the individualised, medically bound body in medical terms is often at odds with people's wider socially and culturally embedded understandings of self (Broom and Whittaker 2004; Weaver 2018) and relational being in the world. As asymmetries in doctorpatient relations persist (Greco 2020), patients' social worlds and relational obligations are often framed as causing 'non-compliance', asking why patients do or do not follow prescribed lifestyles that are good for them from the biomedical vantage point (Becker, Gates, and Newsom 2004; Broom and Whittaker 2004; Hunt, Pugh, and Valenzuela 1998; Weaver 2018). In this context, familial relations and obligations informed by social and cultural norms, such as gendered familial care, are often seen as hindrances to comprehensive patient self-care (Borovoy and Hine 2008; Seligman et al. 2015). At the same time, models of patient-centred care and shared decision-making have made medical practitioners increasingly interested in patients' social lives outside the clinic (Elwin et al. 2013; Wahlberg 2014).

Anthropologists have shown how such self-care practices and modes of attention are woven into the broader social worlds of people with chronic illness: their family relationships, gendered positionalities, and marginalisation (Banerjee 2020; Guell 2012; Livingston 2012; Yates-Doerr and Carney 2016; Weaver 2018). Care is relational and openended; it entails 'tinkering' as it responds to the contingent and changing needs of a person, and thus differs from a practice grounded in the logic of choice (Mol et al 2010). As a mode of attention, care may be directed not only towards specific bodily needs, but to relationships which constitute embodied subjectivities. We take our cue from Felicity Aulino (2016) and attend to care in its specific contexts and in relation to local moral worlds. In this way, we do not take for granted (but consider where necessary) the Western and normative categories of care, which are often rooted in Christian moral ideals. Care, understood as a relational and ethical practice (Black 2018), informs practices and ethics of kin and relatedness. Care is 'simultaneously moral, relational, historically specific and embedded within forms of governance' (Buch 2015;287). Indeed, care can be definitive of relatedness and kinship

(Borneman 1997). Some care practices that are essential in chronic care, such as feeding, are constitutive practices of relatedness (Carsten 1995). Thus, the practices and 'technologies of self' (Rose 2001) and chronicity trajectories interlink with the relational projects that undergird peoples' life worlds.

In this special issue, we build on and extend the inquiry into the sociality of care and chronicity by placing it alongside an examination of kinship and the internal dynamics of relational responsibilities of care. We draw on and expand this work to specifically address kinship care dynamics and dilemmas around ethical responsibility among individuals and families with chronic illness. We seek to go beyond the instrumentalist view of families and explore how the 'logic of care' (Mol 2008) is entangled with the logics of kin. Taking inspiration from Strathern's notion of relations and relational knowledge (2020; 2005), and Pinto (2011; 2014), we examine not 'right' or 'wrong' relations, and their effects on health and chronicity, but 'the kinds of knowledge that emerge from relations in general' (Pinto 2014, p. 254). Such relational knowledge and ethics inform chronicity in both, illness experiences in everyday life and in clinical settings, as well as health governance initiatives and larger structural rearrangements of institutionalised forms of care. The contributions in this special issue collectively demonstrate that care-giving, care-receiving, and self-care are interwoven ethical practices born out of a social life lived in proximity to others.

Beyond economic calculations, the organisation and division of care across intimate and public healthcare realms, care is also about the ethics and questions of responsibility towards the other. Caring in the face of chronicity is an ethical endeavour, underscored by questions about what is good and about moral striving (Fassin 2012; Lambek 2010). This relational responsibility of care is an ethical orientation of subjectivity towards the other (Levinas 1985; see also Butler 2006). Here, the concept of infinite responsibility serves to interrogate the ethical underpinnings of intimacy, relationality and obligation in the lives of

families with chronic conditions. It also highlights how families navigate the normative and medical regimes eliciting care responsibilities amidst chronic suffering.

Responsibility for kin care as an ethical undertaking shapes the experience and healing of chronic conditions. In this issue we propose a term of relational chronicities, which highlights how kinship and chronicity inflect each other across multiple settings. Chronicity reproduces, calls into question, disciplines, and reimagines kin care. It demands extensive care in patients' everyday lives and redefines what it means to be a person, a family member, and a carer. It reorganizes subjectivities, affective and embodied intensities of familial relations in patient's everyday lives, and their temporalities. It highlights, transforms, and rearranges the relational commitments and responsibilities that persons and families with chronic illness have for each other, and puts them in question. Yet, chronic illness care is also absorbed into existing relational words and reasserts their long-standing truths and tensions. Chronic conditions themselves become subject to kin temporalities and the ethics of relational care.

These relational and ethical dynamics of care do not only inform everyday lives with families, and intimate spaces: ethical endeavours are also central in clinical practice and medical encounters. Clinical settings, which instil medicalised subjectivities, 'biosocialities' (Rabinow 2017), and self-care practices, are also spaces in which patients' relationalities are negotiated, and where relationships are seen as central to diagnosis, healing, and care.

Kinship and chronic care

In this special issue, we aim to go beyond this dichotomy that sees family as assuming the responsibility of care in the absence or shrinkage of the welfare state and medical care, or limiting our observations to the importance of family in the face of chronic suffering. We build our argument in line with anthropologists who have explored how kinship and chronic

illness are intertwined in more nuanced ways. For instance, as Qureshi (2019) shows, the illness narrative is not only a representation of kin breakdowns and expressive of distress caused by tensions, but is instead, one mode of enactment of conflictual relationships. Domestic relational worlds, which are mediating sites for larger political, economic, and structural forces, shape the expression of mental illness (Gammeltoft and Oosterhoff 2018). Illnesses, as Das shows (2015), may be not so much dramatic events, but absorbed into relational everyday life. If care and illness experience are inherently relational, it is not enough to foreground the importance of relationalities: we need to explore the qualities and dynamics of ethics of relational care. It is the critical eye of kinship studies that allows us to commit to this agenda. By attending the kinds of relations and 'relations as a way of knowing' (Pinto 2014; Strathern 2005), we explore how relational knowing among persons, families, and healthcare providers shapes chronicity. Relations as knowledge can serve as a concept with specific genealogies and cultural contexts (Strathern 2020). This knowledgemaking highlights how a phenomenon comes into being through relations rather than being external to them (ibid., p. 6). By addressing the relations between kin relations and chronicity, we seek not only to highlight the importance of families in accounts of chronicity, but to show how chronicity is itself relational.

The papers in this special issue show how chronic living is underpinned by relational ways of knowing: relational links and explanations are created to make sense of, and manage, disorders, care crises, healing, diagnoses, and worsening conditions. Families, chronically ill persons, medical practitioners, and healthcare systems all participate in the production of relational knowledge and in the negotiation of kin care responsibilities.

Another cue we take from kinship studies is to attend to relationships beyond normative injunctions of care, mutual support, and positive experiences, to explore the difficulties and burdens of kin care, and the tensions, injustices, and conflicts that result

(Carsten 2013; Das 2020; Pinto 2014; Lambek 2011; Reece 2022; Segal 2018). We situate our exploration of ethics of care alongside this inquiry into kinship beyond normative designations of kinship as 'good'. The vagaries of kinship shape care and chronicity, but this may not be an aberration. As Danely (2017) observed, the difficulties of care are inherent in its ontology and carers' subjectivities.

Such difficulties and harms of kinship may accumulate over time, give meaning to chronic experiences and have an effect on life with an illness, healing and therapeutics (Qureshi; Zabiliūtė; McNeilly; Diodati; Saria et al.; Sciolli; this issue). They inform medical and institutional care (Chase; Ranganathan; Saria et al.; Sciolli; this issue). While it is often family neglect and conflict that animate clinical modes of attention and are linked to worse health outcomes, positive attachments and 'too much' care can also be seen as detrimental (Sciolli, this issue). Thus, kinship affects, relational dynamics of connections and disconnections, and negotiations – rather than fixed ideas about relationships and their deficiencies – are what structure chronicity.

Chronicity

Chronic illness is an unstable, contingent, and shape-changing phenomenon, and is continuously redefined through biomedical and scientific knowledge, global health practice and politics, patient experience, practices of care, and the temporalities of illness. Recent studies in medical anthropology have argued for adopting the concept of chronicity instead. While some have shown how chronicity opens up possibilities of dialogue between medical practice and anthropological critique (Weaver and Mendenhall 2014), others have adopted the concept to avoid the contradictions and inconsistencies of biomedicine and global health in their work on chronic illness (Greco and Graber 2022; Manderson and Smith-Morris 2010; Montesi and Calestani 2021; Whyte 2012). The concept of chronicity allows us to circumvent

some of the problems that the biomedical paradigm poses when following classical clinical distinctions between chronic and acute, or chronic and infectious, disease. These distinctions blur in the wake of new drug development, medical technologies, changing societal realities, and patients' experiences. For instance, long covid, antiretroviral drug therapy for AIDS, and prolonged tuberculosis all call into question the categorisation and definition of what chronic illness is. Social relationships, healthcare systems, and structures of care all challenge a singular definition of chronicity.

In light of these social and medical realities, in this special issue we aim to contribute to conceptualisations of chronicity by examining how it takes shape through the intimate, relational worlds of patients and families. As a social and medical condition, chronicity demands continuous attention and treatment, technological assistance, and care incorporated into patients' everyday lives. It takes shape in these care relationships and gives new meanings to relationships between patients and carers (Kleinman 1988). A common theme running through the contributions to this special issue is the relational temporalities of chronicity. Health conditions are chronic in the sense that they are prolonged, and so is their management with medicines, biomedical technologies, kinship care, and family biographies. They have specific timelines, as diagnosis may be dependent on treatment prospects; and onset is slow and 'creeping up' (Whyte 2012). As Kleinman (1988, 8) noted, 'the trajectory of chronic illness assimilates to a life course, contributing so intimately to the development a particular life that illness becomes inseparable from life story'. In this issue, we show how such life stories do not concern singular individuals, but persons in relational webs, and that they are not separable from biomedical renderings of chronicity. Yet, chronicity does not only disrupt biographies (Bury 1982), but is itself refracted through them. The contributions highlight how relational temporalities inform therapies and diagnostic work, and how they are mobilised for new forms and visions of care (Chase; Ranganathan; Saria et. al.; Sciolli;

this issue). Relational care and relational temporalities also give meaning and define the temporal trajectories of chronicity (Diodati; McNeilly; Qureshi; Zabiliūtė; this issue). Chronicity is enabled by kinship, and in the process, kinship itself becomes chronic (Saria et. al). Along with biomedical modes of attention, relational care dynamics punctuate, extend, structure, and define the temporal possibilities and affordances of life, which is both, social and biological.

Exploring the temporalities of chronicity alongside familial temporalities further problematises the category of chronic illness – or its subject. In everyday contexts, boundaries between the carer and the cared for become less clear and shift over time, for instance, when children begin to care for ageing and ill parents, or women with caring responsibilities develop a chronic condition (Diodati; Qureshi; Zabiliūtė; this issue). The ways in which kin positionalities and responsibilities of care change in time shape how chronicity unfolds in families' lives and relational bodies. Improvements or deteriorations in health, and its fluctuations, are often attributed to relationalities (Chase; McNeilly; Ranganathan; Sciolli; Saria et al.; Qureshi; Zabiliūtė, this issue).

Contributions and ethnographic locations

This issue puts together papers based on ethnographic research across diverse contexts which diverge in many ways in terms of healthcare provision, the politics of kinship, social organisation of care, and the social status of persons and families with chronic illness. The papers examine dynamics of kin care and chronic illness in and outwith clinical settings and in Brazil, India, Italy, Nepal, and the United Kingdom. By assembling papers presenting research on kin care across such diverse contexts, we highlight how relational care and kinship inform clinical encounters and experiences of illness, health, and healing in both the Global North and the Global South. The history of anthropological inquiry upholds the

imagination and the idea of 'distant' places. Kinship, it is often assumed, matters more in places subject to othering, and less in the 'Western' world (Strathern 2020, 11). Frequently, medical anthropologists focusing on the West pay less attention to kinship, but it becomes an imperative when exploring 'othered' places, such as India, because it captures a certain colonial modality of anthropological imagination. This is despite increasing attention in Western public health, medical practice, and scientific advancements to family and community care, family, self-help groups, and heredity – topics directly linked to questions emerging from in kinship studies.

In this issue, we do not assume a causal geography that would explain why kinship matters more in specific places than others. Instead, we attend to how the particularities of kinship care unfold in diverse and specific contexts, with histories and political economies that shape people's intimacies, dependencies, and relations. Inspired by studies of kin relationships and care in other places than the West, and the anthropology of kinship more generally, we hope this work will help to 'provincialise' (Chakrabarty 2009) anthropological blind spots and use ethnographic insights to explore the dynamics of kinship care in therapeutic settings and everyday life.

By highlighting kin responsibilities, the papers explore the ethical, political, and existential dimensions of caring for others, and being cared for in the face of chronic conditions, in a variety of medical, religious, and domestic settings. The authors examine how diverse notions of responsibility and relational care travel to, and are utilised in, therapeutic and clinical settings (Chace; Diodati; McNeilly; Ranganathan; this issue). For example, family relations inform clinical encounters in Patna, India, when doctors practice 'kin-testing' and delay diagnoses (Saria et al., this issue), and the absence of family care legitimises long-term stays in Indian shrines (Ranganathan, this issue). Family relations may also interfere with and disrupt medical care for the chronically ill when community

psychosocial workers in Nepal are entangled in their clients' family networks (Chase, this issue), or when family members' care is seen as excessive in an Italian eating disorder clinic (Sciolli, this issue). In some therapeutic settings, we see the establishment of family(-like) relations, like in a Candomblé community in Brazil (McNeilly, this issue), or in the abovementioned Italian eating disorder clinic and the Indian shrine (Sciolli; Ranganathan, this issue).

Contextualised notions of kinship and relational responsibility define and challenge experience of chronic conditions (McNeilly; Qureshi; Zabiliūtė, this issue). They highlight how illness exposes the limitations of care and the negotiation of affective relationships and care responsibilities (Diodati; Sciolli; McNeilly; Ranganathan; Zabiliūtė; Qureshi; this issue), and how medical and therapeutic practices seek to define, redistribute, and reconceptualise responsibilities of care and relationalities (Chase; Sciolli; Diodati; Saria et al.; McNeilly; this issue).

The limitations of the care that family members are able or willing to offer are highlighted in several contexts, for example, when young Indian women care for their mothers-in-law 'without heart' (Zabiliūtė, this issue), when filial carers in Italy share a narrative of caring fatigue (Diodati, this issue), and when Pakistani women in the United Kingdom insist that they need to take care of themselves in order to care for their families (Qureshi, this issue). Self-care and care can become thoroughly intertwined: caring for others can be experienced as self-care in 'circular care' dynamics (McNeilly, this issue).

All eight papers emphasise the inherent ambiguity of care and kin relations, paying close attention to the flipside of care: possible harmful effects on carers, the cared-for, their health, and their social networks. These generate vast potential for tension and conflict.

Specific moments in families' lives and clinical encounters when facing chronic illness highlight ongoing kin dilemmas as new reconfigurations of family and kin care crystallise.

Such tensions are apparent in all the papers: in the form of stigmatisation of the chronically ill (Chase, this issue), carers' fatigue (Diodati, this issue), religious obligations (McNeilly, this issue), the absence of family ties (Ranganathan, this issue), semi-public kin dramas in doctors' clinic (Saria et al., this issue), the difficult balance of too much and too little care (Sciolli, this issue), the neglect of carers (Qureshi, this issue), and family conflicts that result in ambivalent, unloving care (Zabiliūtė, this issue).

Kaveri Qureshi's paper examines the ethics of gendered familial care among women from the disproportionally chronically ill Pakistani diaspora in the United Kingdom. She revisits her own earlier interpretation of the endurance ethic of *sabar* among women to explore the effect of time on care responsibilities, health, and family relationships. Qureshi shows how, in retrospect, middle-aged Pakistani women revisit seemingly unconditional care for the family and emphasise the need to care for themselves to be able to care for others. This highlights the limits of family care, where difficulties with kin relations intertwine with the burden of caring on the ageing body. Care for the self, a much-discussed category in social studies of chronic illness, is here incorporated into a religious ethical project of endurance and care for others, balancing the high toll placed by caring responsibilities on women's health.

In a similar vein, Hannah McNeilly's paper highlights the muddled boundaries between self-care and kin care and argues that 'circular' forms of care can simultaneously be directed at the self and the other. Based on fieldwork with a Candomblé group in Brazil, the paper traces the entanglement of self-care in the face of chronicity with care for deities who are kin. Self-care is here constituted by caring practices within a religious community and through collective worship of the *orixá* deities. Yet, if the religious care obligations are neglected, people might find their bodies 'open' and vulnerable to harm.

Francesco Diodati's paper examines the limits of care by tracing how family carers of elderly parents in Italy narrate caring fatigue in self-help groups. He shows, too, how care is not a straightforwardly positive experience or an unchallenged moral duty, but takes shape through tensions and the recognition of its weight and limits. In Diodati's paper, adult children carers deliberate about the exhaustion and ambivalence they experience when caring for their parents in the context of a shrinking welfare state and moral regimes that often place on them expectations of unquestioned care for elder family members.

The dilemmas around ageing, intergenerational kinship care and its limits are also explored in Emilija Zabiliūtė's paper, which traces a life with diabetes in an urban poor family in Delhi. Here, crises of care and illness temporality are integral to family events and conflicts. As a result, the notion of *care without heart* emerges as a modality of care situated between moral regimes and their shortcomings, one that sustains kin relationalities, but is disinvested with emotion and love.

The work of Vaibhav Saria and colleagues explores how similar notions about the aberrations of kin care underscore chronicity and clinical modes of attention in primary healthcare clinics in Patna, India. Here, the doctor's care involves an assessment of the patient's familial care support, a mode of attention the authors call 'kin-testing'. Kin-testing figures in the decisions practitioners make regarding adherence and prescriptions, and may result in delayed diagnoses. Attention to primary healthcare reveals how, in the context of global health concerns about missed tuberculosis diagnoses, practitioners' reasoning and delayed diagnoses emerge in specific and localised relational milieus.

Similarly, Giulia Sciolli's paper highlights how dynamics of kinship and family care inform diagnostic and therapeutic practices in eating disorder clinics in Italy. Based on long-term fieldwork in a residential facility, Sciolli shows how the intensities of care, associated with familial affection, can be conceptualised and treated as harmful for patients. Chronicity

here depends on the types of familial relationships, and treatment focuses not only on patients' bodies, but also on the relationships between patients and their kin, who are seen as providing 'too much' or 'too little' care. Yet, these 'harmful' attachments can also develop between patients and medical staff, as they themselves develop kin-like relationships with patients who often relapse and need to be readmitted to the same clinics due to a combination of lack of proper family support and outpatient care in Italy's public healthcare system.

Shubha Ranganathan's paper also explores how an institution may become 'home' through an examination of how women suffering from family problems and mental health conditions seek care in religious shrines in South India. Her ethnographic work, on the religious and biomedical forms of care provided in a shrine that was reformed after the community mental health movement, highlights the blurred boundaries between abandonment and care. The shrine emerges as a substitute for the care offered by the family, but, as in Saria et al.'s paper, the deficiencies of family care linger as a diagnostic category or grounds to decide about potential forms of care.

Finally, Liana Chase traces efforts to scale up mental health services in the aftermath of the 2015 earthquake in Nepal. She shows how newly trained community psychosocial workers are oftentimes kin and neighbours to the care recipients, and share their moral worlds. Psychosocial care providers must balance their different roles in the community and continuously alternate between professionalised counselling and practices of informal advice-giving. This shows how therapeutics are informed not only by relationships, but also by attempts to draw a line between relational dependences and kin responsibility and what is seen as a professional intervention.

Together, these different contributions draw a picture of how chronicity takes shape in relationships, and how the necessities of caring shape, challenge, disrupt, and sustain the functioning of family networks, clinical encounters, and social groups. The ethnographic

accounts show how chronic care responsibilities are shifted, negotiated, and tested within the contexts of different social welfare systems, idealised notions of the family and of loving care, clinical pragmatism, limitations of caring, and changing notions of self. As such, chronicity presents an arena with potential for conflict, where underlying family and social dynamics are exposed, as well as for deepened social ties and support. By bringing the anthropology of kinship and medical anthropology into a dialogue about chronic care, we hope to have opened a fertile field for discussion that will strengthen the anthropological conceptualisation of chronicity as a relational dynamic, with wide-reaching effects on social life and institutions.

Footnotes

¹ We use Kleinman's (1988) notion of illness meaning making. However, we do not limit our inquiry to the socially produced meanings of chronicity only to patient experience, and to what earlier medical anthropologists have called 'illness' as opposed to 'disease'. Instead, we explore both biomedical and everyday settings as reciprocating sites that produce relational meanings of chronicity.

REFERENCES

- Aulino, Felicity. 2016. 'Rituals of Care for the Elderly in Northern Thailand: Merit, Morality, and the Everyday of Long-Term Care'. *American Ethnologist* 43 (1): 91–102. https://doi.org/10.1111/amet.12265.
- Banerjee, Dwaipayan. 2020. Enduring Cancer: Life, Death, and Diagnosis in Delhi. 1st edition. Durham and London: Duke University Press.
- Becker, Gay, Rahima Jan Gates, and Edwina Newsom. 2004. 'Self-Care Among Chronically Ill African Americans: Culture, Health Disparities, and Health Insurance Status'. *American Journal of Public Health* 94 (12): 2066–73.
- Black, Steven. 2018. 'The Ethics and Aesthetics of Care | Annual Review of Anthropology'. *Annual Review of Anthropology* 47: 79–95.
- Borneman, John. 1997. 'Caring and Being Cared for: Displacing Marriage, Kinship, Gender and Sexuality'. *International Social Science Journal* 49 (154): 573–84. https://doi.org/10.1111/j.1468-2451.1997.tb00046.x.

- Borovoy, Amy, and Janet Hine. 2008. 'Managing the Unmanageable: Elderly Russian Jewish Émigrés and the Biomedical Culture of Diabetes Care'. *Medical Anthropology Quarterly* 22 (1): 1–26.
- Broom, Dorothy, and Andrea Whittaker. 2004. 'Controlling Diabetes, Controlling Diabetics: Moral Language in the Management of Diabetes Type 2'. *Social Science & Medicine* (1982) 58 (11): 2371–82. https://doi.org/10.1016/j.socscimed.2003.09.002.
- Bury, Michael. 1982. 'Chronic Illness as Biographical Disruption'. *Sociology of Health & Illness* 4 (2): 167–82. https://doi.org/10.1111/1467-9566.ep11339939.
- Butler, Judith. 2006. Precarious Life: The Powers of Mourning and Violence. Verso.
- Carsten, Janet. 1995. 'The Substance of Kinship and the Heat of the Hearth: Feeding, Personhood, and Relatedness among Malays in Pulau Langkawi'. *American Ethnologist* 22 (2): 223–41.
- ———. 2013. 'What Kinship Does—and How'. *HAU: Journal of Ethnographic Theory* 3 (2): 245–51. https://doi.org/10.14318/hau3.2.013.
- Chakrabarty, Dipesh. 2009. Provincializing Europe: Postcolonial Thought and Historical Difference. Princeton University Press.
- Danely, Jason. 2017. 'Carer Narratives of Fatigue and Endurance in Japan and England'. *Subjectivity* 10 (4): 411–26. https://doi.org/10.1057/s41286-017-0037-7.
- Das, Veena. 2015. *Affliction: Health, Disease, Poverty*. New York: Fordham University Press.
- ———. 2020. *Textures of the Ordinary: Doing Anthropology after Wittgenstein*. New York: Fordham University Press.
- Fassin, Didier. 2012. 'Introduction: Toward a Critical Moral Anthropology'. In *A Companion to Moral Anthropology*, edited by Didier Fassin. Malden, Oxford, Sussex: John Wiley & Sons.
- Foucault, Michel. 2009. Security, Territory, Population: Lectures at the Collège de France 1977--1978. Edited by Michel Senellart, François Ewald, and Alessandro Fontana. New York: Picador.
- Gammeltoft, Tine M., and Pauline Oosterhoff. 2018. 'Mental Health in Domestic Worlds'. *Medical Anthropology* 37 (7): 533–37. https://doi.org/10.1080/01459740.2018.1504216.
- Greco, Cinzia, and Nils Graber. 2022. 'Anthropology of New Chronicities: Illness Experiences under the Promise of Medical Innovation as Long-Term Treatment'. *Anthropology & Medicine* 29 (1): 1–13. https://doi.org/10.1080/13648470.2022.2041550.
- Guell, Cornelia. 2012. 'Self-Care at the Margins: Meals and Meters in Migrants' Diabetes Tactics'. *Medical Anthropology Quarterly* 26 (4): 518–33. https://doi.org/10.1111/maq.12005.
- Han, Clara. 2012. *Life in Debt: Times of Care and Violence in Neoliberal Chile*. Berkeley: University of California Press.
- Heinsen, Laura Louise, Ayo Wahlberg, and Helle Vendel Petersen. 2022. 'Surveillance Life and the Shaping of "Genetically at Risk" Chronicities in Denmark'. *Anthropology & Medicine* 29 (1): 29–44. https://doi.org/10.1080/13648470.2021.1893654.
- Hunt, L. M., J. Pugh, and M. Valenzuela. 1998. 'How Patients Adapt Diabetes Self-Care Recommendations in Everyday Life'. *The Journal of Family Practice* 46 (3): 207–15.
- Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Basic Books.
- Lambek, Michael, ed. 2010. *Ordinary Ethics: Anthropology, Language, and Action.* 1 edition. New York: Fordham University Press.

- ———. 2011. 'Kinship as Gift and Theft: Acts of Succession in Mayotte and Israel'. *American Ethnologist* 38 (1): 2–16. https://doi.org/10.1111/j.1548-1425.2010.01288.x.
- Levinas, Emmanuel. 1985. 'Responsibility for the Other'. In *Ethics and Infinity:*Conversations with Philippe Nemo, by Emmanuel Levinas, translated by Richard A. Cohen, Pittsburgh. Duquesne University Press.
- Livingston, Julie. 2012. *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic*. 1 edition. Durham: Duke University Press Books.
- Manderson, Lenore, and Carolyn Smith-Morris. 2010. 'Introduction: Chronicity and the Experience of Illness'. In *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, by Lenore Manderson and Carolyn Smith-Morris. New Brunswick, New Jersey: Rutgers University Press. https://www.jstor.org/stable/j.ctt5hj44p.
- Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. 1 edition. London; New York: Routledge.
- Montesi, Laura, and Melania Calestani. 2021. 'Introduction'. In *Managing Chronicity in Unequal States*, edited by Laura Montesi and Melania Calestani. London: UCL Press. https://www.uclpress.co.uk/products/176699.
- Moran-Thomas, Amy. 2019. *Traveling with Sugar: Chronicles of a Global Epidemic*. Oakland, California: University of California Press.
- Pinto, Sarah. 2011. 'Rational Love, Relational Medicine: Psychiatry and the Accumulation of Precarious Kinship'. *Culture, Medicine and Psychiatry* 35 (3): 376–95. https://doi.org/10.1007/s11013-011-9224-0.
- ——. 2014. *Daughters of Parvati*. Philadelphia: University of Pennsylvania Press.
- Qureshi, Kaveri. 2019. *Chronic Illness in a Pakistani Labour Diaspora*. Durham, NC: Carolina Academic Press.
- Rabinow, Paul. 2017. 'Artificiality and Enlightenment: From Sociobiology to Biosociality'. In *The Ethics of Biotechnology*, by Paul Rabinow, Paul. London: Routledge.
- Reece, Koreen M. 2022. *Pandemic Kinship: Families, Intervention, and Social Change in Botswana's Time of AIDS*. The International African Library. Cambridge: Cambridge University Press. https://doi.org/10.1017/9781009150200.
- Rose, Nikolas. 2001. 'The Politics of Life Itself'. *Theory, Culture & Society* 18 (6): 1–30. https://doi.org/10.1177/02632760122052020.
- Segal, Lotte Buch. 2018. 'Tattered Textures of Kinship: The Effects of Torture Among Iraqi Families in Denmark'. *Medical Anthropology* 37 (7): 553–67. https://doi.org/10.1080/01459740.2018.1462807.
- Seligman, Rebecca. 2010. 'The Unmaking and Making of Self: Embodied Suffering and Mind–Body Healing in Brazilian Candomblé'. *Ethos* 38 (3): 297–320. https://doi.org/10.1111/j.1548-1352.2010.01146.x.
- Seligman, Rebecca, Emily Mendenhall, Maria D. Valdovinos, Alicia Fernandez, and Elizabeth A. Jacobs. 2015. 'Self-Care and Subjectivity among Mexican Diabetes Patients in the United States'. *Medical Anthropology Quarterly* 29 (1): 61–79. https://doi.org/10.1111/maq.12107.
- Strathern, Marilyn. 2005. 'Relatives Are Always a Surprise: Biotechnology in an Age of Individualism'. In *Kinship, Law and the Unexpected: Relatives Are Always a Surprise*, 15–32. Cambridge, New York, Melbourne, Madrid, Cape Town, Singapore, São Paulo: Cambridge University Press.
- ———. 2020. *Relations: An Anthropological Account*. Durham and London: Duke University Press. https://doi.org/10.1215/9781478009344.

- Takashi, Erika. 2021. 'Publicly Privatised: Relative Care Support and the Neoliberal Reform in Finland'. In *Managing Chronicity in Unequal States*, edited by Laura Montesi and Melania Calestani. London: UCL Press. https://www.uclpress.co.uk/products/176699.
- Wahlberg, Ayo. 2009. 'Serious Disease as Kinds of Living'. In *Contested Categories: Life Sciences in Society*, by Ayo Wahlberg and Susanne Bauer, 89–112. Burlington: Ashgate.
- ———. 2014. 'Knowledge of Living | Somatosphere'. 2014. http://somatosphere.net/2014/11/knowledge-of-living.html.
- Weaver, Lesley Jo, and Emily Mendenhall. 2014. 'Applying Syndemics and Chronicity: Interpretations from Studies of Poverty, Depression, and Diabetes'. *Medical Anthropology* 33 (2): 92–108. https://doi.org/10.1080/01459740.2013.808637.
- Weaver, Lesley Jo. 2018. Sugar and Tension: Diabetes and Gender in Modern India. New Brunswick, New Jersey: Rutgers University Press.
- Whyte, Susan Reynolds. 2012. 'Chronicity and Control: Framing "Noncommunicable Diseases" in Africa'. *Anthropology & Medicine* 19 (1): 63–74.
- Yates-Doerr, Emily, and Megan A. Carney. 2016. 'Demedicalizing Health: The Kitchen as a Site of Care'. *Medical Anthropology* 35 (4): 305–21. https://doi.org/10.1080/01459740.2015.1030402.
- Zabiliūtė, Emilija. 2021. 'Ethics of Neighborly Intimacy among Community Health Activists in Delhi'. *Medical Anthropology* 40 (1): 20–34. https://doi.org/10.1080/01459740.2020.1764550.



To cite this article: Zabiliūtė, E., & McNeilly, H. (2023). Relational chronicities: kinship, care and ethics of responsibility. Anthropology and Medicine

Durham Research Online URL:

https://durham-

repository.worktribe.com/output/1729360

Copyright statement: This content can be used for non-commercial, personal study.