

Introduction

Literary Explorations of Health and Kinship

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Humans are inherently social beings. In both good times and in bad, in sickness and in health, we care for and rely on those close to us. Their lives affect ours, just as ours affect theirs. Sooner or later, almost all of us find ourselves close to someone suffering from health issues – be it an aging parent, a partner, a daughter, a brother, or a friend. Although this is a universal existential experience, it does not come without practical, cultural, and emotional complications. Quite the contrary: health issues that create a need for care often challenge our most strongly held beliefs about the ‘familial bond,’ whether this bond is biologically or socially founded. Our understanding of kinship becomes contingent on the changes brought about by altered health and the demands these changes often place on close ones to provide care. Illness thus serves to accentuate both the ties that bind us to others and our expectations and demands towards relatives and close ones.

Literary Explorations of Health and Kinship is a special issue in the interdisciplinary *Journal for Research in Sickness and Society*, which focuses on medical anthropology. Medical anthropology is a subfield of anthropology that examines how cultural, historical, and political forces shape our experiences and understandings of health and illness. While stories and storytelling are well-known sources of knowledge within this field – for example in (auto)ethnographic writing (Dwyer, Davis & emerald 2017) – this special issue concentrates on a specific type of stories: literary works. The articles explore how fictional works and forms of life writing serve as sources of knowledge about the ties that bind us together in times of sickness or changing health. We work from the premise that literature provides a privileged vantage point for interdisciplinary investigation into the intersections of health and kinship. All the works studied in this issue have roots in lived experience yet draw on literary and subjective modes or genres that allow authors to improvise, fictionalize, and distort facts in expressing subjective experiences. Literary scholar Rita Felski suggests that literature contributes a “repertoire of sense-making devices” that are “firmly anchored in the formal and generic properties of the text,” and that might “expand, enlarge, or reorder our sense of how things are” (2008, 83). By offering new perspectives on familiar constructions of encountering a sick relative, a health care system, or cultural expectations of caregiving, literary texts can serve as laboratories for our understandings and experiences of health and kinship.

The works under scrutiny are characterized by a ‘next of kin perspective’ meaning their vantage point is, at least partly, based on events that have happened to someone other than the protagonist or narrator. These stories are fundamentally relational: they are not solely about the narrator nor about the other, but about how the health-related life events of one party have broader implications on the lives of both parties. Our examples span from co-written illness memoirs to comics and poetry. What these works have in common is their exploration of relationality through themes of how changed health also changes social and family bonds, relationships, and responsibilities. What separates them are the various ways in which they explore these intersections of health and kinship – across different genres, media, modes, and narrative forms. Similarly, the articles share a common vantage point in exploring how these works deal with health and kinship, yet they vary in their perspectives. Asking about the role kinship plays in literary works about health and care touches on several fields of inquiry. While all the articles in this issue perform literary analyses, they draw on insights from various fields, including Ethics of Care Philosophy, Health Humanities, Social Work, and Anthropology.

'Kinship' is a key concept in this issue. Anthropology is perhaps the discipline most readily associated with the study of kinship, extending beyond the notion of biological relatives (Rubin 1975, Sahlin 2013). Yet kinship also relates to a broader interest in interdependencies within the Humanities, related to care and Ethics of Care Philosophy (Kittay & Feder 2002; Puig de Bellacasa, 2017; The Care Collective 2021), vulnerability (Fineman 2004, 2008), and precarity (Butler 2006, 2009). To include these various perspectives, our understanding of the concept departs from literary scholar Gero Bauer's definition in *Hope and Kinship in Contemporary Fiction* (2024), where kinship denotes the "structures of belonging and care that bind individuals to one another and to the world" (Bauer 2024, 14). As Judith Butler points out, kinship is bound to "social, legal, and economic powers and institutions", making these structures politically regulated (2022, 26). As such, the concept is contested and easily associated with heteronormative notions of the heterosexual and the patriarchal family. Like Bauer, we are interested in the ways literary works explore the complexities of notions of kinship by positioning them against or alongside family as "nuclear", heterosexual, and reproductive.

The other key concept we explore is that of health. In recent decades, several scholars within the field of Health Humanities have focused on situations involving the triangulation of health, care, and kinship (Morris 2017, Kleinman 2019, Frank 2022). Literary criticism concerned with health and kinship often discusses questions of care and the role of the (informal or familial) caregiver in literary works (Berman 2020; DeFalco 2016, 2023; Nesby 2021; Nesby et.al. 2024). The care demanded from next of kin in situations of changing health is often experienced as what literary scholar Amelia DeFalco (2016) calls para-ordinary care. The term signifies a care that, while not extraordinary because it is both common and quotidian, is experienced as adjacent to ordinary expectations (7). This form of care often catches participants off-guard and highlights "the ethical difficulty of responding to another's needs" (2016, 7). Several articles in this issue touch on caregiving in this respect, exploring 'desperate care' (Hultmann & Bernhardsson), co-writing with carers (Loddo), memory work as a form of care (Warberg), and curography as a genre term for writing about care from a next of kin perspective (Simönhjell & Nesby). Exploring care in triangulation with health and kinship can, as David Morris puts it (2017, 26-27) help broaden our perspective from the doctor/patient dyad to the many interactions between family and healthcare institutions in which next of kin play important roles. In literary works, the complexity of the relationship between patient, family, and health care institutions is often foregrounded, and the norms and practices connected with our responsibility to care interrogated.

Examining the intersection of kinship with health in literary works helps us see the complexity of relationality and its often-processual nature. Our examples include estranged sons who return home, daughters' refusal to care or care overload, homosexual and heterosexual couples co-writing their lives, and modern hospital rooms taking on the aspect of an Egyptian burial chamber. In these varied contexts, kinship serves as a concept that describes the processual and performative nature of relationality and belonging. Viewing kinship through the lens of literary works also allows for an oscillation between scales – literary representations of personal, close-knit kinships have the potential to affect our understanding of kinship on a larger, cultural scale, where they may be read by and affect diverse populations.

This special issue consists of six articles that address questions such as: How do we navigate the needs of the others and the needs of ourselves and other close ones in situations of changed health? How is the relationship transformed by what has happened, and with what sense of 'ownership' can the experience be told as one's own story rather than that of the other? These questions intersect with the responsibility to care, but are fundamentally relational: How, why, and with what result am I affected by what happens to you, and how do I respond to that?

Cecilie Ellefsen's "Seeing the Other: Using fiction in a social work reflection on perception, language, and ethics" addresses the question of how to respond to what happens to another from the perspective of Social Work. Ellefsen uses the Norwegian author Olaug Nilssen's prize-winning autobiographical novel *Tung tids tale* (A Tale of Troubled Times, 2017) and Toril Moi's (2024 [2013]) take on language and attention to reflect on the Social Work tenet "starting where the client is". Social Work ethics stress the importance of reflecting upon the complexities involved in fulfilling the obligation to endeavor to understand the other (Levin 2004, 76). Focusing on the novel's depiction of a neurodivergent child and his mother's struggle to mediate between her own way of seeing her son and that of various professionals from the welfare system, the article argues that the novel can provide a source of enhanced insight into the importance of Social Work professionals' attentive language.

In "...to be pulled between two such different stories'. Vigdis Hjorth's *Will and Testament* (Arv og miljø 2016) as a curography", Nora Simonhjell and Linda Nesby offer a new perspective on a much-debated Norwegian novel. The narrator in *Will and Testament*, Bergljot, is estranged from her family partly because they do not acknowledge that she was sexually abused by her father as a child. When the father dies after an illness, the family becomes embroiled in a dispute over inheritance rights and recognition. Nesby and Simonhjell argue that the novel can

be read as a curography, understood as a narrative that takes the perspective of next of kin and thematizes care (Nesby 2023). The article examines how the novel negotiates moral and normative questions related to health, care, and kinship, as well as the economic frameworks involved in the inheritance dispute. Simonhjell and Nesby contend that a conflict between a dominant family narrative and the main character's counter-narrative runs throughout the novel, and that reading the novel as a curography allows for an exploration of what this narrative conflict reveals about the complexities of care and kinship.

In "Mediating Kinship: Relational Perspectives on Dementia in Two Norwegian Graphic Novels", Silje Haugen Warberg explores the links between memory work, kinship, and mediation. The article compares two graphic novels that depict a son's experience with a parent's dementia: *But Who Are You?* (Men hvem er du? 2023) by Martin Erntsen and *My Mother* (Mora mi, 2023) by Trond Bredesen. Both narratives explore the parent's institutionalization and loss of cognitive abilities, using self-representations (avatars) and first-person narration. However, their depictions of the parent-child relationship and the impact of dementia differ significantly. Warberg's analysis focuses on how the two graphic novels approach the changes in familial memory that follow the onset of dementia, how care is linked to memory work, and how these practices mediate kinship through processes that simultaneously produce, uphold, query, and transform the parent-child relationship. The ways in which these processes are aesthetically mediated through the comics medium result in different relational perspectives on dementia: where Erntsen draws vast inner landscapes of shared associations, memories, and fantasies that point towards a process of commemoration, Bredesen's use of synecdochical tropes serves to establish what Warberg calls a familial gaze. Warberg sees the graphic novels as testaments "to the primary force of relationality in both shaping and maintaining identity" (Bitenc 2020, 154), and the article provides examples of how this processual understanding of relationality and kinship is given aesthetic form through the comics medium.

The comics medium is also under scrutiny in Anna Hultman and Katarina Bernhardsson's "When Caregiving Becomes Desperate: Subjectivity, responsibility, and ethics in contemporary mother-daughter narratives of care". The article provides a comparative close reading of two contemporary Swedish semi-autobiographical works on dysfunctional dyadic mother-daughter relationships. Marie Tillman's graphic novel *En trasig historia* (2020) is about a daughter trying to care for, and keep alive, her mother suffering from symptoms associated with bipolar disorder, and Sara Gordan's novel *Natten* (2022) depicts a mother's care for a teenage daughter whose adolescent unruliness becomes life-threatening due

to the daughter's diabetes. A fundamental similarity between the works is how desperate care shapes the identity of the caregiver: their subjectivities become tied up in an intense, dyadic dynamic and highly calibrated towards and dependent on the care recipient. Focusing on the narration and practices of desperate care, the authors discuss the caregivers' subjectivity, responsibility, and hyper-attentiveness, as well as their defeats when the dyadic dynamic is abandoned as the caregiver turns to institutions for help. The article also discusses the ethics of narrating desperate care.

The Ancient Egyptian burial chamber is visited in Anders Juhl Rasmussen's article "'To be able to live among the dead'. On empathetic images of death and dying in Harald Voetmann's *Amduat. An Oxygen Machine*". Voetmann's book of poetry combines two stories. One story is about the Egyptian sun god's journey through the underworld at night, depicted on tomb walls in the Valley of the Kings and called *Amduat*, meaning "that which is found in the underworld." The other story is about a man who dies of pneumonia at Holbæk Hospital, as seen from the perspective of his son. Rasmussen shows how the merged stories of dying in present-day Denmark and ancient Egypt explore death as a condition of human life and the literary work as a form of ritual. His analysis argues that the work exaggerates and distorts the usually sincere discourse of pathography in a parodic manner, yet also uses verbal, visual, and auditive modalities to create empathetic images. These different literary devices serve to interrogate the triangulation of the dying, the medical institution, and next of kin within the modern-day burial chamber: the hospital room.

Finally, Mariarosa Loddo's article is a comparative study of two co-authored breast cancer memoirs: *Cancer in Two Voices* by Sandra Butler and Barbara Rosenblum (1991 [1988]) and *The Use of Photography* by Annie Ernaux and Marc Marie (2005). The American memoir is composed of diary entries and was published shortly after Barbara's death from breast cancer, whereas the French work departs from the newly established relationship between Ernaux and the much younger Marie and ends with Ernaux' breast cancer being successfully treated. In "Shared stories: Co-authorship and relational perspectives in two breast cancer memoirs", Loddo compares how the notion of kinship acts and is interpreted in the two works, focusing on narrative authority and the ethical implications of writing collaboratively about illness. The article shows that the narratives are pervaded by tensions between introspection and acceptance of otherness, the private story and the public dimension, the role of the caregiver and that of the sick person – but that they also thematize extended notions of kinship that reach beyond the co-writing dyad. The comparative analysis thus widens the exploration of health

and kinship beyond genealogical ties and across geographical distances, making the article a valuable contribution to the scope of this special issue.

Collectively, the articles contribute to a growing field of study within Health Humanities and Literary Criticism. The past decade has seen an increased interest in the thematization of health, care, and kinship in literary works, with the publication of several book-length studies departing from the figure of the caregiver: Amelia DeFalco's *Imagining Care: Responsibility, Dependency, and Canadian Literature* (2016), David Morris' *Eros and Illness* (2017), Ce Rosenow and Maurice Hamington's *Care Ethics and Poetry* (2019), and Jeffrey Berman's *The Art of Caregiving in Fiction, Film, and Memoir* (2020). The recent anthology *I skyggen av sykdom. Skandinaviske pårørendefortellinger i vår tid* (In the shadow of illness. Scandinavian next of kin-narratives in our time, Nesby, Ramberg & Simonhjell 2024) was the first book-length study to focus specifically on the Scandinavian context, where the Nordic welfare model frames the relationship between the individual and the state in specific ways, shaping expectations towards the responsibility to care and the right to receive care. With this special issue, we seek to bring the emerging Scandinavian research on these themes into contact with the international research, and to invite further interdisciplinary explorations into the role of health and kinship in Health Humanities and beyond.

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