Literary Explorations of Health and Kinship

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Formål:

Tidsskrift for Forskning i Sygdom og Samfund er et tværfagligt tidsskrift, der tager udgangspunkt i medicinsk antropologi. Tidsskriftet har til formål at fremme og udvikle den forskning, der ligger i grænsefeltet mellem sundhedsvidenskab og humaniora/samfundsvidenskab. Tidsskriftets målsætning er at fungere som et forum, hvor disse fag kan mødes og inspirere hinanden – epistemologisk, metodisk og teoretisk – i forskellige forskningssammenhænge. Tidsskriftet formidler den debat og teoretiske udvikling, der foregår i de voksende faglige samarbejds- og forskningsinitiativer, der udspringer af dette grænsefelt. Tidsskriftet henvender sig til alle med interesse for forskning i sygdom og samfund og i særlig grad til sundhedsmedarbejdere i forsknings- og undervisningssammenhæng med forbindelse til tværfaglige miljøer.

Aims and scopes

The Journal for Research in Sickness and Society is an interdisciplinary journal which has a theoretical background in medical anthropology. The aim and purpose of the journal is to promote and develop research in the borderland between the health sciences and the humanities/the social sciences. The goal of the journal is to function as a forum in which these disciplines may meet and inspire each other – epistemologically, methodologically and theoretically. The journal conveys the debate and theoretical development which takes place in the growing collaboration and research initiatives emerging from this borderland. The journal addresses all with an interest in research in sickness and society and especially health professionals working with education and/or research in interdisciplinary institutions.

Indhold

Forsidetekst

Maleri: 'HVERDAG'

Kunstneren om værket:
Maleriet HVERDAG fra 2024 indgår i livsfortællingen om FASTER, som består af 14 kunstværker og et digt. Faster døde som 92-årig lige før corona satte landet på pause. Faster sagde selv, at hun led af den værste sygdom af alle: SKIZOFRENI. På baggrund af fotobøger, breve fra hendes familie gennem livet og ikke mindst kladder som hun skrev til breve samt mine erindringer, havde jeg til hensigt at fortælle en anderledes slægtsfortælling til mine børn/børnebørn og samtidigt få en større indsigt i og forståelse af ophobningen af psykisk sårbarhed i familien, hvor tre ud af fem søskende samt min farfar periodisk havde brug for psykiatrisk støtte. Det endte med at blive til livsfortællingen FASTER, som består af digtet Frataget Livets Drømme og kunstværkerne.

I alle værkerne indgår den røde farve som symbol på det, der tager magten fra faster eller/og familien. Maleriet HVERDAG har jeg laseret med rødt som symbol på en af de dage hvor faster synker lidt ned i sorte tanker. Selvom denne del af livet måske er en af de bedste livsperioder, så er der som hos alle andre forskel på dagene og humøret.

Det blev for mig tillige et tilbageblik på den historiske udvikling inden for psykiatrien og synet på psykisk sårbare mennesker.

Jeg har altid i mere eller mindre omfang udtrykt mig billedligt. Faster-serien er noget særligt og jeg har haft den glæde at få den udstillet på Kunstpunkt i Augustenborg; Galleri Gallo og senest Galleri Årøsund og fået lov til at fortælle om værkerne.

Det er en stor glæde, at maleriet HVERDAG nu pryder forsiden på denne udgave af Tidsskrift for Sygdom og Samfund. Jeg tror, at faster ville have været stolt af det.

Netop det billede var med på den anerkendte censurerede udstilling KS 2023. (Tistrup/Vardemuseerne).

Marianne Lyngsø Foged

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 hightlights “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 (Simonhjell & 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 Humanitites 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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Originalartikel

Seeing the Other

Using fiction in a social work reflection on perception, language, and ethics

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The article explores how a work of fiction can contribute to a social work reflection on the helping process and the challenging task of seeing the Other. The article has an interdisciplinary purpose and aims at creating a dialogue between social work discourse and the language of fiction. Drawing on Moi, Felski and Tygstrup & Holm, an argument is made that narratives, language and ethics are intertwined and to some extent transcend boundaries between literature and social work discourse. The novel analyzed is Tung tids tale (Tale of Troubled Times, *my translation) by the Norwegian author Olaug Nilssen. Selected passages from the novel are interpreted through a psychological as well as a systemic perspective, highlighting the importance of language and theoretical lenses for social work ethics. The concept of institutional identities is suggested as the most fruitful approach, attributing the professionals' conduct in the novel to systemic factors.*

Introduction

In the essay *Språk og oppmerksomhet*, the literary scholar Toril Moi (2024/2013) reflects upon the connection between language, attention, and ethics. When we pay attention to a situation or person, we are also doing something moral, she writes. Building on a concept of attention developed by the philosophers Charlotte Weil and Iris Murdoch, Moi suggests that language, insight, and judgement are fundamentally intertwined. Our moral assessment is conveyed through the words and concepts we use to describe what we see. An attentive language, Moi writes, seeks to bring words in accordance with reality (23). Moral action depends upon our ability to perceive the world and other subjectivities with a fair, compassionate gaze. Only if we see and acknowledge the other are we able to provide the form of help that is needed, and not the form that is shaped by our own preferences or quick assumptions (69). A similar call for attention can be found in the social work tenet "starting where the client is" (Marsh 2002), resonating with Soren Kierkegaard's classic quote on the art of helping: to help, one must first and foremost find the Other where the other is, understand what the Other understands, and start from there.[1]

Taken literally and to its fullest extent, seeing the Other through the prism of his own subjectivity is of course utopic. The road to reaching a clear comprehension of another is beset by a multitude of obstacles, filtered through language and narratives, which lead our attention in certain directions while ignoring others. Still, in social work practice, striving towards the Other, the endeavor to understand, is an invariably moral demand (Chambon 2013, 125). Social work ethics stress the importance of reflecting upon the complexities that are involved in fulfilling this obligation (Levin 2004, 76). Can some relationship be made between this ethos of social work and Moi's take on the role of language in fostering our ability to perceive? This article contemplates this question. More specifically, I will explore how a novel can contribute to a social work reflection on the challenging task of seeing the Other.

Social work strongly identifies with a field of practice and gains much legitimacy from a social science knowledge base. A novel, on the other hand, is a cultural form associated with language and narratives. Can these two quite different epistemological sources of knowledge be bridged? In this article I argue that they can. The overall aim is to foster an interdisciplinary dialogue and reveal how a work of fiction can be a valuable contribution to social work discourse of helping

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[1] In this article, «Other» is used synonymous with «client» or «service user», i.a. a generalized term for a position within a professional helping relationship (see for instance Chambon 2013).

the Other. The novel chosen for analyses is *Tung tids tale* (2017) by the Norwegian author Olaug Nilssen (hereafter *Tale of Troubled Times*). Olaug, the novel's narrator, is the mother of Daniel – a young boy diagnosed with neurodevelopmental disorders. The story portrays the family's everyday life and thematizes what being parents to a disabled child can entail. The novel is the first in a trilogy where Nilssen explores the topics of disability, responsibility and family dynamics. For *Tale of Troubled Times*, Nilssen was awarded Brageprisen, a prestigious Norwegian literary award. The novel was praised for its nuanced and bold descriptions, and for highlighting the situation of informal caregivers (Fontene 2017). Dealing with various helpers and an institutionalized support system comes with the territory and is a recurring motif in the novel. It explores interactions between the welfare system's helpers and the recipients from the recipients' point of view.

Social work is one of several professions that provide help to individuals and families within the Norwegian state welfare apparatus. The help provided does not necessarily match the help needed: A common experience among parents of disabled children is that the heaviest burden is not having a child with extensive helping needs, but rather the interaction with the welfare system (Tøssebro and Wendelborg 2018). The system seems to incorporate certain "thresholds" that require parents to be persistent and not give up in the process of accessing help (214). This challenge is also depicted in *Tale of Troubled Times*. As will be elaborated and analyzed, the helpers' attempts to assist are often a source of frustration for Daniel's parents.

In the next section, I outline my theoretical background – the meeting between social work discourse and literary discourse. The second and main section is a literary analysis of how the encounters between Daniel's parents and the professional helpers are portrayed in the novel. The analysis will make use of different perspectives related to social work, casting different lights upon the interaction, thereby illustrating one of Moi's central points – that language is a form of attention. Through this, I hope to demonstrate the intimate relationship between language, attention and ethics.

Theoretical background – social work discourse and literary discourse

Social work discourse

According to Julkunen and Rauhala (2013), social work can be regarded as "a knowledge producer and professional activity that develops and delivers methods and strategies in organizing the care of people who in one way or another are defined as being outside of normative ways of living, especially of waged employment" (106). Traditionally, the notion of deviance has been connected to and is constitutive of social work, as responding to different forms of social deviance in some sense is what social work does (Ellingsen & Levin 2015, 52). Today, a more common theoretical frame for describing social work's target groups is the concept of marginalization (Julkunen & Rauhala 2013). Approaches to studying marginalization tend to focus on situations and positions of disadvantaged groups, and incorporate concepts like social exclusion, deprivation and segregation (113). Poverty, crime, substance use disorders, mental health challenges, child neglect and disability are some of the conditions that social workers are involved with today.

In a Norwegian context, social workers are sometimes referred to as "the heart of the welfare state" (Fellesorganisasjonen 2022). Broadly embedded in its institutions and practices, the profession is often said to be situated in the space between help and control. Social workers are the welfare state's door opener, and its gatekeeper (Levin 2015, 42). Being closely associated with the field of practice generates distinctive dilemmas. Social work is to work for the betterment of vulnerable groups and contribute to empowerment and inclusion, issues of ultimate importance to the profession. At the same time, social workers are responsible for administrating current social policy. Being part of the state apparatus, helpers are there to assist, but also to educate, regulate, and modify (Chambon 2013, 122). These conflicting considerations cause considerable tension in social work practice (Levin 2015). For many social work clients, declining welfare services is not an option; the social worker might have a legal mandate to interfere, or the service user might lack the resources to get by without the offered assistance (Levin 2015, 42). This structural element of power cannot be bypassed and adds a normative and ethical dimension to social work practice. Reflecting upon this situated side of social work is central, as the political discourses and institutional demands of a specific time and place are not necessarily in alignment with social work's core values and principles (Askeland 2006).

A defining feature of social work, ethically and theoretically, is its strong commitment to foregrounding the role of societal conditions and structures in the unfolding of life. Acknowledging the impact of "the social" is central to the profession. The global guidelines emphasize social work as a discipline that recognizes historical, socioeconomical, cultural, political, and personal factors as being intertwined (IFSW 2014). As a multi-disciplinary profession, social work utilizes knowledge from different disciplines such as sociology, psychology, philosophy, law and social pedagogy (Kleppe 2015, 132). Although social work knowledge base contains a diversity of branches, perspectives, theories, and methods, social work tradition and discourse is characterized by a clear preference for contextual frames of interpretation as opposed to individualistic. The significance of taking structures and context into account is expressed in the discipline's vocabulary through the terms "person in environment" and "holistic view" (Ellingsen & Levin 2015, 59). "Person in environment" is social work´s analytical unit and a guiding principle for practice, which mirrors the discipline's comprehension of the problems as also having social and contextual prerequisites. Although the individual might be the "bearer" of the problem, the analysis must transcend the individual level. In seeking solutions and ways forwards, the practitioner should approach the situation in a holistic manner and consider the interplay between the client's resources and limitations on the one hand, and the surrounding relations and social systems on the other. In stressing the importance of structural and social mechanisms, the Other in social work becomes the antithesis of the liberal subject – a subject that, as the American philosopher Martha Fineman (2008) makes clear, is conceptualized as self-sufficient, and free from vulnerability and circumstances beyond its control. In contrast, social work discourse highlights a subject that is immersed in social context and dependent upon a social structure. The central place of the terms "person in environment", "holistic perspective" and "context" underscore social work's insistence on seeing the social and structural aspects in the challenging task of seeing the Other.

Literary discourse - fiction and representation

Fiction can encompass insight into stratification, social life and subjectivity. In Moi's view, fiction can assist us in seeing reality more clearly, as it is a genre through which an attentive language can be expressed. At its best, the attentive language of literature "forces us to open our eyes, to see language and reality as something important and concerning us, and as something we should reflect on" (18). In *Uses of Literature*, Rita Felski (2008) claims that literature – and the novel genre in particular – creates distinctive configurations of knowledge about social reality and selves immersed in this reality, – about “how worlds create selves, but also of how selves perceive and react to worlds made by other selves” (91). The novel has a flexibility that enables it to capture and render the deep intersubjectivity and complexity of social interaction. The novel’s shifting attention between interiority and exteriority, the alternation of reading minds and portraying behavior, is the novel’s privilege and its strength (91). In Felski’s view, the novel doesn’t mirror reality but provides a “window” to see it anew: “Literary works rework the works of culture, redescribes that already described” (85). Through its redescriptions, literature can augment our understanding of how things are (86). While a mirror can only reflect, “window” points to the possibility of seeing something different, of gaining a new (in)sight.

How literature relates to society is also discussed in an article by Tygstrup and Holm (2007). In their perspective, literature is one of many practices which take part in public discourse where images of social reality are produced and circulated. Society constantly creates figurations of “how things are”, and of how we can and should relate to ourselves and others (150). Tygstrup and Holm state that this activity is inherently political, as constructing specific models of social reality simultaneously obscures other aspects of that reality (157). At the level of symbolic forms, literature is a practice of representation among others (159). What separates fiction’s representations from other representations circulating in the culture is as much a question of the position fiction occupies in society as it is of its specific “literariness”. Contrary to social work, literary discourses lack a clearly defined societal function. The discourse of fiction is not expected to deliver solutions beyond itself or to improve any aspect of reality. Fiction is without such a societal obligation. This non-pragmatic status that fiction holds, and the distance accompanying it, enables fiction to be attentive to marginalized aspects of social reality, and to produce figurations that diverge from, or exploit, the hegemonic representations in the surrounding culture (158). From its space of freedom, fiction holds the potential to contest and question “the order of things”.

In this article, *Tale of Troubled Times* and social work are both regarded as practices of representations that are involved in producing images of subjectivity, interaction, and social reality. Whether the issue at stake is helping someone in a practice field or narrating the subject matter in fiction, some form of meaning construction takes place. This common landscape between literature and social work is what this article seeks to explore and, in some way, construct. Sæther (2022) points out that an interdisciplinary approach must seek to achieve a certain balance, permitting both “parties” to premise the dialogue. In this, I’ve been inspired by what the philosopher Hans Skjervheim (1976/1996) writes about the nature of dialogue and its prerequisite: Equality between two parties can be ensured by what he refers to as a "common third" – a shared focus for attention. The passages chosen from the novel depict the role of the informal caregiver, the issue of defining Daniel and the conduct of the helpers. In the literary analysis, I will make use of resources from social work discourse which seem relevant to the novel, as I attend to a topic at the heart of social work – the complicated task of seeing the Other.

Understanding the Other in a novelistic discourse

Parenting Daniel

> *It's been six weeks since I lost it at work. Was it tears, rage or fainting, I no longer remember, nor whether it was the fifth or tenth time. But I do remember catching a glimpse of myself in the mirror, seeing that I was wearing old sneakers, with pants that were too small, face looking harsh, hair being grey.* (14)[2]

These words belong to Olaug, the narrator of *Tale of Troubled Times*. Daniel is her first-born child and is undergoing diagnostic assessment. In his first few years, he seemed to be a normal child, with linguistic skills above average. Or so his parents thought, until he suddenly began to lose his acquired language and motor skills and changed behaviour. Now, at nine years old, Daniel has been diagnosed with autism, and the parents are currently disputing another diagnosis, that of intellectual disability. As the quote illustrates, the novel leaves the reader in no doubt that Olaug's everyday life is challenging. Combining a professional life with the role of parenting Daniel comes with severe difficulties, pushing Olaug to her limit, again and again: "I often went to the doctor, always thinking that one sick leave would be enough, like a short rest to recover, but it wasn't, week after week, it wasn't" (19). After several attempts to stay in the workforce and with strong encouragement from her doctor, Olaug has applied for care allowance.

In the novel, we become well acquainted with how the parents have experienced the changes in Daniel, and how baffling it has been, trying to make sense of and reconciling with this unexpected reality. Accepting the diagnoses suggested by the psychiatric assessment has been –and still is – difficult. Olaug frequently returns to the issue of Daniel's identity and how she can understand what has happened. In some of these passages, Olaug explicitly addresses Daniel, as the novel's "you":

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[2] All translations of quotations from the novel are my own.

“When you were small, you had a synthesizer in your room. You had a shelf, a desk with drawing materials, and a stair shelf filled with books. You fetched books yourself and asked to be read to” (43). Through her, at times scrutinizing, memories of the younger Daniel – often a stark contrast to his present being – the novel provides the reader a window to intimately access the parents’ experience of shock and despair.

Also portrayed in the novel is an aspect of parenting Daniel that can perhaps be described as “cultural loneliness”. That a child’s socialization, development, and life quality require resources beyond parenthood is captured in the well-known saying that it takes a village to raise a child (Reupert et al. 2020). To most parents in contemporary Nordic societies, a village is open, with its arsenal of resources, offering advice and guidance and access to sports, music, theatre, or whatever activity suits our child. As an effect of compliance with the norm, we often benefit from the surroundings without realizing it. When one’s child’s needs and behaviors deviate from those of the majority’s, being parents is a whole different ball game. *Tale of Troubled Times* portrays parenthood from outside the village, where everything around the child must be organized on completely different terms, without getting the support from, or finding rest in, the matrix of normality. Rather, in everyday situations, Olaug often brushes up against its standards and expectations. As a schoolboy, Daniel wears large nappies and generates much more weekly waste than the outdoor garbage can hold, which causes their neighbour to carefully guard his own (84). For safety reasons, the nursery’s furniture is kept to a minimum, as Daniel can tear down curtains and throw things out the window. Exposing family life to others is stressful to Olaug, as she is often painfully aware of how her coping strategies and ways of organizing might appear to those who are unfamiliar with Daniel:

> *I hesitate to show the room to others, it’s like an institution – it must be explained, and when I think about it, I always think about the case manager from the social services who visited us, standing there silently, with a stiff look on her face, and me, getting more and more frantic, apologizing, and explaining that your room wasn’t ugly. She didn’t say a word.* (41)

Even to a professional helper, making a home visit to get acquainted with the family’s coping needs, Olaug feels the need not simply to describe and lay out the “matter of fact” but to justify and defend herself. Having internalized the normal gaze and the judgement it might contain, Olaug, understandably enough, interprets the case manager’s silence as a lack of validation.

In the role of the informal caregiver, Olaug finds herself in a double span (Simonhjell 2020, Warberg 2021). On the one hand, Olaug is oriented towards Daniel, trying to understand his needs and conditions of existence through other forms of communication than verbal and neurotypical. On the other hand, Olaug must continuously mediate between what she perceives as Daniels needs and the broader surroundings, including the world of professional helpers. As the mother of a disabled child, Olaug is tasked with speaking about and for the child (Warberg 2021, 59). In Olaug's interactions with the welfare system, this task of "representing Daniel" is heightened. By virtue of being Daniel's mother, Olaug is not a client in her own right: rather, she represents what Lawrence Shulman within the context of social work discourse has termed "the second client": a person of vital importance with whom the system must cooperate to meet the actual client's needs (2003, 35).

As is often the case when power and help run together, Olaug's relationship to the system is ambivalent. At times exhausting, yet inevitable – to families with severely disabled children, the welfare apparatus can in a certain sense be thought of as the "village", as a potential source of non-parental resources, enabling the child to have a life and impulses outside the domestic sphere, as well as assisting the parents in helping their child. A prerequisite for cooperation in a helping process is that the helper succeeds in "contracting": between the parties, a somewhat united understanding must be reached, of the situation, the problem, and the road forward (Shulman 2003). For this to be obtained, the helper must actively search for areas where the client's challenges and the resources of the system coincide (157). In *Tale of Troubled Times*, such a joint understanding is hardly present. Often, interactions between Daniel's parents and the system are portrayed as an abyss between different perceptions, between the family's everyday life and an organized apparatus of support. Accessing the system's resources is anything but simple. The helping needs must be presented, conveyed, and documented. Olaug's continuous efforts at making Daniel and the situation visible to the system is a prominent theme in the novel. Portrayals of her encounters with various professional helpers often have a strong emotional charge. Time and again the impression is of a system which adds insults to injury; to an already demanding situation comes another layer of stress, resulting from interaction with professional helpers, which pushes Olaug to the limit of what she can endure. Despite recurring periods of sick leaves, the welfare administration gives her little hope of having her application for care allowance granted, as this benefit is not meant for situations when the one being cared for is one's own child (23). Somewhat ironically, the comprehensive amount of case papers, documents, and letters of correspondence, which are dutifully sorted by Olaug in binders according to dates and years, speaks of "representing Daniel" as a continuous and time-consuming activity.

Defining Daniel

A dominant theme in the novel, which causes much friction between Olaug and the system, concerns the labelling of Daniel through diagnosis. That he needs extensive help is indisputable, both to the parents and the various helpers. The nature of his difficulties, on the other hand, seems to be less clear. To the parents, Daniel's development is a puzzle. Faced with the diagnostic categories, Daniel long seems like an equation that does not quite add up. In their attempts to understand what has happened to him, and as a way of providing the system with documentation, the parents have filmed him in everyday situations, at various stages of his development, capturing both his loss of function and moments where he exhibits neurotypical demeanor, like playing and singing (57).

The novel narrates three diagnostic assessments of Daniel, of which the first concludes with a variant of autism. But due to his atypical development, neither the parents nor the special education teacher in the kindergarten feel comfortable with this diagnosis. Daniels regressive development is not compatible with the diagnostic criteria, and the special training he receives, targeted around this diagnosis, has not resulted in any progress – on the contrary, Daniel regresses despite the efforts made. Initiated by the special education teacher and in accordance with the parents, a new meeting with the diagnosticians takes place, where they call for a new assessment of Daniel's condition. At the meeting, the diagnosticians strongly oppose this request:

> *-But it doesn't work, we are not getting results, said the special education teacher.*
>
> *-No, but as you know, you must keep trying it out, find out what motivates him, said the senior physician.*
>
> *-But as I said in the presentation, nothing motivates. We can't make it work. He has moved backwards. The parents have videos showing how huge the difference between then and now really is, it's a gradual regression, said the special education teacher.*
>
> *-I don't doubt it, the senior consultant said, and added that he didn't need to see them. He'd already risen and commanded us to follow him to draw a family tree, of mental disorders and diagnoses on both sides of the family. We went along, not knowing what else to do.*

> *-Autism and depression occur frequently in families with many creative and intelligent members, he went on saying (...), and we took the bait, listed the mathematicians and artists in the family, speculated on the sanity of family members. The senior consultant nodded and took notes.* (68-69).

The scene is illustrative of a recurring dynamic between Daniel's parents and the helpers. Interactions where "defining Daniel" come into play are often depicted as a clash between the parents' comprehension and that of a system, where only certain experiences and interpretations are recognized. The senior consultant's dismissive response to the parents' videos of Daniel is somewhat typical of the encounters involving various helpers in the novel; he does not need to see them, he says, clearly not regarding them as a potential source of enlightenment, as a gateway to Daniel's being in his everyday surroundings. Instead, the parents are steered towards an activity of speculation and interpretation, but from which nothing can possibly be gained except for confirmation of the diagnosis that has already been given.

The parents conform to the physician's redirection of the meeting and perform his instruction to interpret their family in psychiatric terms. But at night, Olaug is haunted by what happened: "I lie awake, thinking about the brutal dismissal, that I'm not the only one experiencing this, that this is how they do it. Dismiss. See the one that is now. Close their eyes to the one who was. Forcing the parents to do the same" (73). Olaug's behaviour at the meeting and its aftermath exemplify what Shulman (2003) calls an "illusion of work": the client conforms to the course that is staked out by the helper, but the agreement is only superficial (246). Without genuine ownership of the process, the client is not onboard. Olaug went along with the senior consultant's suggestion, but the truth is that she experienced the focus and direction of the meeting as forced. The parents are still grappling with the issue of "defining Daniel", which means that the nature of his being is a somewhat open question to them. But the power to define the situation lies with the diagnostician, and how Daniel is to be classified, is not up for negotiation. This case seems closed.

When power is unequally distributed, as is the case in professional helping relationships, the helper's power to define and determine relevance can take subtle forms and still be effective. In the novel, this aspect of power is also embodied: Daniel's father says that they have video clips of Daniel showing regression in several areas, but "no one asks about them" (79). In a conversation with the child psychologist, Olaug describes several episodes involving Daniels behaviour, of which some seem to undermine the criteria of the given diagnosis and others seem to confirm it. But only examples of the latter make the psychologist reach for her pen: "It was only episodes like these that she wrote done. We wondered if we were lying. We had to prove that we were telling the truth" (52). Recounting Daniel's previous skills at meetings, silence is the response that the parents receive from the professional helpers. Their experiences and inputs are sometimes excluded from the minutes: "They didn't record anything" (57). In the novel, the examples are numerous: taking notes or not taking notes, silences, long pauses and averting gazes all become markers of a lack of recognition and of what is not considered valid – markers of micropower.

Referring to the videos appears to be an act of resistance, as the parents' attempt to oppose the diagnosis and argue against it. But when Daniel's being is on the agenda, inputs such as these are poorly received. The helpers often seem to have little room for curiosity, ambiguity, and uncertainty. Instead, the parents, in their broader comprehension of Daniel, are subjected to corrections and modification.

The portrayal of a multi-disciplinary meeting that takes place shortly after Daniel has started school provides a striking example of this. The school that he is attending is for children with severe learning disabilities. In their communication with the school staff, the parents are eager to convey Daniel's gradual regression and the skills he once had, in the hope that the school can be perceptive of this "broader" Daniel: "I repeated my phrases about what you could do, made a number of that we wanted the teachers and assistants to be aware of it, that also they looked for remainders of the one you once were (...)" (78). This approach to Daniel gains little sympathy from the professionals attending the meeting. As events unfold, the school principal takes charge and strongly implies that Daniel's neurodevelopmental disorder has been more encompassing from the start than the parents believe:

> *-But isn't it just the language? the principal asked.*
>
> *-He hasn't really regressed in other areas beside that, he proceeded, and from the tone of his voice and how he asserted himself, from how the others sat there, silent, and stiff, I realized that they'd been talking about us (..) they thought we were crazy, living in a dream world. There and then I was silenced, primarily because my chest tightened, but also because, at that moment I couldn't remember. Was it true? Was it just the language? Have you, apart from that, been different since you were born? (...) In my brain and throat, a compressing sensation began to take hold (...). (78)*

The intensity of Olaug's reaction plays tricks on her memory, leaving her in a state of silent impotence, tongue-tied, and unable to counter the argument with examples of Daniel's former skills. In yet another attempt to oppose the principal's description, Daniel's father gives several examples of regression besides the language ("Previously, he ate sandwiches in a completely normal way") but is seemingly unable to influence the terms of the discussion. No remarks are made by the helpers to show any confirmation of, or interest in, this other Daniel. Bringing up the fact that they have videos, is of little use: "Everyone fell silent. The whole group sat still" (79).

Supported by the passivity of the other professionals, the principal undermines the parents as credible witnesses to Daniel's life and development. Their narrative of Daniel has its starting point in and can therefore include nuances of "the normal child". The principal's act of interpretation goes in the opposite direction and becomes retroactive as it takes the disorder as its point of departure, thereby downplaying any possible features of normalcy. In underlining the diagnostic category (and perhaps stretching it) as the most essential viewpoint, "the deviant Daniel" is foregrounded and becomes "the true Daniel" – the one he always was. Yet again, the parents' videos are not granted relevance. They are not used by the helpers as an opportunity to adjust their own outlook, to weigh their perceptions against another background or as a chance to see something else. Nor are they used as a gateway to understand what the parents are talking about, to try to see what they see –in other words, to empathize.

From the outlook of social work values, the novel's depictions of various interactions between the parents and the system are often disturbing, deviating from principles such as avoiding objectification, the importance of aligning oneself with the service user's perspective, using communication skills in creating a dialogue, and making room for the client's experience and comprehension of the situation. In facing the parents' understanding of who Daniel is, who he has been and who he perhaps can be, the helpers' lack of responses, and lack of attention, beyond the discourse of diagnosis is conspicuous. Little vocabulary and few horizons that would surpass "Daniel the diagnosis" emerge. In order to meet the obligation of creating a fruitful dialogue with the parents, one may also wonder why the helpers' responses are not more in line with: We're not sure, but this diagnosis is our best guess at this point; sometimes the diagnosis is wrong; a diagnosis is not a perfect description of someone; perhaps we need to reconsider; keep documenting Daniel's development; show us the videos, etc. Instead, a picture is drawn of professional conduct that appears to be reductionist, insensitive and at times manipulative, in their attempts to steer the parents' understanding of Daniel closer towards that of the system.

Posing the social work question: What is driving the helpers?

Do the novel's depictions of the relationship between the professionals and the informal caregivers give a believable account of the welfare state's helpers, outside the novel's domain? Is this really the state of affairs? Nilssen has openly declared that the novel is based on her own experiences as a mother of a disabled child, and that she hopes the novel will influence policy makers (see for instance Warberg 2021, Simonhjell 2020 and Nesby 2021). There are statements in the novel where Olaug seems to speak from an activist position that includes other caregivers in similar situations: "It is not any worse if I fall apart than if others fall apart. I don't have any more right not to fall apart, even if I can speak the cause" (24). The experiences are not just hers – it is challenging for them all and they are all barely holding it together, the narrator claims.

A work of fiction is not a piece of empirical evidence of reality. And yet, it is through its portrayals of what might have been and what might take place that the novel opens the door to social work reflection. According to Tygstrup and Holm (2007), concrete figurations in fiction can display the social matrix as well as what does not fall "naturally under" the current order of things. By typifying dominant ways of thinking, literature can make hegemonic representations visible and available for critical debate (160, 161). Let us therefore assume that the novel's portrayals of interactions between the parents and the helpers do pick up on something real; and as disturbing conduct calls for explanations, let us ask: How can we understand the behaviours of the professional helpers, and their lack of willingness to question their own interpretation of Daniel? In what follows, two hypotheses will be explored. The first one is grounded in an individualistic, psychological perspective and is congruent with how the helpers in the novel seem to perceive themselves. The second one is sociological and anchors the helpers' pattern of behaviour in institutional mechanisms. These two perspectives are both derived from social work knowledge base, and – as will become apparent – they give very different interpretations of the interaction.

"The parents are in denial"

Perhaps the issue at stake regarding Daniel's diagnosis is that the parents are simply wrong. In her understanding, Olaug herself sometimes alternates between viewpoints, of which one echoes the system's: Perhaps the helpers' approach is not too categorical, perhaps it is her own that is too broad? Perhaps blinded by shock and grief, they as parents have not been able to face reality? Their attempts to solve the puzzle are nothing more than movements away from the truth, driven by wishful thinking and denial. Perhaps their wish to see normalcy has prevented them from seeing the autism that was always there?

Distance can sometimes be a prerequisite for seeing clearly; in searching for recognition and confirmation, we are easily drawn to idealized pictures, to the positive outlines (Felski 2008, 49). And as pointed out by Warberg in her analyses, Olaug is always on the lookout for presence and agency in Daniel, for him seeking her out and making contact, and for signs that are more in keeping with how he was before (2021, 70). As readers, we come to empathize with Olaug's sense of loss and her wish to make connections with her son. We understand how difficult it must be to witness him needing more and more help, the hope that arises, again and again, the long road to accepting that Daniel, as he was before, perhaps is gone. We also come to see that the emotional upheaval this causes is such that in facing the diagnosis, it can drive one to question it. It may be irrational, but nonetheless understandable. And perhaps a dialogical approach should be toned down by professionals facing situations like these, when it is not a matter of different but equal perspectives, but a matter of one being in grief and denial and the other, having a bit more distance, seeing more clearly. In situations like these, a dialogical approach only risks adding grist to the mill and feeding the denial. At one point, Olaug herself interprets the helpers' signals in this way: "(...) we had already understood, from the way they asked, that they looked for signs of the abnormal, and signs that we had also seen of what category you belonged to, right from the start (...)" (57). Although we do not have access to the minds of the helpers in the novel, it often appears as if this is how they fulfill their role – that the parents must be helped to face reality, be guided out of their self-deception, and firmly but subtly be led towards the truth that is presumably also held by them, beneath the layer of denial. In this light, the helpers' acts of silence become acts of patience, of waiting for the parents to come to terms with the truth about Daniel.

The dimension of denial and truth does have some affinity with social work's theoretical discourse. Following Shulman (2003), getting the client to accept the offered help is part of contracting, though it is not always easy. Getting to grips with a painful situation can take time, and the client may need the helper's support to face the realities and to acknowledge what is true (227). Some ambivalence and reluctance are to be expected along the way (197). Similar reasoning can be found in Prochaska and DiClemente, who thematize how, when confronted with needs for change, not acknowledging the problem and its aspects is a common psychological mechanism, and for some, difficult to overcome. In facing the unknown, contradictory thoughts and emotions can keep the client locked in a state of paralysis, unable to take necessary steps forward (Prochaska & DiClemente 1982).

That some defense mechanisms are in play when life is turned upside down, surely seems sensible. But still, there is something unsatisfactory about how this level of explanation fails to cast light upon the dynamics of the social or address patterns of interaction. As readers, we are kept in suspense for a long time regarding the nature of Daniel's challenges. The parents continue to fight for a reassessment ("we didn't give up") and eventually succeed. This results in Daniel getting a more specified diagnosis within the autism spectrum. The new diagnose is more congruent with the parents' perception of Daniel' development, but which for a long time was not acknowledged by the helpers ("no one believed us"). To the extent a diagnosis holds some truth, the system turns out to be a bigger obstacle than the parents.

Seeing the Other through an individualistic psychological perspective always risks serving as a protective shield around the helper and the system as they are both left unquestioned. This is also the case here, as this framing does not take us any further than how the helpers seem to perceive themselves – that their insight, when it comes to Daniel, is a privileged insight. In reflecting on the professionals' conduct, I will therefore propose a second framing. A case can be made that the collision between the parents and the professionals is grounded in the phenomenon of "institutional identities".

Daniel – an institutional identity

The concept of institutional identities is derived from sociological research. It focuses on how institutions interact with so called "problematic identities", and how the organization of the system influences the interaction between the helper and those receiving help (Järvinen & Mik-Meyer 2003). In some sense, institutions can be regarded as "ideas in action" – as knowledge systems put to work. Like theories, they assume a structure and attribute resemblance through classification and diagnoses (Douglas 1986).

An institutional identity can be thought of as the premise on which the Other becomes visible to the system. Becoming a client also means becoming a "case" – a process in which the challenges are sorted, categorized, and assessed. To welfare institutions, "schizophrenia", "autism" and "substance use disorder" are not only labels meant to refer to specific beings in the empirical world; they also exist as institutional identities, as categories that are formed by and that function within the systemic apparatus tasked with handling them (Järvinen & Mik-Meyer 2003, 11). Institutional identities can be viewed as systemic constructions that make it possible for institutions to act. No institution relates to "the whole person" or innumerable variations of the Other – characteristic of institutions is that they function by reducing complexity, by limiting the scope of interpretation (Borch 2011,7). The service user must be "translated" into a format that is compatible with the categories, diagnosis, routines, and directives of the welfare apparatus. If this is achieved, the client is assigned a "problematic identity" with which the system can interact. Based on assessments, documentation, and diagnostic mapping, a decision is made as to which institutional identity the client is ascribed to. In this process, the institution makes use of analogous reasoning; questions concerning what something "is" are subordinate to questions of "what fits with the problem categories" (Järvinen & Mik-Meyer 2003,17).

The assessment of what is to count as relevant aspects of the situation or problem occurs within an institutional framework, giving weight to the professional gaze. When helper and client have different understandings, the professional's interpretation is considered "hyper real" compared to the client's, because the former's assessment is already intertwined with and stems from the institution's range of action. For the welfare institutions, institutional identities are a pragmatic necessity in the sense that they reflect the system's need of sorting: for it to implement measures, the problem description and suggested solutions must align with the system's organization. Thus, receiving a certain diagnosis is not just about the person's challenges being defined in a specific way. In an institutional context, diagnosing is far more exhaustive than a linguistic ordering of things, but is part of a larger system structure, where specific categories and resources are linked together. Hence, to the client, institutional identities come to play a crucial role as they are the "entry ticket" to the welfare institutions system of support.

That specific diagnoses are linked to the system's possibilities for action is recognizable in *Tale of Troubled Times*, and is particularly evident when the parents apply for, and are granted, more days and nights at "Solgløtt" – a respite care facility where Daniel already spends time. But the implementation of this measure is dragging on. The funding that is involved is associated with the Agency for Intellectual Disability, but because the parents have refused to accept the diagnosis of intellectual disability, Daniel currently falls under the Agency for Children and Youths. This creates a "plug" in the systemic chain, which is not cleared until the parents go along with the system's demand and accept diagnosing Daniel with "unspecified intellectual disability". This additional diagnosis is made without further assessment, but it speeds up Daniels "path" through the system, and results in the granted additional hours at Solgløtt eventually being executed (143).

When aligning with the professionals' perspective opens doors to key services, power and interpretation come together. Despite being strongly encouraged by the helpers, the parents refuse for a long time to accept this diagnosis ("I understand that this is a small issue for you, but for us, it's existential", 118). When they eventually agree to it, it appears to be an act of resignation, as a trade-off to receive the necessary help. What this additional diagnosis adds to the helpers' comprehension of Daniel seems unclear. However, increased or more adequate understanding does not seem to be the main point; embedded in the organization of resources, the diagnosis becomes a gateway which, if accepted, creates movement within the fabric of the system.

"Institutional identities" shed light on a systemic pivot, causing a pressure towards making a diagnosis, which, when defined, subsequently becomes preservative. The first autism diagnosis that Daniel receives turns out to be inaccurate, but efforts to get the system to reconsider are met with resistance and pressure to drop the issue – the diagnose seems to have a life of its own, relatively detached from Daniels actual being and what the parents have to say about his development. Encumbered with this quality of inertia, the threshold for changing the diagnosis is high.

Reading the novel through the concept of institutional identities makes the unarticulated premises of the interactions between the parents and the helpers visible. The perspective draws attention to the structural weight of definitional power and enables a reversal of the system's self-understanding. Of course, it takes time to come to terms with one's child's loss of functions. But it is also the case that the diagnosis in an institutional context serves as a sorting mechanism, and as a lens through which the system acts. Once made, the diagnosis carries its own weight within the space of interactions. In this context, doubt and ambiguity become "noise" because they lack a systemic resonance. The unambiguity of Daniel's diagnoses, communicated by the helpers as a privileged insight, is in fact a prerequisite, disclosed by what is excluded from the interactions, topics not being raised, questions not being asked, and the system's resistance to reassessing Daniel.

In their interpretation of Daniel, the parents and the system have differing and partly colliding driving forces, which makes a fruitful collaboration difficult. Whilst the parents, faced with the first diagnosis of autism, seek to expand it, as they are prepared to see Daniel as something else and something "more", the system's approach is oriented towards "peeling away", towards making the diagnosis unambiguous. In this picture, the absence of recognition, the long pauses and silences, and the averted eyes, become expressions of the system's limitation, where whatever or whomever does not fit the category simply falls through.

The social work tenet of "starting where the other is at" may give the notion of the helping process an ethical touch, but as a guideline in an institutional context it fails to provide it with a direction. The concept of institutional identities elucidates how diagnosis, as institutional categories, have indicative force and exert power in the client – helper interaction by guiding the helper's gaze and interpretation. The perspective does not speak of a category's "truth", but of its function and performativity. It speaks of the professionals' narrative and interpretation of the Other as conditioned by a systemic structure. In the novel, we observe how this institutional discourse influences the spaces of interaction, as the diagnosis constitutes a practical, thematical, and organizational force field.

Framing, ethics, and social work

The concept of institutional identities enables us to see the system's presence in specific, embodied professional practice. One objection to this structural interpretative frame is that it reduces the professionals' status to that of the system's marionettes, without a psyche of their own. Admittedly, structurally oriented perspectives do not speak of individual differences, and they tend to miss nuances. And indeed, not all the helpers in the novel are portrayed as equally reductionist, but in the few exceptions that we do come across, the helpers are often apologetic about the system's demands (147). Neither in the novel nor in the field of practice can the system be circumvented. The system will always take its toll.

Bringing attention to the structural dimensions of professional practice seems particularly important in these neoliberal times, where there are strong tendencies for "context" and "structure" being disparaged and downplayed in the locus of explanations (Degen et.al.2022, 3). Although social work tradition and values underscore the importance of a holistic approach and of highlighting societal factors, it is well-documented that the profession across the globe is subjected to neoliberal influences (Brockmann & Garrett 2022). The impact of neoliberalism is also evidenced in Norway by structural and contextual perspectives losing ground.

Increasingly, support and assistance are offered in the form of conversations, parental guidance, and the like – methods that are intended to mobilize change in the client (Kleppe 2016, 257), and that center the client and the professional around an individualized conceptual apparatus. Individualizing the "social" in social work is a challenge to the profession which can be attributed to neoliberalism – diminishing structural and systemic conditions is its mode of operation. In such a professional climate, calling forth aspects of reality that are not reducible to the client's or the helper's individual psyche, motivation, or choice is critical. Reading the novel through the perspective of institutional identities subverts neoliberal logic as it guides our attention towards a social, contextual layer of reality.

My analysis makes evident how *Tale of Troubled Times* both reflects and distances itself from prevailing representations in society. The institutional discourse, and particularly a language of medical diagnosis, is mimicked as well as questioned and complicated. Though often necessary in the process of helping, the novel highlights how the mapping of the Other can go hand in hand with the invalidation and suppression of divergent experiences. To the parents, navigating around the institutional categories holds an existential dimension to which the helpers in their conduct seem oblivious. The helpers seem unable to handle both a diagnostic frame of reference and the parents' experiences. Revealing their absence of recognition, the novel highlights the close relationship between language, attention, and ethics. To professional helpers, the diagnosis is a working tool and a systemic requirement. But as the novel shows, this tool is anything but neutral, as it dominates the helpers' outlook and makes them ill-prepared for responding or attending to other aspects of the situation or of Daniel. In this respect, the novel cautions us against the reductionism of diagnostic labels.

Based on the helpers' conduct, we have no reason to believe that they are aware of what not being heard does to Olaug. If they did, their striving towards seeing what she sees would be greater, and the videos of Daniel would be less easily dismissed. In reading *Tale of Troubled Times*, we come to know Olaug's inner world in a way the various helpers in the novel do not, as they only have access to her "outer layer" and social masks. As readers, we also have access to her motivation and what her behavior means; we know that Olaug's silence is a paralysis and not a sign of tacit agreement with the helpers. We know that her silence at meetings conceals disagreement, resistance, and sometimes rage. Literature's ability to "read minds" (Felski 2008, 89) makes us aware of this antagonism that is present in the interaction, and what it involves.

If it had only been the case that a diagnosis served to open doors, the question of which category one fitted into would primarily be a pragmatic one, and the diagnosis could have been met with a shrug of indifference, or eagerly embraced to access help. But in the novel, the picture is more complex. The portrayal of the already described multi-disciplinary meeting shows how a category at the ground level becomes a frame for interpretation and for what is brought into focus. Even in an interdisciplinary meeting, where a diversity of perspectives could potentially have been highlighted in the interest of coordinating the efforts around Daniel (which is the purpose of such meetings), deviance from normality becomes the centre towards which the meeting gravitates. In this discourse, "Daniel the boy" seems to have no place. This opens a window to the dilemma and the discomfort that parents of disabled children may face: that a category that opens one door, also serves to close important other doors, that the child becomes mirrored and recognized only as a deviant, making the diagnose an encompassing identity.

Final words

As I hope to have demonstrated, a literary narrative can be a valuable contribution in a reflection on the challenging task of seeing the Other. In my analysis, *Tale of Troubled Times* heightens the reader's sensitivity to the systemic forces at play. Although attention is an individual capability, its allocation is, at least partly, a matter of organization and systemic structure. In reflecting on the ethical dimension of social work, reclaiming the power of structure and context in shaping the professional gaze is a necessary step. The social worker will always represent some part of the welfare system. Reflecting on how practice is shaped, or undermined, by institutional demands is indispensable. It is also essential to be aware that the system can pose a challenge to clients and in some respects, even make the client's situation worse.

As Felski argues, a novel can sometimes point towards insights through what is not explicitly portrayed: "To really see a thing may require an absence rather than an abundance of words (...) knowing is shaped as much by what is left out, as by what is kept in" (2008, 102). In many ways, the protagonist in *Tale of Troubled Times* is resourceful. Olaug belongs to the upper-middle class, is married, well-articulated, capable of "speaking the cause", as she puts it, and can give detailed descriptions of the situation and of Daniel's needs in the many applications she writes to the welfare administration. She possesses the resources that wrestling with the system seems to require. And yet, the battle is long and exhaustive. Even she becomes silent instead of speaking her mind. Challenging the authority of the professionals comes at a cost, even to her. Because Olaug is portrayed in the way that she is, the novel gives rise to some essential questions, which reach far beyond the singularity of the novel and are of utmost importance for social work: What about other parents of disabled children, with fewer resources, and perhaps with additional burdens and challenges, but who also must interact with similar systems? Do they have the energy to contest a diagnosis that they feel is inaccurate, and that perhaps is in fact incorrect? Are they able to describe their needs in such a way that elicits (enough) help? Do they have the resources to carry out this continuous "work of visibility"? What are the prospects and life quality for those disabled children whose parents cannot advocate their rights and who, when called for, cannot challenge the system's decisions? Because we understand what these struggles cost someone like Olaug, our attention is drawn towards the conclusion that class and verbal resources are related to the chances of receiving necessary assistance. We come to see that making vulnerability visible to the system – whether one's own vulnerability or that of one's child – is a highly demanding task. A task probably far too demanding for many of those living on the margins.

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Originalartikel

"… to be pulled between two such different stories"

Vigdis Hjorth's Will and Testament *(*Arv og miljø *2016) as a curography*

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Vigdis Hjorth's novel Will and Testament *(*Arv og miljø*, 2016) is one of the most discussed Norwegian contemporary novels. The first-person narrator and main character, Bergljot, is struggling to get acknowledgement and recognition of her life story from her family. A central element in the plot is her incest accusation towards her recently deceased father. The exploration of conflicting narratives and normative expectations takes place thematically as well as through the text's genre and form. The conflict influences the family members' way of communication and, not least, their way of performing care and acting as next of kin. This article focuses on the novel as a* curography. *Curography comes from* cura *which means care, and* graphein, *meaning to write. The article argues that there is a conflict between a dominant family narrative and the main character's counter-narrative. Reading the novel as a curography allows for an exploration into what this narrative conflict reveals about the complexities of care and kinship.*

Introduction

Will and Testament (2019) was the international breakthrough for the Norwegian author Vigdis Hjorth.[11] In this article, we will focus on *Will and Testament* as a next of kin novel, or *curography*, which is a newly coined generic term. Curography comes from *cura* which means care, and *graphein*, meaning to write. Curographies, therefore, are stories about care from a next of kin perspective (Nesby, 2023). *Will and Testament* is a story in which the first-person narrator and protagonist oppose the prevailing conventions related to the role of next of kin. The novel provides a counter-narrative to a prevailing personal, but also cultural, understanding of what a next of kin narrative should be. In a Norwegian cultural context, a next of kin is supposed to step up, take action, and provide care in situations where a relative is in need of help. The normative notions of what a relative is, what is required of a next of kin, and what a next of kin is, are thematized in the novel. Through the narrator, Bergljot, such normative understandings of the next of kin role are explored and challenged. What makes the novel particularly interesting from a next of kin perspective is how Bergljot breaks out of a normative pattern. We will discuss this thematically by looking at the various next of kin and care relationships depicted in the novel. We will also reflect upon it from a genre perspective, and narratively by studying the narrative technique, especially the importance of the narrator. Due to the discrepancy linked to the understanding of a childhood, the family narrative creates strong discord in the group of siblings. Bergljot's personal story challenges the common family story and its normative structures related to care and caregiving.

Will and Testament has sold 170,000 copies in Norway and received the Norwegian Critics Prize for Literature and the Norwegian Booksellers' Prize, as well as being nominated for the National Book Award and Nordic Council Literature Prize.[2] The novel has also been dramatized for the theater stage and translated into twenty-two languages.[3] Hjorth (b. 1959) made her literary debut in 1983. She was already a highly acclaimed and visible contemporary Norwegian writer when this novel was published. In 2012, she received the Gyldendal prize (Gyldendal-prisen) for her *oeuvre*. In the jury speech following the presentation of the prize, Vigdis Hjorth's talent and courage in contributing to a political as well as existential agenda were emphasized:

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1. The novel was originally published in Norwegian in 2016 and translated to English in 2019.

2. See the presentation of Vigdis Hjorth on https://www.versobooks.com/

3. The theater version was directed by Kjersti Horn, and the play had its premiere at Den Nationale Scene in Bergen, November 2018. The production, which was well received by the critics, was nominated for two categories of the Hedda Prize: "Performance of the Year", and "Best Direction".

> *Perhaps like no other contemporary Norwegian writer, Vigdis Hjorth has explored, developed and challenged the role of the author. By means of stories and chronicles the prizewinner has contributed to the public dialogue about the warfare of the NATO-countries, about human rights and international politics; about existentialism, psychology, feminism, gender, and sexuality.*[4]

Will and Testament added yet more relevant topics to the list, most visibly that of suppression and abuse. The novel could be said to anticipate the global MeToo movement from 2017 where so far unknown experiences of sexual abuse and harassment were publicized. In the novel's plot, the protagonist's accusation of incest towards her father is central. Even though the story is published as a novel and the characters have fictional names, critics as well as family members publicly claimed that the novel built on Hjorth's biographical experiences. A public debate ensued, in which members of her family took part. This debate contributed to a family conflict in real life and to the publication of a counter-narrative *Free Will* (*Fri vilje*, Hjorth, 2017 *our translation*).[5] by Vigdis Hjorth's sister, Helga Hjorth. Will and Testament is thereby one of the most discussed novels in Norway since the turn of the millennium.

The starting point for the novel's plot is an inheritance dispute between four siblings. While the two younger sisters, Astrid and Åsa, have a close relationship with their parents, it is different for the two eldest children, Bergljot and Bård. Bård has felt neglected throughout his upbringing, while Bergljot carries a repressed history of abuse, and her experiences are mostly silenced in the family's main narrative. In therapy, Bergljot has accessed memories revealing that she was sexually abused by her father from the time she was five until she was seven. She has made this known to her mother and siblings, but only Bård shows sympathy and understanding. The novel takes place right after the father's death, and the subsequent inheritance settlement sharpens the fault lines in the family since the two youngest daughters are being favorized. This leads to Bergljot having to re-establish contact with her family after many years of estrangement. The cabins in dispute are located at Hvaler, an attractive leisure area in Norway. This makes them presumably worth a lot – although an amount is never mentioned. The fact that the inheritance conflict takes place shortly after the father's death, but while the mother is still alive, makes the siblings perform their next of kin role in radically different manners. Åsa and Astrid provide care for their mother, while Bård withdraws, and Bergljot actively confronts her family with the reasons for her

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4. See: https://www.tv2.no/nyheter/innenriks/gyldendalprisen-2010-til-vigdis-hjorth/12998758/

5. Our translation.

conflicted feelings towards both parents. These different interpretations of the next of kin role contribute to the affective intensity in the novel.

Critics' approaches are mixed. Most of them read *Will and Testament* as based on real events. Several critics believe that the novel is about a family in a state of internal disintegration (Mollerin, 2017, p. 172), a story of incest (Krøger, 2016; Økland, 2016), and in NRK, Anne Cathrine Straume wrote that "It is about the gaze that sees. About whom owns and defines a story. About the will to take the other truth seriously" (Straume, 2016 *o.t*). Eirik Vassenden (2019), for his part, is concerned with the demarcation between the literary criticism of the novel and the general ethical discussions that developed as extensions. From his position, the Hjorth debate is an example of a discussion where you need the kind of resistance that criticism can offer. The critics' reflections have democratic value, he believes, since "they allow readers to meet opinions other than their own" (Vassenden, 2019, p. 115 *o.t.*). The dispute over the contents of the story and the interpretations of them is also one of the things that, from our perspective, is one of the most central elements of the novel. Our perspective offers another reading where the characters' dispute about the grand family narrative is central. Due to this, the questions of how to practice care are also prevalent.

An aspect which is, however, almost absent from the many reviews and scientific contributions about the novel[6] is *Will and Testament* as a next of kin novel. The novel explores how a relative can be both next of kin and caregiver; the first is bound to familial relationships while the other is a term that implies practical care. The novel demonstrates how Bergljot as a next of kin refuses to take on practical care work within the family. Based on Bergljot's experiences of being silenced by the rest of her family, it becomes impossible for her to act according to the dominant, normative understanding of being a caring and supporting daughter to her elderly mother. This exploration of conflicting narratives and normative expectations takes place thematically as well as through the text's genre and form. It influences the family members' way of communication and actions towards each other – and not least, their way of performing care and acting as next of kin.

In 2020, the Norwegian conservative party under Prime Minister Erna Solberg launched a next of kin strategy entitled "We – the next of kin" which stated: "When

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[6] Several MA theses are interested in the novel as "reality literature" (Johannessen, 2019; Kyrkjebø, 2023; Larsen, 2019; Ramstad, 2018; Rolland, 2022; Skadberg, 2020). Sortland (2024) discusses the novel and its reception as a recurring performance made by Hjorth and involving her as an author, the text and the readers. Slotnes (2018) discusses the novel's early readings and is concerned with how the literary critics paraphrase the novel's plot. Jønsson (2023) is concerned with how Hjorth crystallizes problematic mother-daughter relationships in her novels and shows how this is linked to the novel's narrative technique.

someone you are close to becomes ill or needs help, it usually feels both good and natural to help and assist with what you can. Family care and care from close others is a significant resource from a societal perspective and a value we want to support" (2020, p. 4 *o.t.*). In *Will and Testament*, this cultural narrative is represented by the two youngest sisters. They enter the role of formal and informal caregivers as both parents and society expect and demand of them. Bergljot, on the other hand, opposes this next of kin role. With this, she challenges traditional care models.

Theoretically, we rely on a relational understanding of care, as understood from feminist care ethics (Førland et al., 2018; Gilligan, 1982; Wærness, 1996, 2003).[7] The literary scholar Maurice Hamington states that care is "most adequately reflected in the stories of people's lives, where more is brought to light than the rules or outcomes of a given situation" (Hamington, 2004, p. 35). From our perspective, it is precisely how Hjorth's novel shows something more and something different than the expected, that makes it a particularly interesting next of kin novel. In this way, we are also in line with Amelia Defalco who claims that "narrative fiction [is] an ideal form for the study of care" (DeFalco, 2011, p. 239).

Care and the next of kin role

Caring is a prominent theme in relation to next of kin and family relatives in *Will and Testament*. The theme of care in the novel is central as it appears in a series of relationships: in the siblings' relationship with their mother, in the father's relationship with his mother, and in the distribution of inheritance. It is most prominent in relation to the mother of the four siblings. As an elderly woman, the mother has become a widow, and she needs help and practical care from her children and other relatives. Yet the role of next of kin is something the four siblings practice quite differently. Åsa and Astrid practice a traditional relative's role by comforting, helping, and supporting their mother. Bård and Bergljot, on the other hand, challenge the next of kin role by distancing themselves from the mother. Bård does so because of a skewed distribution of inheritance and Bergljot because of her father's abuse which she believes her mother knew about but chose to ignore. Bård's break with the family does not represent the same threat to his mother as Bergljot's does: "Yet it was more important that Mum saw me because

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[7] "Caring includes values such as responsibility, belonging, loyalty, generosity, sharing joys and sorrows, values that do not belong to the area of individual freedom, but which, on the contrary, can often only be realized if one renounces something of this individual freedom" (Wærness, 2003, p. 15).

the issue with me went far deeper than the inheritance dispute with Bård" (Hjorth 2019, p. 125).[8] This points towards an 'economy of care', where what the children have gained or lost relates to the care they owe or do not owe to their parents. Similar perspectives are discussed by Amelia DeFalco in her study *Imagining Care*, where she asks: "How to care for the one who has failed to care for you?" (2016, p. 48).

The emotional pressure in the situation is emphasized by the fact that the narrator, Bergljot, gives us an insight into how her attention is as much directed at herself as it is directed at the people she meets. She has a detailed awareness of the social situation she is going to enter, and that affects the way she presents herself to the world and the way she is presenting herself. The narrator underlines that she has dressed with "care", and "I was wearing my face for facing the world. They weren't wearing theirs" (p. 128). The metaphor of putting on the face as a mask reinforces the performative element of the novel (Sortland, 2024). Bergljot apparently gives the impression of having the upper hand in the situation as she finds weaknesses in her sister and mother's expressions and appearances. This can be read as an expression about their deep mourning, while the death of her father, from Bergljot's perspective, represents more of a liberation and relief.

In addition to the siblings' different ways of practicing next of kin roles towards the mother, it is the deceased father who is most clearly linked to a normative understanding of the way the next of kin role is supposed to be performed. Åsa, one of Bergljot's two sisters, highlights her father's care when his mother was elderly and in need of care:

> *Then she talked about how kind Dad had been to Granny, towards his mother, when she got ill in her old age. It was true, I had completely forgotten that, how Dad had visited his old mother when she fell ill, how Dad would drive to the care home where she lived several times a week to help care for her. Åsa went on to say that Dad had arranged for a family member to visit his mother every day.* (p. 160)

From the discourse of the dominant family narrative, his caring skills had been exemplary. For Bergljot, her father's caring actions towards his mother not only reads as altruism, but more as an exercise in penance: "not for those he had failed, but for a harmless, sick old lady he no longer feared?" (Ibid.) By not mourning her father, and by being skeptical towards and questioning her mother's weakness, Bergljot represents a different view of the caring relation within the family than her sisters does. In the wake of their father's death, Bergljot experiences prejudice

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[8] All quotes from *Will and Testament* are from the 2019-edition and will from now on only be referred to by page numbers.

and injustice from her family. The valuable cabins are at the core of an inheritance dispute. However, the most dramatic thing for Bergljot is that she does not gain recognition for her dramatic memories and childhood experiences. "Bergljot is obsessed with getting the recognition she demands" (Hamm, 2017, p. 107 *o.t.*). In the aftermath of their father's death, the younger sisters do everything they can to ensure that their mother is well and thus provide practical care for her. Bergljot, for her part, leaves everything related to the father's deathbed and the preparation of and execution of the funeral to her two sisters.

In the same way as the father provided care for their mother, the two youngest sisters demonstrate an impeccable caring role as next of kin when the father becomes ill and eventually dies. He thus receives care similar to what he himself gave to his mother – it is an inherited form of care practice which is demonstrated – a recurring, repetitious, redoubled act of care that is passed down from generation to generation. The sisters' narrative about his deathbed is built up as a beautiful and heroic story, where the adjective "fantastic" dominates: "Åsa, Astrid, Mother, Aunt Sidsel and the health service – all are said to have been fantastic" (p. 141-143). The use of "fantastic" works as hyperbole and helps build the narrative of a beautiful deathbed. Its use, which is attributed to several of their father's relatives (the sisters), stands in sharp contrast to the perspective of Bergljot, who experiences her father's death as a "relief" (p. 188). Bergljot's relationship with her father is complicated. Marthe Ramstad writes about how the fact that the abuse "[…] happened when she was a child, and by a father who is supposed to be a protector and caregiver, means that the abuse was 'disguised' as care, and as an expression of love" (Ramstad 2018: 91 *o.t.*). Bergljot's feelings of care towards her father are ambivalent: "A deep compassion rose in me at the thought of Dad and Dad's life, poor, poor Dad, who had done some stupid things as a young man which couldn't be undone, which he couldn't fix, and he didn't know how to bear them, how to live with them" (p. 109). Bergljot's care, but also her anger and powerlessness in the face of her father's abuse, puts her in emotional cross-pressure, and that question of care often becomes central to conflicts of inheritance.

Family narratives and the question of inheritance

Will and Testament is a novel that shows how the roles of caregiving and next of kin are also pivotal regarding inheritance. The disagreement about who will take over the two cabins and at what price is important because it is based on the siblings' former and present relationship with their parents. The cabins, as an advance on an inheritance, are not unimportant in a family novel. Inheritance is a frequent source of conflict both in real and fictional worlds – and perhaps another prosaic reason why the novel gained such a large audience. The topic of inheritance is packed with potential pitfalls. Should the inheritance be distributed purely mathematically or is there also an emotional calculation that must be considered? Is it reasonable that the child (or children) who has stood up for the parents the most, and how about those who have suffered the most, should be compensated with more of an inheritance settlement?

The topic of inheritance thus not only raises economic but also psychological and anthropological questions. Bergljot does not seem to have any material interest in the two (presumably) valuable estates. However, exclusion from them makes real the more vague and emotional feeling of exclusion from the family narrative. Bergljot's memories, feelings, and narratives, in particular that of the abuse, are excluded from the family's main narrative. In a subtle manner, Bergljot is locked out of the cabins just as her perspective on the family story is not included: "that is the emotional and emotional and moral legacy that they have left behind along with the significant personal and real property associated with family history" (Selmer, 2021, p. 156). The motivations for Bergljot and her brother's claims to the cabins are different: whereas Bård is mainly occupied with the cabin's material values, Bergljot's main concern is "the emotional estate that is materialized in the cabins" (Selmer, 2021, p. 158).

A cabin is a material, social, and emotional place that creates unity and discord across generations. The cabins play an important role in the articulation, maintenance, and confirmation of relationships, and can thus metaphorically be considered a family member and a suitable arena for investigating "how kinship and family relations (relatedness) is organized and experienced in Norway today" (Lien & Abram, 2018, p. 33). From their anthropological perspective, favoring some of the children is one of the "worst things you can do in relation to a group of siblings" (Lien & Abram, 2018, p. 37). We thus see how the concepts of material and immaterial values cannot be separated from each other. The argument about the cabins thus functions as a cover and a form of rationalization for the more emotional and deeper conflicts within the family.

Will and Testament is a novel about heredity and social environment – which is also, when directly translated, the Norwegian title of the novel. The title makes the novel connect to naturalism and thinkers and writers like Taine, Balzac, and Zola. They were influenced by Darwin's evolutionary writings proclaiming that heredity and social environment determine one's character and the way people act. In Hjorth's novel, the original title subtly creates expectations of a concrete inheritance settlement and the social environment of a middle-class Norwegian family. Whereas Zola, Flaubert, or other naturalistic writers rarely questioned the truth claim of the individual's heritage and environment, this is the critical point here. The story of Bergljot and her siblings' social environment, their background, and upbringing turn out to be quite different experiences. The novel is thus seemingly about the ownership of the cabins, but more subtly it is about the ownership of the family narrative, and the structures, both social and familial, that led to the conflict.

Curography as an analytical approach to family narratives

In a close reading of Hanne Ørstavik's novel *ti amo*, Linda Nesby (2023) launched curography as a generic term. Here, Nesby discusses how caregiver narratives are situated in the tension between the story of the one requiring care and the story of the caregiver. A curography is an offspring to the story of the one needing care due to illness, age, drug addiction, or other issues. The relation between these stories may be complex and not always idyllic. The caregiver is often portrayed with heroic qualities. But what if the caregiver is negative, even reluctant, to the role they are given? Either way, the caregivers always find themselves carrying a story based on the story of the patient, the elderly, or the addicted person in need of care. It is a relation, no matter if it is characterized by presence or absence. Containing this multiplicity of different stories makes curography a distinctly elastic term. Curographies hold the perspective and voice of the next of kin whereas in the related genre of pathography, the patient is the center of attention. Curographies are stories rooted in someone else's history of suffering. You cannot be a caregiver without someone to care for. Curographies explore the different ways stories of the caregiver and the ones needing care may relate to one another. This understanding of curography as a genre in which the relatives' narrative is influenced by other narratives has drawn inspiration from Harold Bloom's *A Map of Misreading* (1976). Six different ways of dealing with influence are presented, representing a gradient influence of the former poet on the *ephebe*. The most important, overarching term is *clinamen* (Armstrong 2019, p. 35). Bloom defines clinamen as "poetic misreading or misprision proper" (Bloom 1973, p. 30). *Clinamen* captures how the poet follows his precursor up to a certain point, then radically re-orientates. In *Anxiety of Influence* (1973), the trope is substitution, in *A Map of Misreading* where Bloom elaborates on his theory of influence, substitution is replaced by irony. Both tropes, however, point to an absence or opposition between the former and the later poets' works. *Clinamen* signals how the former poet's work is necessary for the existence of the later poet's writing, which is written in opposition to the former. Bloom's reflections on influence were originally used as an exploration on how to become a poet. The concept of influence, and of *clinamen* more precisely, point to the dialectic of presence and absence, which is also central to curography. Just as the strong poet is said to swerve away from their precursor even as they build on their work, so the next of kin must leave the patient's story behind in order to narrate a new, autonomous story, even as that story remains the premise for their role as next of kin.

Bergljot's sisters hold on to the established family story, influencing their view on their elderly parents. For Bergljot, however, this story of old age, vulnerability, and need for care is absent. The views on care and caretaking uttered by Bergljot's sisters, and represented by her father and mother, are linked to a story about familial care that does not resonate with Bergljot's story of abuse. According to the catalogue of concepts marking influence, the figure of *clinamen* captures how the protagonist's story takes another direction than the established family narrative that is being upheld by her sisters. Instead of being a story of care and caretaking, Bergljot makes it into a story of abuse: the abuse that her father put her through as a child which was the opposite of care, and which was known to her mother according to Bergljot.

The family is split by the appearance of many incompatible stories and mythologies connected with the past. The first-person narrator reflects on how it is and has been and imagines how her relatives will meet up to reinforce established family narratives and their associated roles:

> *I sat in the forest with no peace. I imagined them gathering in Bråteveien to continue the myth of Bård as a troublemaker and Bård's wife as a warmonger, she had been allocated the role of the woman who had seduced Bård away from his family. I knew exactly how it would play out; once I had contributed to it myself, I had been so completely enmeshed in the family's version of its own story. It wasn't until I became estranged myself, until I had distanced myself, that I started to look at things differently, but still slowly, taking baby steps, such is the power parental stories have over a child's concept of reality that it's almost impossible to free yourself.*
>
> *And had I managed to free myself? Or was I still stuck, and had the name of the villain merely changed?* (p. 54-55)

Hjorth's novel explores whether Bergljot has managed to break free from her family's self-narrative. It reflects how a traumatic childhood story offers little, if any, room for other stories to be heard or acknowledged. Bergljot's history of abuse leaves no room for her siblings' or her mother's story, and their story leaves no room for Bergljot's. The narratological means used to gain this effect is a first-person narrator who, with the help of indirect discourse, blurs the distinction between the different stories and narrators. An example is a telephone conversation between Bergljot and her sister Astrid: "I couldn't find Bård's number online and called Astrid. She said she didn't have it. But you talked to him yesterday, didn't you? Åsa had it, she said, I asked if she could call Åsa and call me back, it was late, she said reluctantly, but she found it after all" (p. 19-20). This use of indirect discourse illustrates the "layers of literary language" (Bakhtin, 1981, p. 7) and it is a narratological device providing access to a real, or an illusory, polyphonic universe. Indirect discourse "creates the illusion of 'preserving' or 'reproducing' aspects of the style of an utterance, above and beyond the mere report of its content" (Rimmon-Kenan, 1983, p. 109) to create a dominant point of view and voice at the same time as the move promotes pluralism. Indirect discourse is a narrative device that makes it possible to make room for multiple voices, perspectives, and stories.

Interestingly, the narrator almost imperceptibly shifts from first-person to third-person narration when Bergljot describes how she has been abused. This creates an impression of neutrality and factuality:

> *To give his wife a break Dad would take his oldest daughter along in the car with him when he went to look at building plots for the construction company he worked for, and Dad and his oldest daughter would spend the night in a hotel and it was fun to stay in a hotel, in a hotel you were allowed to get into bed before dinner and close the curtains, that's what you do when you're in a hotel, said Dad who knew how you behaved in hotels.* (p. 278-279)

The narration gives the narrator the opportunity to influence the reader's perception of a character, event, or complex case without making direct judgments or assessments. *Will and Testament* is a novel where the authority of the family narrative is directly linked to the understanding and practice of providing and performing care. There is no objective truth to this question of care. The choice of narrator and narration therefore plays a crucial part in deciding upon these questions.

The role of a friend and narrative work

Narratologically, curography is a flexible genre that can use different narrative positions, orders, durations, frequencies, and moods – to use Gerard Genette's classic categories for narrative analysis. Hjorth's novel also explores the role of the narrator themselves. Bergljot, as a first-person narrator, is seemingly a reliable and trustworthy storyteller. However, by using free indirect discourse, Bergljot tells the story of her siblings, her mother, and father in a manner that they do not recognize. Bergljot, however, sticks to her own story. In addition, the voice of her friend, Klara, who knows Bergljot's history of abuse and who supports her, is given much weight. Klara repeats and reinforces Bergljot's story, and thus increases its credibility. Klara's mirroring of Bergljot's feelings gives Bergljot's narrative additional strength and persuasiveness. It is Klara who gives Bergljot the vocabulary to present her own story. Klara's words and images are militaristic and contribute to raising the level of conflict:

> *It's a matter of life and death. There are no peace negotiations, it's a battle to the death for honour and legacy, she said. I had to give up thinking Mum would ever understand me. I had to give up thinking Mum would ever accept me. I would get nothing from Mum and Dad unless I gave up my truth. Mum and Dad would rather see me dead than acknowledge my truth, they would sacrifice me for their honor. This is war, she said, and I had to become a warrior.* (p. 205)

Klara represents a doubling of Bergljot's story, which, in addition to Bergljot's own insistent, repetitive, exhorting style, helps to hammer home the understanding and experience of Bergljot's story as the most trustful one.

When reading the novel as a curography, Klara has a central function, both narratologically and thematically. Both Klara and Bergljot have lost their fathers. Klara's traumatic childhood mirrors Bergljot's experiences and helps Bergljot put them into words: "The street of my childhood, Klara said, quoting Tove Ditlevsen, is the root of my being" (p. 147). The reference to the Danish poet Tove Ditlevsen shows how the two friends situate themselves within a cultural and intellectual context. More subtly, it also invokes Ditlevsen's difficult childhood and tragic fate. Klara shows the severity of her own, and Bergljot's, childhood trauma. It is she who Bergljot turns to when she needs clarity in her thoughts: "I called Klara and asked her why I got so wound up, why I absolutely had to talk about it, given that nothing terrible had happened" (p. 14). In the beginning of the novel, Klara acts as an empathetic witness, who supports and reinforces Bergljot's self-narrative, and makes her realize how "deep it went, how it pushed me into the abyss, how it weighed me down" (p. 15). Before meeting the siblings and the mother at the auditor's office after the funeral, Bergljot asks Klara to tell her what she aims at:

> *Justice, she said. Restoration, she said. But they can't give me justice or restoration, I said. They'll have no choice but to listen to you, she said. They shouldn't get away with their underhand behaviour. They've never supported you, never listened to you, they've silenced you for all these years, and now they want to cheat you as well whereas you should have been awarded damages, as should Bård, the neglected son, but instead you'll both get less, instead they'll profit from your misery.* (p. 172)

Klara's words serve as a re-interpretation and strengthening of Bergljot's own story. Klara makes Bergljot feel safe. Talking to Klara helps her to strengthen the belief in her own narrative, and Klara also arms her with the words and metaphors she needs to confront both the family, particular her motherbut also, as we shall see, the larger societal narrative of being next of kin.[9] Klara's strengthening of Bergljot's story is crucial for Bergljot when confronting her sisters and mother at the auditior's office. It shows how difficult it is for Bergljot to write her own autonomous story based upon, but different from the dominant family narrative. Klara's presence in *Will and Testament*, often ignored and left uncommented by the critics, is crucial when the novel is read as a curography. Her addition to Bergljot's story illustrates, and perhaps even strengthens, Harold Bloom's reflections on how difficult it is to "swerve away from his precursor" (Bloom, 1997). To gain clinamen in *Will and Testament,* Bergljot as a strong poet needs the narrative help of a friend.

Bergljot's counter-narrative as opposed to dominant cultural narrative

In Norwegian society, there is a strong anticipation to the idea that family members should live in peace and tolerance (Gullestad, 1989). This ideal family constellation is, however, rarely present in Norwegian contemporary literature (Hverven, 1999) – and neither in older literature. *Will and Testament* has resemblances to Henrik

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[9] However, it can be objected that Bergljot was drawn into Klara's friendship in a somewhat involuntary way, and that in several places in the novel she returns to her ambivalent feelings about the friendship relationship. Before divorcing her husband, she describes visiting Klara as being "drawn to my destruction" (p. 26). It is also Klara who brings the knowledge that the man the mother had an extramarital relationship with is dead. In this way, Klara contributes not only as an emotional support for Bergljot, but also to supplement her knowledge of her mother's inner emotional life, and the conflicts between her parents. Klara is also one of the few outside the family who has met Bergljot's mother and seen how paralyzed Bergljot becomes when she meets her.

Ibsen's dramas; something Johnsson (2017) demonstrates: Bergljot's mother is criticized for not leaving her father (as Nora does in *A Doll's House*), the father resembles Peer Gynt, a character with no boundaries, while the inheritance motif is present in *Ghosts* (1881) – something Hjorth herself also highlights (Mollerin, 2017, p. 40). Another similarity to *Ghosts* has further interest from a next of kin perspective. Ibsen develops a character, namely Osvald's half-sister Regine, who disclaims kinship responsibility. When it becomes clear that she cannot use Osvald to climb socially, she abandons her seriously ill half-brother. Regine's demonstration of an alternative, and somehow brutal, next of kin who is reluctant to perform care has yet not been recognized in the many interpretations of the play. Bergljot in Hjorth's novel is also a reluctant next of kin but with a large repertoire of reflecting and performing her dilemma. While Regine is a dramatic figure, Bergljot, as a first-person narrator and by virtue of being a writer by profession, presents different narratives, not least her own counter-narrative in order to explain her own next of kin-role.

Hjorth shows a brutal family feud where the battle for the narrative is, as always, part of the war. So, what kind of narratives are at stake? McLean distinguishes between three different types of narratives, namely "master, familial and personal narratives" (McLean, 2015, p. 30). The master narrative is related to Leotard's "grand narratives", i.e., stories that are rooted in a common cultural value set. The family narrative is linked to a shared view of what constitutes a good family, good parenting, and a good childhood. The personal narrative deviates to a greater or lesser extent from the overall family narrative: "In a family context, for instance, cultural expectations exist about what constitutes a good family, parenting and childhood" (Markussen & Knutz, 2021, p. 134). When personal narratives do not match, or are in direct opposition to the family narrative, they are called counter-narratives. Bergljot has a narrative that diverges from the rest of the family's narrative(s) about how their shared childhood and adult family life has been. Read in this way, *Will and Testament* is a counter-narrative that challenges the dominant social narratives:

> *Being observant of narratives represented in the social world, and of the power relations they are embedded in, can contribute to the gathering of insights on marginalized positions. Stories revealing these marginalized views can be called counter-narratives* (for a definition of hegemonic narratives see Lueg, Graf, & Powell, 2020). *Counter-narratives resist another narrative (Bamberg & Andrews, 2004, p. 1), this one often being, or being perceived as being, more powerful.* (Lueg & Lundholdt, 2021, p. 4)

The novel excels as a counter-narrative by transcending the opposition between the personal narrative and the family narrative. Bergljot's history of abuse not only questions the family narrative about family life, parenthood, and childhood taking place in the villa in Bråteveien where Bergljot and the siblings grew up. It also challenges the master narrative's societal expectations of what a good relative should be.

Astrid seems to be a gentle and careful communicator of the family narrative. Ironically, it is when Astrid, in an email, uses the tentatively mitigating phrase "everyone can make mistakes" (p. 76) that Bergljot's fighting spirit increases and her personal narrative of abuse finds its form. Triggered by Astrid's words, one evening she hammers out a letter and sends it to Astrid, with a copy to the other two siblings. Then "I drank in order to sleep and read and reread my own text over and over, I read it, and I drank myself to sleep" (p. 85). When she wakes up the next morning, no one has answered her:

> *If she had heard the story, as she must have done, from Mum and Dad, who needed to explain my absence, then it was their version that she would know and I had no idea what that was like, but I presumed it was about my overactive imagination, which I'd always had even as a child, how good I was at making things up and telling tales, as well as me probably wanting someone to blame for my unhappiness, my outrageous behaviour, my divorce, or it was something a therapist had planted in me, the possibilities were endless.* (p. 85)

In the quote, we see how Bergljot lays bare the many different possibilities for falsification mechanisms she attributes to her parents. Bergljot as a first-person narrator utters her view of the world, and it is her perspective and premises that we gain access to; how she thinks the other family members think of her, and how she thinks they justify her choices and actions. The first-person narrator's lack of neutrality also comes to the fore when Bergljot revisits her mother after more than fifteen years of absence. Bergljot sees the sisters and her mother as "[…] three uncomfortable figures, Mum as I remembered her, only less spectacular, everyone was as I remembered to the extent that I remembered them, to the extent that I looked at them, they looked like themselves, all three of them, only less spectacular" (p. 128). The phrase "to the extent" signals to the reader that doubts can be raised about the narrator, where the modification suggests that she is not completely sure of her own remembrance. The first-person narrator insists on the truth of her story, while on the novel's semantic level some uncertainty is poked loose.

Hjorth questions a premise of the familial narrative, namely that the people involved in the next of kin relation share the same fundamentals of this relationship.

The next of kin narrative is most often based on a common perception of what the next of kin relationship is about. Curographies reflect upon how the story of the caregiver meets the story of the cared for; should the caregiver's story annex all or part of the story of the cared for, ignore it, or write in opposition to it? And what happens if you dispute it? *Will and Testament* is a curography in which central parts of the origin story are disputed. The narrator is the daughter of an aging mother in need of help – a caring relationship she shares with her two sisters and brother. The siblings have different stories related to their relationship with their parents. Bergljot says that as a child, she was abused by her father. Bård says he has been neglected, while Åsa and Astrid tell of a good, caring upbringing. As readers, we must choose whether we perceive Bergljot as a credible narrator or not. In this way, we also see how these questions are raised on a metanarrative level. Who owns the "true" narrative? Whom can we trust: Bergljot, the other family members narratives, or the normative understandings in the society?

The novel constitutes a counter-narrative to a prevailing personal, but also cultural, understanding of what a next of kin narrative should be. The novel is only to a small extent an exploration of whether Bergljot was exposed to abuse as a child. Rather, it is a novel negotiating the role of next of kin – when the one you are expected to care for is someone you believe has inflicted abuse and neglect. Bergljot insists that her story must be heard, recognized, and accepted as a re-evaluation of the family narrative. Her two sisters and mother refuse, and this leads to radically different ways of practicing the next of kin role.

A central scene in the novel is the opening of the father's will at an auditor's office. The economic aspect is signaled through the presence of the auditor and not a solicitor as one could have expected. The will is about money and not about truth, and economy is, as we have seen, the initial core of the conflict. At the auditor's office however, Bergljot insists on the existential aspect of their father's will: at this crucial event, with her mother, brother, and sisters present, Bergljot finds the courage and the will to tell the full story of the abuse she has suffered. She bases her narrative on her own diary. Present at this event, listening to and witnessing Bergljot's narrative, is the auditor – and the readers of the novel. In the same way that the mother and siblings are forced to listen to Bergljot's story when she reads it out at the auditor's office, the reader is also forced to make up their mind: "When Bergljot confesses straight up and in a well-intelligible and coherent text that she misses recognition of the narrative about the abuses, the reader is forced to react more directly to the text. Among other things, it leaves no room for misunderstandings and wonder" writes Hamm (2017, p. 113 *o.t.*), and emphasizes that "Hjorth's readers have to face the discomfort of listening to the story of a trauma" (ibid. *o.t.*). The novel demonstrates the consequences of the various family members' interpretation of the caregiver role, how the "traditional caregiver role" is challenged, and how the family relates to Bergljot's persistent and forceful language and behavior. Nor do we as readers go unnoticed. *Will and Testament* read as a curography, makes us reflect on how the caregiver role is practiced, and acted out when the relationship between the one needing care and the caregiver involves disagreements and disputes about disappointment and betrayal.

Final remarks from a curographical point of view

Hjorth's *Will and Testament* is a dense and complex novel based upon an incompatibility of different narratives: the master-, family-, and personal narratives do not coincide. This has tragic implications both for the extended family and not least for the narrator Bergljot, whose identity as an absent, non-participating caregiver morally depends on her story of childhood abuse being annexed by the family. The caregiver role is not something you can easily reject. Bergljot's childhood memories become central when she refrains from assisting her elderly mother and dying father. The attention the novel attracted was largely due to a present celebrity culture creating a thin line between the real-life author and the first-person narrator. Yet the novel's bestselling status may also be due to a caregiver role which most of the population would recognize in one of its many shapes.

Recognition is a central effect of reading. *Will and Testament*, which can be said to have faced and challenged the master caregiver narrative – far more recognizable than both inheritance disputes and family feuds. When the next of kin motif is not mentioned in previous readings of the novel, it may be because of recognition, not repetition, or as Rita Felski writes:

> *Recognition is not repetition; it denotes not just the previously known, but the becoming known. Something that may have been sensed in a vague, diffuse, or semi-conscious way now takes on a distinct shape, is amplified, heightened, or made newly visible.* (Felski, 2008, p. 25)

Felski's widely acclaimed *Uses of Literature* (2008) reflects upon why we read literature. Hjorth's novel, and Hjorth as a public figure and literary celebrity, were part of a bookmarked and interpretative practice in which the borders between fact and fiction are blurred. The recognition aspect became largely a matter of living models, and psychological discussions of false memories and post-traumatic behavior. The novel's connection to real-life literature became a Damocles sword that gave it attention and sales, but which perhaps also overshadowed some of the more intriguing aspects of the novel's universe. The next of kin perspective is one such entry.

After having scrutinized the intentions of the narrator in *Will and Testament*, and her insisting on her story, it is reasonable to ask why we as researchers decided to dwell on the next of kin perspective of this novel. It is a question which obviously has multiple answers. It may be because we both are and have been next of kin. It can be because we know Hjorth's writing and have reflected upon how several of the secondary characters (daughters in particular) find themselves in demanding relationships with mothers who drink too much, as in *What is it With Mom?* (*Hva er det med mor?* 2000), *A Norwegian House* (*Et norsk hus*, 2014) in which Norwegian stereotypes among other about parenthood is questioned, or *Is Mother Dead?* (*Er mor død?* 2022) whose female protagonist is obsessed with her old mother who she has no contact with – a plot resembling that of *Will and Testament*. Another reason why the next of kin perspective of Hjorth's novel seemed relevant was because we as researchers have worked with the questions of care and next of kin for some time. As with *Ghost*'s we have noticed how this is a perspective that tends to be under communicated – perhaps because it tends to form an often-challenging counter-narrative.

Reading the novel as a curopraphy, has, regardless of what brought us here, been an eye-opening experience. The novel's insistent way of telling, linked to the dissemination of the main character's history of abuse and trauma, led to her role as victim and then survivor far overshadowing the challenging next of kin roles in the novel. In a subtle way, this invisibility of the next of kin perspective mirrors the invisibility that next of kin also encounter outside of literature. Our reading shows how the novel also recognizes something outside itself – as only great literature can. The reading of *Will and Testament* as a next of kin novel can be said to demonstrate how the novel transcends its own fictional intention and thus reveals itself as a true literary triumph. Even though the novel insists on the truth of Bergljot's story, that story depends on the established family narratives to which it becomes a clinamen. According to Harold Bloom, to read a text in the light of clinamen, is to take also former texts into consideration. He stresses how the power and the complexity of the new story is enhanced if the former one is taken into consideration. Bloom's theoretical reflection is manifested in *Will and Testament*. However, the insistence of Bergljot's story of abuse is not only demonstrated within *Will and Testament*. The importance and strength of this story is utterly underlined as it is repeated seven years later in Hjorth's latest novel *Repetition* (*Gjentagelse* 2023). But that is yet another story.

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Originalartikel

Mediating Kinship

Relational Perspectives on Dementia in Two Norwegian Graphic Novels

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This article compares two contemporary Norwegian graphic novels that depict a son's experience with a parent's dementia: But Who Are You? *(*Men hvem er du? *2023) by Martin Ernstsen and* My Mother *(*Mora mi*, 2023) by Trond Bredesen. The analysis focuses on kinship from a relational perspective. In the first part of the article, various relational challenges related to caregiver accounts of persons with dementia are outlined. The subsequent section presents an anthropologically informed view of kinship and relationality as intersubjective processes mediated through practices such as care and memory work. This perspective allows us to shift attention from the dialectic between the caregiver and the vulnerable person toward the relational processes they take part in, and from questions about narrative and narratability towards the aesthetic mediation of various relational practices. The analysis explores how care is linked to memory work in the two graphic novels, the ways in which this memory work is conveyed through the comic format, and how these practices mediate kinship—simultaneously producing, sustaining, questioning, and transforming the relationship between son and parent with dementia. In conclusion, the article revisits relational perspectives within dementia literature and examines the specificities of aesthetic mediations of kinship and community.*

Introduction

This article presents a comparative analysis of relational perspectives on dementia in two Norwegian graphic novels: *Men hvem er du?* (*But Who Are You?* 2023) by Martin Ernstsen and *Mora mi* (*My Mother*, 2023) by Trond Bredesen.[1] Dementia is a prominent topic in contemporary Norwegian literature across various genres (Simonhjell 2018; Bjørkøy 2020). In Norway, the publication of these graphic novels in 2023 signifies the movement of filial memoirs that focus on dementia into the medium of comics.[2] Both *But Who Are You?* and *My Mother* share a common theme: they take a son's perspective on a parent (a mother and father respectively) who is ageing, experiencing a form of dementia, and residing in a nursing home. Both narratives explore their 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. Additionally, the ways in which the comics medium is employed to convey interactions and practices related to that relationship and its challenges vary. How should we approach these distinct relational perspectives in two filial graphic memoirs about dementia; what characterizes their relationality; and what can these graphic novels tell us about the affordances of the comics form to aesthetically mediate how the changed health and cognitive abilities of a parent might influence a filial relationship?

Departing from these questions, the first part of the article outlines several relational challenges that have been discussed in scholarly work on narratives told from the perspective of next-of-kin or informal caregivers. I then suggest the term kinship, here understood as a processual form of relatedness mediated by practices such as interactions, care, nurture, and memory work, as an analytical optic. This approach implies a shift in focus from the dialectic between the carer and the vulnerable person towards the relational processes they take part in, and from questions about narrative and narratability towards the broader aesthetic mediation of various relational practices through the comics form. The following

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[1] For the sake of readability, I will refer to the English translation of the titles in the following.

[2] Prior to this, dementia had been depicted in Jason's (John Arne Sæterøy) graphic short story "Ingenting" (Nothing) from the collection *Frida Kahlos papegøye* (Frida Kahlo's Parrot 2015), about an elderly woman with dementia, and Anders N. Kvammens commissioned work *Jeg husker ikke… Historier om demens* (I don't remember… Stories about dementia, 2020) which follows three families where a parent is diagnosed with early onset Alzheimer's disease. Ernstsen and Bredesen's contributions differ from these previous works in that they openly build on personal experiences and, importantly in our context, take a filial perspective.

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 Ernstsen 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 I will call a familial gaze. I conclude the article with a discussion of how an analytical approach focused on kinship might suggest new perspectives on the relational challenges inherent in dementia literature and what characterizes aesthetic mediations of relatedness.

Relational challenges of dementia literature

Dementia literature is dominated by relational perspectives in the sense that the narratives are often told by someone other than the person who has dementia, usually a relative or a close one (Bitenc 2020, 128; Sako & Falcus 2019, 88; DeFalco 2010). The structural development of dementia makes this hard to avoid: dementia comes with a loss of communicative skills and increasing cognitive deficits, making it difficult for many persons with dementia to tell and publish their own stories (Simonhjell 2018, 135).[3] As a result, narratives about dementia often take an outside perspective on the condition, and this comes with several challenges insofar as we are studying how (the person with) dementia is being represented. Studies show that characters with dementia often become increasingly 'othered' by their cognitive deficits throughout the narratives in ways that have been described as uncanny (DeFalco 2010) and gothic (Goldman 2017). As dementia literature is dominated by forms of life writing, an umbrella term for many varieties of personal

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[3] Notable exceptions exist. Internationally, there are several examples of dementia literature written by persons with dementia as well as fictional works where the narrator has a form of dementia (see Bitenc 2020; Sako & Falcus 2019). In Norwegian literature, several fictional works take the perspective of persons with dementia, while autobiographical works are rare (Simonhjell 2018, 139-140). See, however, Lothertington and Obstfelder (2023) for an analysis of the published diary of Thomas Christian Wyller.

narratives including (auto)biography and memoir[4], the outside perspective often also comes with ethical challenges connected to whether the person with dementia has consented, or is even able to consent, to their exposure. The risk of misrepresentation includes, but is not limited to, the many intimate moments connected with "confusion, hallucination, or loss of control over bodily functions" that might be depicted in relational autobiographies, and that can violate the privacy of the person with dementia (Couser 2004, x cited in Bitenc 2020, 129). These misrepresentations may be harmful not only to the person depicted but also to the larger group they belong to by reinforcing stigma or disseminate stereotypes.

Both *But Who Are You?* and *My Mother* are filial memoirs about dementia that openly build on auto/biographical experiences.[5] *But Who Are You?* explores a conflicted relationship between Martin and his father, Leif. Martin travels to visit Leif, who has Alzheimer's and is admitted to a nursing home. The visit sparks an inner journey through memories from childhood, youth, and adulthood which are narrated retrospectively, as Martin tries to understand and reconcile with his father considering both the past and the present. Emotions, memories, and inner life are expressed in a cartoonish and expressive style fraught with visual metaphors, often depicting Martin and Leif walking together through surreal associative landscapes. In contrast, Bredesen's *My Mother* is focused on how Trond sees his mother, Johanne, during her final two years in an assisted living facility. Bredesen presents a mix of portraits, single-panel comics, and comic strips detailing Johanne's everyday life, the exasperating and often humorous conversations arising from her memory loss and confusion, and the significance of certain objects – such as a pair of winter boots or an embroidered pillow. Trond himself appears only as a minor character and witness, and the past is seldom mentioned. Bredesen's artistic style varies from sketch-like to detailed, realistic drawings, sometimes within a single panel, where inner life is presented

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[4] Various generic terms have been coined to point towards the specificities of life writing concerned with health related vulnerability, such as illness narratives (Frank 1995); pathography, defined as "a form of autobiography or biography that describes personal experiences of illness" (Hawkins 1999, 1); somatography, which recounts the experience of "living with, loving, or knowing intimately someone" with an "odd or anomalous body" (Couser 2009, 2); and curography, a recently coined generic term for narratives that take the perspective of a caregiver (Nesby 2023, 223). When it comes to life writing that takes a relational perspective, terms such as relational autobiography (Couser 2012, Smith and Watson 2001) and care writing (Bitenc 2020) have been proposed.

[5] While I consider both works to be auto/biographically founded, there is no 1:1-relationship between the author and the main character and narrator. In my analysis I uphold this distinction by using last names (Ernstsen, Bredesen) to signify the authors and first names (Martin, Trond) to signify the character-narrators.

metonymically or through dialogue rather than visual metaphors. Together, *But Who Are You?* and *My Mother* outline different narrative, formal, and thematic approaches to how the parent–child relationship is affected by dementia.

Figure 1. Front page, Ernstsen 2023. © Gyldendal. Front page, Bredesen 2023. © No Comprendo Press.

Considering the relational challenges outlined above, both works appear to be examples of uncollaborative life writing and thus highlight issues related to the ethics of exposure. Ernstsen makes a point of the uncollaborative status of *But Who Are You?* in several metafictional panels, where we see Martin drawing his father by the bedside. When Leif asks what he is doing, Martin repeatedly lies and says that he is working on a children's book (fig. 2). Martin's unwillingness to tell his father that he is drawing him can have several reasons: Leif's often explosive anger being one, his confused state due to Alzheimer's disease being another, and Martin might not yet have had a book project in mind at this time. Yet the several instances where Martin claims that his father has always supported his work as a comics artist (Ernstsen 2023, 42-43; 88-89) serve to make the ethical status of the work a central part of its metafictional aspects. As with other ambiguities in the relationship between father and son, Ernstsen does not explicitly address or resolve this ambivalence. Instead, the uncollaborative status of the graphic novel can be seen as part of its thematization of a conflicted and ambivalent filial relationship.

Figure 2. Ernstsen 2023, 72. "Are you drawing on that?" "Yes" / "I'm illustrating a children's book" / "Right now I'm colouring in" "Oh, OK". My translations. © Gyldendal

Bredesen, in *My Mother*, does not explicitly address the graphic novel's status as life writing other than in a short epilogue, where he asserts that other family members helped care for his mother towards the end. Yet his sketch-like drawing style gives an impression of immediacy and presence that underscores its status as an (auto)biographically founded narrative. Short narrative sections are interspersed with splash pages and spreads that seem to catch everyday moments as they happen, with broad pencil strokes showing only the outlines of persons and objects. Other panels show detailed portraits of Johanne sleeping or awake in bed, seemingly drawn at the bedside (fig. 3). Differences in style and materials – a lined background suggesting a notebook, or the yellowish and structured grain of a sketch pad – enhance the impression that the person drawing is present in the situation as it is being drawn, giving the implicit reader a complicit or voyeuristic role. This, too, serves to foreground ethical questions connected to the relationship between the graphic narrator and the person who is, perhaps unwittingly, being portrayed.

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Figure 3. Splash page, up. 2023. © No Comprendo Press.

Ethical concerns about exposure relate to the relationship between the narrator and the narratee, which, in this context, extend beyond the roles of son and parent to include that of a a carer and a person in need of care. Both *But Who Are You?* and *My Mother* can be seen as examples of *care writing* (Bitenc 2020). I use the term ‘care’ broadly, encompassing both the emotional aspect of feeling care and the practical aspect of providing care in response to another’s needs. In *Imagining Care. Responsibility, Dependency, and Canadian Literature* (2016), literary scholar Amelia DeFalco encapsulates the multifaceted nature of care: “We give care, take care, care for, care about, have cares, and don’t care” (2016a, 5). The role of carer is intricately tied to shifts in our understanding of kinship when someone close to us experiences illness, an accident, or other significant physical or psychological changes.[6] This altered affinity, sympathy, or closeness often entails a responsibility to provide what DeFalco terms "para-ordinary care" – care that is not extraordinary but exists "adjacent to the ordinary", not "taken for granted or habitually represented within popular culture" (2016a, 7). While the experience of caring for a parent with dementia is not uncommon, it often constitutes a form of para-ordinary care.

Para-ordinary care comes with relational challenges of its own. When someone is vulnerable or in need, often precipitated by illness or impairment, it "creates an imbalance of ability or means between the two parties involved" (DeFalco 2016a, 5). This imbalance is what produces care, whether felt or practiced, but it also poses one of the fundamental challenges of stories told by the carer: that they too are necessarily asymmetrical. DeFalco points out that "[o]ften, and perhaps inevitably, the vulnerable subject's story becomes occluded by the caregiver's, whose socially unrecognized, typically unsupported labour begins to dominate the narrative" (2016a, 35). This danger of occluding or silencing the experiences of the person with dementia is present on all levels of the narrative: that of narration (by whom and how the story is told), emplotment (what elements or events are included and given weight in the story), and narratability (what is deemed capable or worthy of narration). Within dementia literature, the domination of the carer's perspective gives these challenges cultural and political implications. Literary scholars Katsura Sako and Sarah Falcus suggest in *Contemporary Narratives of Dementia: Ethics, Ageing, Politics* that "given the sheer volume of carer accounts of dementia" there is "a danger that these accounts shape our perception of the experience of dementia in ways that make our intimate engagement with and empathy for the person with dementia more difficult" (2019, 86). Instead, we are invited to engage with the often overwhelming demands that para-ordinary care places on their close ones, in ways that might inform our views on the need for informal as well as professional care services.

Literary scholar Linda Hamrin Nesby has a different view on the asymmetries of care writing, however, in which it is the caregiver's story that is in danger of

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[6] In recent years, there has been an increased scholarly focus on the role of care and kinship within the broad, interdisciplinary field of *Health Humanties*. Literary scholar David Morris' *Eros and Illness* (2017), anthropologist Arthur Kleinman's *The Soul of Care* (2019), and sociologist Arthur Frank's "vulnerable reading" of *King Lear* (2022), have in common that personal experiences with caregiving become a vantage point for reflections on the intersections of medicine, health, ethics, and art. The same period sees an increase in book-length studies at the intersection of literary studies and care ethics philosophy, including Amelia DeFalco's *Imagining Care* (2016) and *Curious Kin in Fictions of Posthuman Care* (2023), Jeffrey Berman's *The Art of Caregiving in Fiction, Film, and Memoir* (2020), and Maurice Hamington and Ce Rosenow's *Care Ethics and Poetry* (2019).

becoming overshadowed by that of the vulnerable person (2023, 236; 225). Nesby's premise is that (auto)biographical accounts told by carers need to navigate between the story of the caregiver, for which she suggests the term *curography*, and that of the care-receiver, the (often untold and unwritten) *pathography* (2023, 221; 227). Building on Algirda Greimas' actant model, Nesby argues that carers hold the role of helper in a traditional pathography and will have to break free from this story's influence to become the subject of their own narrative (2023, 225; 226-229).[7] This constitutes, to Nesby, the fundamental "literary dilemma" of care writing: how to write freely and autonomously from the shadow of a brutal or harsh story linked to another person's vulnerability, as subject rather than helper? This, too, is an important aspect of carer accounts where authors frequently feel that they are betraying a loved one (Miller 1996 quoted in Bitenc 2020, 130) or experience their writing as transgressive (Bitenc 2020, 130), indicating the continued presence and influence of the vulnerable person's story over the carer's narrative.

These different perspectives on the fundamental asymmetries of care writing are interesting because they invite us to look to narratology and literary form to query our expectations regarding the relationship between carer and care-receiver. Issues related to narrative subjectivity, agency, and autonomy become particularly important in situations where a vulnerable person's story remains untold and unwritten, perhaps even untellable, as is often the case with dementia. In fact, DeFalco came to her studies of care and caregiving in literature from a project about narratives on old age, *Uncanny Subjects: Aging in Contemporary Narrative* (2010), in which she wrote a chapter on dementia literature. It was the dementia narratives that made her aware of the complexities of the relationship between caregiver and care-receiver and became the starting point of her studies on the ethical questions raised by literary representations of care and caregiving (2016a, 6). Dementia, then, seems to foreground the challenges inherent in narratives that take a relational perspective on another's vulnerability in particular ways.

A part of this particularity, I will argue, lies in how the condition affects cognitive abilities, including memory, in ways often perceived to destabilize and change familiar and generational identity as well as the person with dementia's own personhood. As literary scholar Åsta Marie Bjorvand Bjørkøy writes towards the conclusion of her chapter "Å leve med demens" (Living with Dementia):

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[7] Linda Hamrin Nesby builds her argument on Harold Bloom's studies of influence in poetry (1973, 1975) as developed on by Paul de Man (1983) and Gilbert and Gubar's (1979) study of patriarchal influences on female authors in the 19th century. She suggests that the narrative of the curography draws on the same rhetorical tropes to navigate, and attempt to break free from, the influence of the underlying pathography (Nesby 2023, 226-229).

> *A person without memory is still a person with feelings. But a person without memory will hardly be able to be an equal part of their relationship with others, which will affect the nature of the relationship and, of course, have serious and difficult consequences for the relationships the individual is part of.* (2020, 149, my translation)[8]

The relational challenge outlined here pertains to the role memory plays in relationships rather than dementia's effect on narrative agency, the ability to verbalize one's own story, or consent to being exposed in that of another. While Bjørkøy also points towards an asymmetry caused by the changed memory of one party, the citation suggests that it is the relationship itself that becomes affected in negative ways, suspending the question of whose story dominates, overshadows, or influences that of the other. Bjørkøy's reflections on dementia highlights the intersubjective functions of memory, emphasizing its relational rather than individual nature, and how it plays out *between* the two parties in the relationship. While this perspective does not eliminate the inherent asymmetries of (the narrative about) the relationship, it encourages us to consider the ways in which relationality is mediated between the two. In this case: through memory.

Several scholars have suggested that this intersubjectivity might be more readily visible in the comics medium than in written narratives. In *Graphic Somatography: Life Writing and the Ethics of Care* (2016b), DeFalco argues this point by highlighting the formal specificities of perspective and narration in graphic narratives:

> *Unlike care narratives told exclusively with words, which are typically characterized by a singular perspective and narrative resolution, comics are by their very nature polyvocal, multi-perspectival, punctuated by absences and gaps, by negative space both within panels and between them.* (237)

The plurality imbedded in the visuality of the comics form puts "embodiment and concomitant dependency front and centre" according to DeFalco (2016b, 226). It allows us to see different bodies simultaneously and continuously throughout the narrative. In their study of dementia literature, Sako and Falcus build on these

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8. "Et menneske uten hukommelse er fortsatt et menneske med følelser. Men et menneske uten hukommelse vil vanskelig kunne være en likeverdig del av relasjonen til sine medmennesker, noe som vil påvirke relasjonens karakter og selvfølgelig få alvorlige og vanskelige følger for de relasjoner vedkommende er del av."

aspects of DeFalco's work, suggesting that graphic novels might "evoke in their readers a form of responsible reading that enables them to empathise, even if fleetingly, with both carers and those with dementia" (2019, 115). However, they also acknowledge that the comics form highlights challenges related to ethics of exposure, as it often represents vulnerable and even abject bodies (115) – as we have already seen in the extracts from *But Who Are You?* and *My Mother*. Similarly, literary scholar Thomas G. Couser warns that the visual embodiment of graphic novels might lead to an increased focus on an individual's personal physical impairment rather than their socially constructed disability (2018, 350). The visibility of intersubjective relations in graphic novels must not lead us to overlook the systemic structures that inform the roles of carer and care-receiver.

Of course, one could also argue that written narratives have their own affordances that might enable polyvocal or multi-perspectival representation, and that the multi-perspectives of graphic novels remain limited. The comics medium invites a placement of characters side by side on the page, but the view we are invited to take on them can still be asymmetrical and – particularly in the case of life writing – favour the gaze of the graphic narrator and their avatar.[9] It seems safe to suggest, however, that the formal affordances of comics foreground not only the narrative challenges of relationality in carer accounts, but also the role played by visual embodiment and questions related to focalization: who do we see on the page, how are they depicted visually, and through whose eyes do we see them? While we should vary of overlooking systemic structures informing these asymmetrical roles, we should also vary of addressing the relational challenges of dementia literature in ways that turn a dialectical relationship into an oppositional one, or that lock the narrator and narratee into specific roles. The relationship of care receiver–caregiver or subject–helper carries different and perhaps even contrasting implications compared to that of parent–child. The asymmetries of these relationships also differ from the authority of parent over child to that of the carer over the person in need. A filial relationship might involve all these roles, often interchangeably and reluctantly. Taking my cue from Bjørkøy's focus on the relationship itself, I will use the term *kinship* as an analytical optic for my own exploration into the relational perspectives taken in *But Who Are You?* and *My Mother*.

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[9] The comics medium necessitates the distinction between verbal narration (text boxes and dialogue), monstration (what is shown on the page) and graphiation (the style in which it is drawn) (Groensteen 2011, 92-93). Here, I use graphic narrator to point to the global narrator "responsible for the whole narrative organisation, including the production of both the words and the drawings, as well as the showing of each image and scene" (Mikkonen 2017, 131).

A kinship perspective on the relationality of care writing

What is implied by a kinship perspective? In this context, kinship determines an "essentially processual" relatedness (Carsten 2000, 16) – a felt and practised social bond that often, but not always, involves genealogy. Anthropologist Maximilian Holland (2012) posits that social bonds and kinship stem from a shared social environment and processes of frequent interaction, care, and nurture rather than solely from genealogical relationships. In approaching the graphic novels through this understanding of kinship, I seek to follow up on Rebecca Bitenc's claim, in *Reconsidering Dementia Narratives: Empathy, Identity and Care* (2020), that we need to attend more closely to the relational aspects of identity in dementia through cross-medial and interdisciplinary analysis. The changed health and cognitive abilities of a person with dementia will necessarily lead to changes in the various practices and interactions that inform the kinship relations they take part in. These changes are a premise for the relational perspectives taken in *But Who Are You?* and *My Mother*. Viewing these graphic novels through the lens of kinship opens up for an analysis that considers the relational challenges inherent in this premise as part of a broader aesthetic mediation of the practices and processes involved in creating and upholding kinship relations.

Care plays a central role in kinship, and Holland states that the "performance of care (...) is considered the overriding factor in mediating social bonds" (Holland 2012, 282). Care is here understood as a performative practice rather than just a sentiment – an understanding that aligns with ethics of care philosophy (Tronto 1993, Hamington & Rosenow 2019). As we saw above, care also figures prominently in scholarly discussions about the relational challenges of life writing, where the relational perspective is often understood specifically as the *carer's* perspective. However, while care is an important theme in both *But Who Are You?* and *My Mother*, neither Trond nor Martin perform unsupported care labour to the extent that it comes to dominate the narrative in the manner described by DeFalco. This necessitates a clarification of the ways in which care and the role of the caregiver feature in these graphic novels. What kind of care do Trond and Martin perform – and in what ways does it mediate the social bonds between themselves and their parent?

The narrative present of both works is anchored in the care facilities where Leif and Johanne live, making them institutional narratives. Both graphic novels focus on filial relationships and other (informal or formal) caregivers figure only as supporting characters. Even so, Ernstsen and Bredesen both depict the formal and informal care provided to their parent as complex choreographies involving several participants: nurses, doctors, family members, visitors, and, in Bredesen's case, even a dentist, a hairdresser, and neighbouring patients. This *careography* (Navne & Svendsen 2017, 254; Nesby 2023, 223) seems to be based on what Eva Feder Kittay (1999) terms nested obligations, where responsibilities and chores are shared, and those who care for others are entitled to societal support. The caregiving depicted here differs significantly from the one studied in DeFalco's *Graphic Somatography: Life Writing and the Ethics of Care* (2016b), which explores graphic narratives of illness and informal care work in situations where the health care system largely fails to alleviate these burdens.

Ernstsen and Bredesen portray care within the framework of a welfare state where – although far from providing perfect care – the responsibility of para-ordinary care is shared by others than the graphic narrators. Trond, in *My Mother*, does perform several care activities and chores. When his avatar figures in the graphic novel, it is often in the role of helper or doer. He helps his mother use the toilet, he cleans her apartment, and he serves as host for her birthday party. It remains clear, however, that he is only one part of the larger careography surrounding his mother. Martin, on the other hand, is primarily portrayed as a guest in *But Who Are You?* He lives far away and has come for a short stay because his father "almost begged" him to come visit (Ernstsen 2023, 18, my translation). Martin helps Leif in and out of chairs, brings him coffee, and holds the cup for him – but he is also served dinner by the nurses, and it is they who interfere when Leif is angered, needs the toilet, or is bothered by his catheter. This makes *But Who Are You?* and *My Mother* examples of dementia literature written from what health humanities scholar Martina Zimmerman calls a "care-free distance", a perspective that, in the US at least, is largely gendered and mostly figures in memoirs written by sons rather than daughters (2017, 49). In these narratives, the focus on care shifts from the burdens of unpaid, unsupported, or unappreciated care labour towards the carer's ability to "see lifetime continuity" and "encourage identity-affirming care" (Zimmerman 2017, 51). These forms of care seem to have more to do with memory work than with activities of labour.

Bitenc notes that filial caregiver's memoirs "are frequently born out of an impulse to memorialise the parent" (2020, 128). In my view, this memory work concerns not only lifetime continuity and identity-affirmation connected to the person with dementia, but also the processes of relatedness that inform the filial relationship as one of kinship. Within the field of cultural memory studies, Astri Erll argues that family memory is a specific type of collective memory. She builds her view on family memory on philosopher Maurice Halbwachs concept of *mémoire* *collective*, developed in the 1920s, in which family memory is given a special status. The family can be seen as a mnemonic community in the sense that it builds on practices, contents, characteristics, and functions that aid memory (Erll 2011, 308). Interestingly, Halbwachs states that family "has its own peculiar memory", and that "[f]oremost in this memory are relations of kinship" (Erll 2011, 306 citing Halbwachs 1992, 63). At the intersection of this view on the significance of kinship in family memory and Holland's claim that care is the overriding factor in mediating social bonds, the different relational aspects of narrating about persons with dementia from a next-of-kin perspective so far seem to merge. When dementia causes changes in a family member's memory, this will affect the family as a mnemonic community and the practices that mediate kinship within it. By taking a kinship perspective on *But Who Are You?* and *My Mother*, we can take an integrated view on the ways in which care, memory, and relationality is thematized and given aesthetic form in the graphic novels.

But Who Are You? Travelling through commemorative landscapes

It has been argued that the comics medium may be particularly apt for the representation of memory. As literary scholar Hilary Chute suggests in *Graphic Women: Life Narrative and Contemporary Comics* (2010), the movement, or act, of memory shares formal similarities with the comics medium:

> *The spatial form of comics is adept at engaging the* subject *of memory and reproducing the* effects *of memory – gaps, fragment, positions, layers, circularities; it recognizes and plays on the notion of memory as located in mind and body and as, perhaps, shiftingly inaccessible and accessible.* (134, author's emphasis)

These formal affordances imply, according to Chute, that the very "art of crafting words and pictures together into a narrative punctuated by pause or absence, as in comics, also mimics the procedure of memory", giving the representations of memory work in comics a performative aspect (2010, 4). Yet any aesthetic representation of memory will necessarily differ from private acts of remembering. In *Autobiographical Comics: Life Writing in Pictures* (2012), literary scholar Elisabeth El Refaie notes that the mediation of memories into the comics form involves "a deliberate and self-conscious act of communication" (100). As a result of this, the memories will be reshaped and transformed into stories, and then actively re-created, interpreted, and sometimes challenged and contested by readers. El

Refaie suggests the term *commemoration* to describe this collaborative aspect of how memories are mediated and remediated in comics. As dementia literature is often already framed as a memorialising act, graphic novels on this theme will often foreground these collaborative aspects of memory and how they are transformed or challenged by the changes in memory associated with dementia.

But Who Are You? unfolds a commemorative memory work in this sense which takes place during Martin's last visit to his father, Leif. The visit takes place shortly after Leif is diagnosed with Alzheimer's disease and admitted to a care facility. "But who are you?", the title's question, points towards the father's memory loss and his resulting confusion as to who those surrounding him are. On the book cover, Leif's portrait is displayed with his eyes hidden behind glasses and the title question filling the headspace of a second outline of his torso, this one made by unravelling bands of colour that can be read as a visual metaphor for Leif's dementia. But Martin also directs the same question at his father throughout the graphic novel, in a manner that reaches beyond the cognitive changes induced by Alzheimer's. Through his many reflections on his own memories – their conflicts, but also moments of support and love – reaching back to early childhood, Martin interrogates his father's identity as well as his own: who were you, who are you now, and who was and am I to you?

Figure 4. Cover, Ernstsen 2023. © Gyldendal

The visual representation in *But Who Are You?* is centred around Martin's attempts at understanding, imagining, and eventually mediating through the comics form how Alzheimer's affects his father's cognition as well as Martin's own perceptions and memories of him. An underlying question is whether and how this affects their past and present relationship which has been a difficult one. Throughout the narrative, depictions of the present lead into episodic representations of past events shown as Martin remembers or imagines them, and where the characterisations often merge into visual metaphors representing thoughts, associations, and empathic visions of both Martin and his father's feelings and states of mind. This is particularly prominent in the prologue and epilogue which frame the narrative and serve as an extended metaphor for Martin's inner journey. These sections show father and son walking through a surreal and associative landscape until, in the epilogue, Martin leaves his father behind, walks into a blank space, and breathes out in what can be interpreted as a sigh of relief.

Father and son continuously change location and age as they move through this surreal landscape in the prologue. The objects that make up landmarks are, as the reader understands later, linked to Martin's memories of his father and what he has always thought characterises him: his work with sound systems, an interest in technology and computers, his childhood by the sea in the north of Norway, and his military service in the navy. By setting these memories side by side in the same landscape, Ernstsen shows how we "tend to make connections between experiences that were originally separate in time and space, and that initially were not perceived to be causally linked" (El Refaie 2012, 100). The landscape also includes references and associations that are not connected to life events, such as the tower (fig. 5) from Torbjørn Egner's classic children's book *Kardemomme By* (*When the Robbers Came to Cardamom Town*, 1955). When Leif states that "They are here now, the bandits!", Martin is shown pondering on this word, "Bandits?", underneath an illustration where Egner's three robbers have merged with Carl Bark's Beagle Boys from the Donald Duck comics. These are references that can point to the childhood of both Leif and Martin, and one of several instances where Ernstsen shows us that the imaginative and social patterns established in early childhood still influence and anchor the filial relationship.

Figure 5. Unpaginated prologue, Ernstsen 2023. © Gyldendal

While *But Who Are You?* presents the reader with key events in Leif's previous life, spanning from his military service and career to his divorce from Martin's mother and the relationship to his present partner, Reidun, Ernstsen continuously challenges Martin's position as Leif's biographer. This is done through visual representations of the imaginative and associative workings of Martin's own mind– in terms of imagination, memory, and reflection – as well as how he pictures those of his father. Several splash pages and spreads show landscapes like those from the prologue and epilogue, depicting father and son in increasingly psychedelic landscapes, fraught with intervisual references to popular culture, artworks, and technological devices from the 1980s and 1990s, in which any narrative orientation becomes difficult.

Figure 6. Ernstsen 2023, 128-129. "I want to go back to my room." / "Dad, I shall have to leave now…" My translations. © Gyldendal

Rather than understanding these visual representations of the workings of the demented mind as an ethically fraught attempt at fictionalising the experience of the person with dementia from the inside, I understand them to be representations of a processual memory work that involves both parties. Ernstsen gives visual form to the ways in which Martin is affected by his father's changes in memory and cognitive ability, the attempts at recognition and empathy that they lead to, but also the ways in which they trigger Martin's own memories or associations and connections. In the prologue, particularly, Ernstsen portrays this memory work as something that can never be entirely individual. The associative world he draws up for us comes into existence through interactions and dialogue with his father and the ways his dementia demands a continuous navigation between the present and the memories, associations, and fantasies of both. The imaginative world that this results in is one where affect and imagination dominate over temporal linearity and causality.

Leif's frequent outbursts of anger figure prominently in Martin's childhood memories, to the extent that Martin questions the trustworthiness of these memories and wonders if his perception of their past relationship is due to how "bad memories stick better than good ones" (2023, 38-39, my translation, see also fig. 7). Scenes from the present seem to corroborate the authenticity of these memories, however. When Leif explodes in anger during Martin's visit at the care facility, Martin is pictured as freezing up or turning into a childlike figure, indicating that Leif's temperament relates to deep-seated patterns in their interaction and results in embodied reactions (fig. 8). The frequent visual metaphors used in these scenes, including characterisations of Leif through cartoonish figures and the use of colour to signal emotions, serve to connect past and present as well as concrete events and affective responses to each other. The result is a felt immediacy, where both Martin and the reader continually reassess the social and emotional bonds between them.

Figure 7. Ernstsen 2023, 38 "I read once about how untrustworthy memories are. / That they change a little bit each time they're recalled." My translation. © Gyldendal

Figure 8. Ernstsen 2023, 92. "There are bandits here! Don't you believe me??", "Yeah yeah …" My translations. © Gyldendal

Ernstsen privileges an affective and associative imagination over the retention of memory or establishment of documentary fact, and this might exemplify a memory work that is concerned with the processual production and reproduction of both memory and subjectivity. The commemorative work this results in is perhaps more aptly described as a form of hyper memory than as the "loss" or absence of mind, memory, and cognitive ability that dementia is often perceived to entail. While Ernstsen's drawings never can depict a truly "*shared* associative landscape" (Ernstsen 2023, paratext, my translation and italics), they do show the affinity between father and son as a continuing process, influenced by both, in which bonds of kinship are maintained even as they are being revisited and transformed. That is not to say, however, that the two parties are equal in this process or that it is a simple one. Ernstsen's commemoration in the comics form uses extended visual metaphors to show us the complex, underlying mental processes that turns even a seemingly simple situation – drinking a cup of coffee and chatting with his father – into a tiring memory work in which both their present and past relationship is continuously being reiterated and interrogated. After reading the graphic novel to the end, readers might want to breathe a sigh of relief themselves, as Martin, on a final and blank page, leaves behind his father for what appears to be the last time.

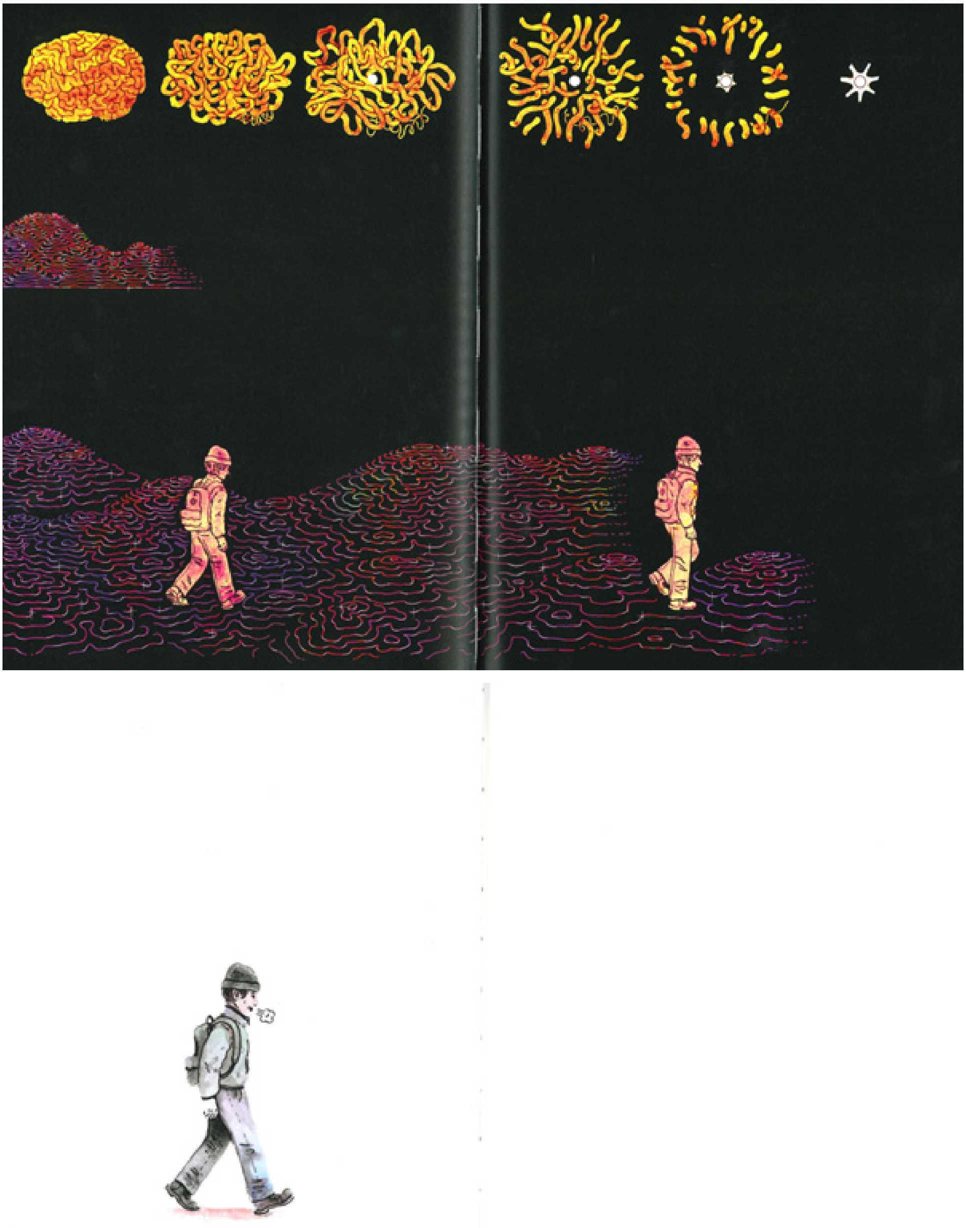

Figure 9. Ernstsen 2023, 136–139. The two final spreads. © Gyldendal

My Mother. Seeing through a familiar gaze

Turning to Bredesen's *My Mother*, we are presented with a filial memoir that is perhaps more readily labelled a portrait than a narrative even though we follow a chronologically ordered and episodic narrative structure covering Johanne's two final years. Rather than the retrospective narration found in Ernstsen's work, Bredesen gives the impression of glimpses into everyday situations through a series of sketch-like drawings. Most of the scenes stem from Trond's visits to his mother, Johanne, in the assisted living facility called Filten, interspersed with portraits and sketches of her in different quotidian situations. Bredesen makes extended use of the figure of metonymy in his representation of Johanne, in the sense that it is mainly the detailed depictions of objects – clothes, belongings, and medical equipment – that provide insight into her personality traits and her past and present life. The ambivalences that are thematised here do not stem from past conflicts or difficult personality traits (as they did in *But Who Are You?*) but arise instead from the needs of the present situation. Implicitly, Bredesen asks whether Trond could and should have done more for his mother in her final years, and what it means to navigate between the remains of a past self and the establishment of a new presence. Trond does not explicitly ask who his mother was before this, nor who she is in the present of the episodic narratives we are presented with. He seems instead to establish and anchor her identity in the bond of kinship stated in the very title: My mother, that is who.

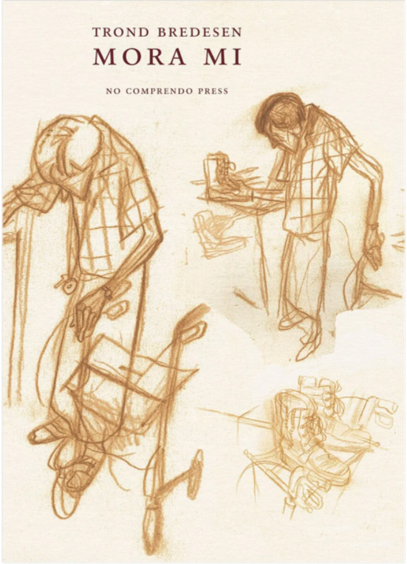

Figure 10. Bredesen 2023. Front page. © No Comprendo Press.

The process of establishing and preserving a kinship relation, and the mnemonic practices that are part of it, is given a more subtle form in this work than in *But Who Are You?* Kinship is linked, primarily, to the establishment of the familial gaze indicated by the title. To do this, Bredesen makes use of a device that we also find in Ernstsen's graphic novel as well as in Anders N. Kvammen's *I don't remember... Stories about dementia* (*Jeg husker ikke… historier om demens*, 2020), which is to outline the person with dementia in a contrast colour in several of the frames. In Ernstsen's *But Who Are You?* coloration marks Leif as the main character and highlights his emotions, particularly by colouring him red when he is angry, irritated, or anxious. In Bredesen's *My Mother*, red is used consistently but without taking the form of symbolic representation of inner life. Johanne wears a red jacket, or her figure is outlined in red, and she is often drawn with more detail than those surrounding her, which places her at the centre of attention. The use of this bright colour seems to point to her character in a metonymical rather than metaphorical sense. Where metaphor creates an implied connection between two concepts that are unlike, such as the emotion anger and the colour red, metonymy refers to a concept through something closely related to it. In *My Mother*, Johanne's clothes and clothing are shown with lively colours throughout the graphic novel, and several panels show her commenting on her clothes and appearance. Metonymically, the characteristics of her clothing – colourful, elegant, joyful – come to characterise the person who wore and still wears them: Johanne. The use of colour in the novel hints at a set of personality traits, and gently insists on them still being present.

Bredesen's representation implies an identity-affirming view on Johanne, even as the past is seldom mentioned explicitly. The memoir is framed by a drawn portrait of a young Johanne on the first page (fig. 11), and a photograph of her with her two sons as children on the last one. Other than these photographs, and those that figure on the walls of her apartment, her past receives no visual representation and is only hinted at in the dialogue. Instead, Johanne's past life and characterisations connected with it are represented through the objects surrounding her. The fact of Johanne's vulnerability and physical and cognitive frailty imbues these objects with significance: an embroidered pillow, made by herself, and a rather new pair of winter boots become fraught with meaning. Here, too, Bredesen makes use of metonymy, in the form of synecdochical *pars pro toto*, where a part of something refers to the whole. Like her clothes, these objects come to represent the remaining parts of a past totality. They allude to who Johanne was and help the reader construct a picture of her former and present identity.

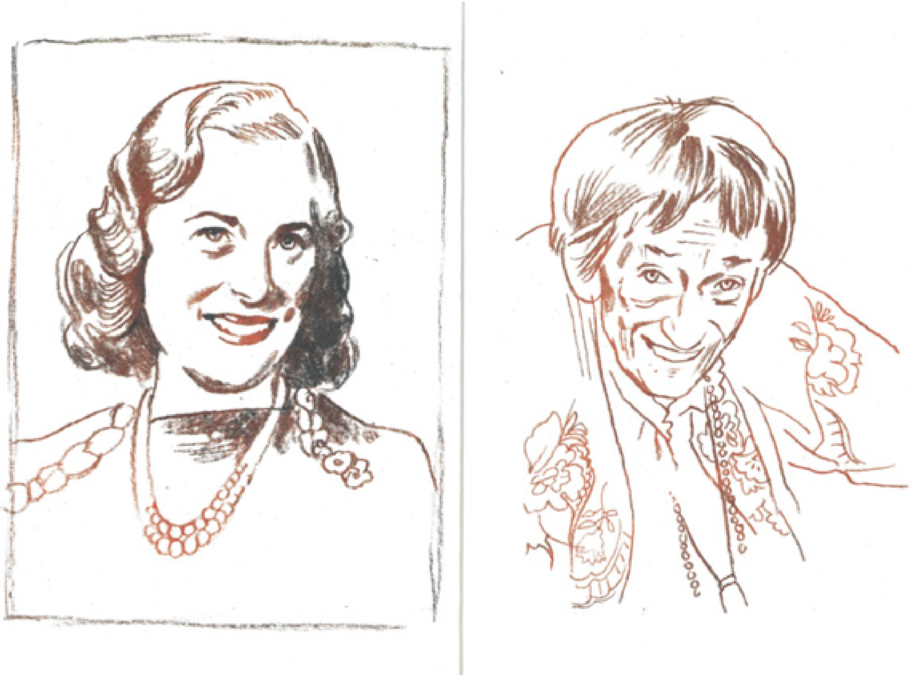

Figure 11. Bredesen 2023, unpaginated. © No Comprendo Press.

Johanne's own mnemonic practices also seem to be based on synecdoche. When she sees her embroidery in her apartment at the care facility, Johanne states that she made those, "So I suppose I'm in my home, then" (Bredesen 2023, my translation). She takes to walking around with her embroidered pillow or the winter boots in the basket of her walking chair, where they seem to instigate processes of social bonding in ways that affirm her identity – even to the point of giving her life meaning (fig. 12). In this manner, Johanne's belongings become part of an ongoing identity work still being performed, in which they by association or contiguity refer to larger concepts: I recognize that pillow as one I made, so I must live here; I am praised for the pillow, so I should live on. On another level, more closely connected to Trond and the process he is going through, the material reality of the objects also points towards an absence that is closing in, but to come. Johanne's things are being moved into the apartment at the assisted living facility when the narrative begins, and at the end of the book we see the furnished apartment without Johanne in it. The objects are, eventually, all that remain when Johanne has gone, and it will soon be Trond's own memories that imbue them with meaning.

Figure 12. Bredesen 2023, unpaginated. Spread: "I really just want to let go, Trond. But when I see that pillow I embroidered, I do want to go on for a bit longer. I get such praise for it." My translations. © No Comprendo Press.

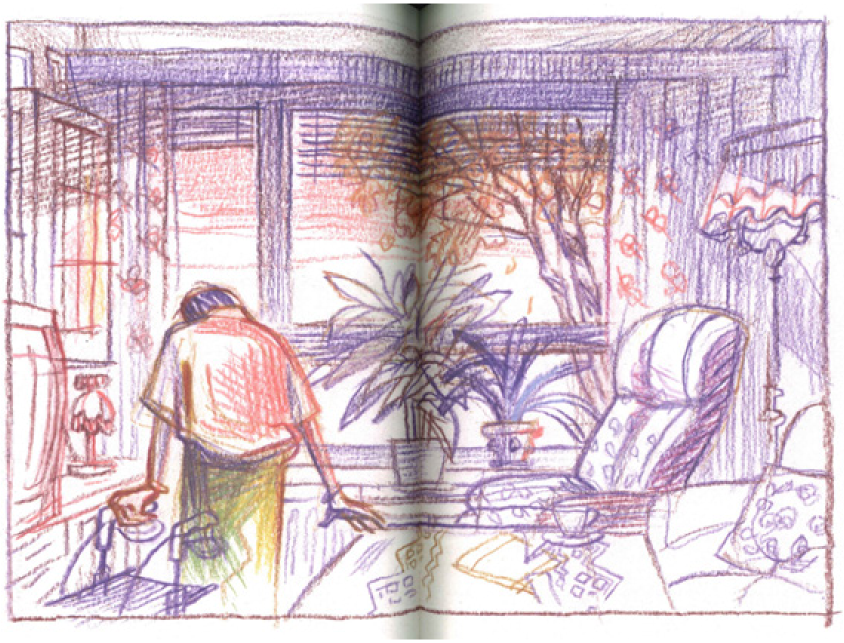

Figure 13. Bredesen 2023, unpaginated. Spread. © No Comprendo Press.

My Mother is filled with humour and interspersed with single panels in which Johanne makes a funny observation or is confused in ways that are both humorous and exasperating. Her interlocutor is often not shown, and this invites the reader to imagine themselves in the place of the one seeing, talking to, and (implicitly) drawing her. While Trond figures rather rarely as a character, and then only as a vague outline, there is still a marked sense of subjectivity to the narrative which highlights "the question of the relation and distance between a perceiving entity and a narratorial identity" (Mikkonen 2017, 146). Trond places himself in the role of witness: in terms of processes of kinship, he is focused on what takes place or is being said in the present, in the many, small moments of everyday interaction that continue to take place.

Bredesen's filial memoir seems to oppose or challenge the idea that either the person with dementia or their carer needs "a story of their own". Nor does it present an inner journey through past events, memories, and associations like the one portrayed in *But Who Are You?* Instead, Bredesen gives visual and narrative form to the present moment and how it is characterised by a being-together, a continuation of everyday interactions even as they are changing and, increasingly, troublesome. Life will simply go on, it seems, until the bed is empty, and that life is over. Even as Bredesen can be said to universalise experiences of old age and dementia by leaving out the past and, to a large degree, inviting the reader to take his place as witness, relatedness remains at the core of the aesthetic mediation of kinship that this graphic novel performs. The project seems to be about creating an intersubjective presence; a presence that is not simply that of his mother, but that of the relationship between her and the people and objects surrounding her, and between her and Trond. Bredesen's drawings imply the presence of a familial gaze that saw Johanne this way, not just as "a woman", "a mother", or even "the woman who used to be my mother", but as "*my* mother, even now".

Conclusion

But Who Are You? and *My Mother* show us that relatedness – even between close relatives – remains an ongoing process even when someone changes cognitively. As Bitenc proposes, "memoirs can be viewed as enacting a form of relational identity, which is both particularly pertinent and particularly troubled in the context of neurodegenerative disease" (Bitenc 2020, 136). This enactment takes different forms in *But Who Are You?* and *My Mother*. Where Ernstsen draws heavily on the past and depicts an elaborate and conflicted inner process relying on memory, association, and imagination, Bredesen is focused on the present and frequently uses metonymy to show how mechanisms of relatedness, including our relation to objects, remain central to how we perceive identity and relationality even as dementia increasingly affects cognitive functions and memory. What they have in common is their portrayal of continuing interactions with their parent, and an attention towards how the onset of dementia complicates and transforms the processes of relatedness that these interactions are part of. Both works can be said to focus primarily on what happens now and what might come next, even as the past figures heavily in *But Who Are You?* The categories used for exploring, understanding, and describing the filial relationship are not taken for granted as something fixed, but inquired as they unfold in concrete situations where parent and son are both present. The graphic novels thus become testaments "to the primary force of relationality in both shaping and maintaining identity" (Bitenc 2020, 154) and give examples of how this relationality is given aesthetic form through the comics medium.

The assumption that kinship is a processual and dynamic form of relatedness does not remove ethical concerns, ambivalences, or "relational challenges". Indeed, I do not propose that a recourse to "intersubjectivity" or "relational identity" might solve the ethical problems related to telling or appropriating another's story. To quote Bitenc, "narrativising the other's life story, while serving the important function of memorialising the other, can never do justice entirely to the subjectivity of a person with dementia" (2020, 136). While the relational challenges connected to these kinds of narratives do remain, a kinship perspective might, however, help us to frame them differently – not as what hinders the free and autonomous narration of either the vulnerable subject or their carer, but as fundamental parts of the processes of relatedness that continuously mediate and remediate kinship. There are arguably no kinship relations that can avoid situations in which the health of one party causes changes that might "affect the nature of the relation" and "have serious and difficult consequences for the relationships the person is part of" (Bjørkøy 2020, 149, my translation), whether it be dementia or something else. From the perspective of literary criticism, the question is how aesthetic forms might help us explore what these consequences are, which processes inform the nature of the relation, and which relationship or sense of kinship and community might emerge when established relational practices are being transformed.

By giving narrative and visual form to different ways in which interaction, care, and memory work mediate kinship (understood as a continuing process of relatedness), graphic novels like *But Who Are You?* and *My Mother* explore how production of relatedness continues and transforms when one party has dementia. But if kinship is understood as a processual social bond requiring mediation, these graphic novels also exemplify a specific kind of mediation, an aesthetic one, that participates in relational processes involving their readers. In scholarly work on dementia literature, it is suggested that life writing about persons with dementia can be seen as a "memorialising act" that "is part of caring" for them (Sako & Falcus 2019, 104). In a kinship perspective, this memorialising act takes the form of what El Refaie calls *commemoration*, involving a shift from the graphic novels' depiction of family memory to what Erll, building on Jan and Aleida Assmann's work, calls cultural memory (2011, 311).[10] Literary commemoration occurs on multiple levels: narrative content (where dementia alters family memory and relationships), form (where the comics medium mediates memory work caused by these changes), and context (where graphic novels contribute to broader cultural memory). As published works of art, *But Who Are You?* and *My Mother* both give aesthetic form to mediations of kinship and engage in the practices through which we produce and sustain social bonds on a collective level.

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[10] A similar view is suggested by Marianne Hirsch (2008) in her analysis of Art Spiegelman's graphic novel *Maus* (1986) as a work of what she calls postmemory, where she shows that familial and cultural memory processes are both mediated and merged by help of the comics medium.

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Originalartikel

When Caregiving Becomes Desperate

Subjectivity, responsibility, and ethics in contemporary mother-daughter narratives of care

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To be a caregiver while also being next of kin is emotionally charged. This article discusses narratives of care that goes beyond what Amelia DeFalco calls "caregiving at the limit", i.e. care necessary for basic survival. In these narratives of what we call desperate care*, not only is life at stake, but the care is anxious and urgent, partly done against the will of the care recipient, and the caregiver is exposed and vulnerable. To explore the concept of desperate care we analyze two contemporary Swedish narratives, in different media and from different perspectives. Marie Tillman's graphic novel* En trasig historia *(2020) depicts a young girl, Mia, trying to care for a mentally ill and unpredictable mother. Sara Gordan's prose work* Natten *(2022), tells the story of a mother who tries to prevent an unruly adolescent daughter from mismanaging her 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. Through these works, the article explores the narration and practices of desperate care, discussing the subjectivity, responsibility, and hyper attentiveness of desperate caregivers, 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 ethical challenges, as well as how the narration can be regarded as an ethical care practice in itself.*

Introduction

To be a caregiver while also being next of kin is emotionally charged in many ways. Close family ties both give meaning to and complicate the caregiving, and this is as true in real life as in caregiving narratives. In this article, we will discuss narratives that not only depict what Amelia DeFalco calls "caregiving at the limit", performances of care necessary for basic survival (DeFalco 2016: 53), but narratives that go one step further. In these, not only is life perceived as being at stake, but the care is partly done against the will of the care recipient. The modus of care is urgent and anxious, and the caregiver exposed and vulnerable. These are stories of care fraught with complications – fear, dependency, control and loss of control, and difficulties in keeping up boundaries between caregiver and care recipient. We will here, through an analysis of two contemporary Swedish narratives of care, Marie Tillman's graphic novel *En trasig historia* ("A broken story", 2020) and Sara Gordan's prose work *Natten* ("The Night", 2022), propose the term *desperate care*. In this care, both the frenzy and the despondence of desperation are crucial features, and our analysis of the works aims to delineate important building blocks of the practices of desperate care and prominent traits of how it is narrated.

The two works focus on the relationship between mother and daughter, but in different media and from different perspectives. Tillman depicts the story of a young girl, Mia, trying to care for, but also eventually emancipate herself from, her mentally ill and unpredictable mother. Gordan tells the story of a mother who desperately tries to save an unruly adolescent daughter and prevent her from mismanaging her diabetes. We read these narratives both as works of art – carefully constructed, aesthetic designs – and as representational – life-like portrayals where the reality of care can be depicted and examined in all its messy and relational complexity. The two are "next of kin"-stories where care becomes a necessity, and where one part of a close-knit mother-daughter dyad attempts to take responsibility for the other. In these narratives, the caregivers have a notably strong focus on the other, which also deeply affects their self-care and their sense of self. By comparing one story where a mother acts as a desperate caregiver for her daughter and one where a young daughter is forced to assume a responsibility beyond her years and attempt to care for her mother, we want to discuss the narration and practices of desperate care, with a primary focus on subjectivity, responsibility, and ethics.[1]

Our analysis is situated within a hermeneutic paradigm. The methodology consists of a close reading and a comparative analysis, where we read and re-read the narratives with an emphasis on similarities and recurring narrative patterns. In the analysis of Tillman's work, there is further a focus not only on the verbal elements but on the medium-specific narrative strategies of the graphic novel: visual style and metaphors as well as the dimension of spatio-topia – the grid structure and layout of the panels (Groensteen 2007). In our analysis, the concept of desperate care is thus both extracted, constructed and explored through the narratives, in a dialectical movement between the primary material and theoretical discussions. Taking our inspiration from DeFalco's discussion on caregiving at the limit and her use of narratives, we want to further this aspect of care research, as well as the growing and multifaceted interdisciplinary research at the intersection between health, medicine and culture.[2]

Narrating desperate care: Mother-daughter auto/biographies in different media

Marie Tillman (b. 1982) is a graphic artist and social anthropologist who has published four graphic novels, *En trasig historia* being her second.[3] Her style is expressive and characterized by a dark humor, and reoccurring themes include mental illness and dysfunctional relationships. With *En trasig historia*, she contributes to one of the strong themes in Swedish graphic memoirs, depicting

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[1] The fact that the stories explore relationships between mother and daughter could also invite a more extensive discussion on gender and care, and also on aspects of class and race, since dependency work, that is paid or unpaid labor to care for "persons who are dependent on an other in order to meet essential needs", is most often "carried out by women, and not infrequently by women (and sometimes men) who are marginalized by virtue of race and class" (Feder & Kittay 2002: 2).

[2] At this intersection many fields meet and overlap, such as medical and health humanities, narrative medicine and graphic medicine.

[3] Tillman's other published works are *Tänk positivt annars kan du dö* (2018), *Fråga livscoachen* (2021), *Familjen fågel – Först är det roligt* (2022) and *Ångest för alla* (2022, together with Sara Ringarp). She was also a regular cartoonist with *Livscoachen* in the newspaper *Metro* 2016–2019.

mental illness.[4] Tillman's story gives a daughter's perspective on attempting to care for – and keep alive – a mother who suffers from symptoms associated with bipolar disorder: intense mood swings, impulsive behavior, excessive shopping and substance abuse. The mother-daughter relationship is unpredictable and isolated: only a few other characters show up on the pages. There is no one else in the family. Sara Gordan (b. 1972) is an author and translator who had published three novels before *Natten*, all playfully making use of intertextual references to other authors.[5] *Natten* became her public breakthrough and won her two national literary prizes.[6] It depicts a mother's desperate attempts to care for a teenage daughter whose adolescent unruliness risks becoming life threatening due to the daughter's diabetes. In this story, many people are present: siblings and half- siblings, father and stepfather, grandparents and friends, and it also includes several other illness stories, forming a whole family history of illnesses. Despite this, the other people and events are consistently relegated to the background as the story primarily focuses on the mother-daughter relationship.

Regarding genre, these narratives are autobiographically inspired. The autobiographical stance is present but also complicated. Tillman's work is not explicitly framed as either autobiographical or fictional on the physical book, even though the genre "graphic novel" suggests a degree of fictionality.[7] The name of the protagonist is Mia (a common nickname for Marie), and the themes, as well as the drawing and lettering style (hand drawn, black and white, raw lines) are all genre traits associated with the graphic memoir.[8] On her blog, Tillman has also

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[4] Mental illness is a common theme and part of a genre tradition in graphic memoirs in Sweden. When Nina Ernst 2017 mapped the genre in a Swedish context, she found the theme present in over a third of the works. Ernst 2017: 83. As discussed below, Tillman's work is not labeled as such but has a lot of common ground with the genre of the graphic memoir; hence it is relevant to relate to that context.

[5] Gordan translates from French to Swedish, notable authors including Hélène Cixous and Michel Houellebecq. After her debut *En barnberättelse* (2006), she has also published *Uppställning med albatross* (2009) and *Martin Andersson. Ett skuggspel* (2013).

[6] In 2022, Gordan received two prestigious literary prizes, from the national newspaper *Svenska Dagbladet* and the literary magazine *Tidningen Vi*.

[7] The text on the back cover does not mention the name of the protagonist and seems almost deliberately vague: "*En trasig historia* is a graphic novel about growing up with a parent lacking boundaries". Swedish original: "*En trasig historia* är en serieroman om att växa upp med en gränslös förälder". All translations from Swedish are done by the authors of the article.

[8] 8. About the genre traits of the graphic memoir see El Refaie 2012; Ernst 2017; Horstkotte & Pedri 2022: 60.

confirmed the autobiographical background (Tillman 2021b).[9] Gordan's work is categorized as a novel, but both the phrasing of the back cover text and several interviews emphasize the lived experience behind the narrative. She explicitly thematizes the challenges of autobiographical writing, pointing out more than once that the story, from the daughter's perspective, probably would read completely differently. She also comments that memory is fragile, and that she deliberately has prioritized the perspective of the worried mother and the subjective truth: "As an author I have tried to be truthful to her, she who tried to hold everything in her hands" (Gordan 2022: 176).[10]

For us, the importance here is that these works can be conceptualized as what G. Thomas Couser calls *auto/biographies,* i.e. stories whose focus is plural rather than singular, and "oscillate between biography and autobiography" (Couser 2004: 56). At first glance, the focus of the story is the family member portrayed, but the relation between author and family member is "so intimate that the author-narrator also comes under scrutiny" (Couser 2004: 56). The writing of the self and of the other is thus intertwined and almost impossible to separate, making the relationship the real center of the stories.[11] This kind of relationality is, as Paul John Eakin reminds us, a part of all autobiographical writing since all identity is relational (Eakin 1998: 63), but Couser's distinction is helpful to distinguish a kind of narrative that explicitly focuses on this relational aspect. The auto/biographical stance in these two works is important to account for when discussing the possibility of reconciliation and the ethical dimensions of the narratives, and both the narration and imagery underscore the messy auto/biographical relationality and the desperation of the caregiving in the two works.

The title *En trasig historia* includes the word "broken", which can be interpreted both in relation to a complicated childhood and to the fragmented construction of the storytelling. The graphic novel presents short scenes from the childhood and adolescence of Mia. In a blogpost on her website, Tillman references how trauma makes it impossible for the subject to experience her life story as a coherent, linear chronology – bringing the theme and the structure of the story together (Tillman 2020b). The bulk of *En trasig historia* consists of episodic chapters spanning from

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[9] The reception also highlighted the lived experience of the narrative as "partly autobiographical" ("den delvis självbiografiska boken") (Lundgren 2020).

[10] Swedish original: "Jag har som författare försökt vara ärlig mot henne, hon som försökte hålla allt i sina händer."

[11] Cf. Nesby commenting that in curographies, her term for caregiving narratives written by next of kin, the next of kin story can be seen as a variation of the care recipients's story, with the care recipent dominating the narrative relationship. Nesby 2023: 227.

early childhood to when Mia, now a young adult, has moved out. Even while trying to emancipate herself, she continues to care for her mother to the point where the situation escalates, and Mia is forced to alert the authorities.

The fragmented episodes are preceded by a prologue, a short story of a laboratory rat that serves as a frame of interpretation for Mia's childhood. A narrator states that when laboratory rats do not know if they will receive food or an electric shock when they press a specific button, they stop trying and instead starve themselves to death. The image of the rat reappears in a later episode, as a framed canvas in their home. This visual braiding of the frames remind us as readers of the prologue.[12] Functioning as a structuring metaphor in the work, the rat emphasizes Mia's vulnerability and subjection to unpredictability, which is opposed to the expectation of the parent as a guarantor of safety and stability. The desperation in the narrative lies not only in the mode of care, but also in the uncertainty and the depletion of trust.

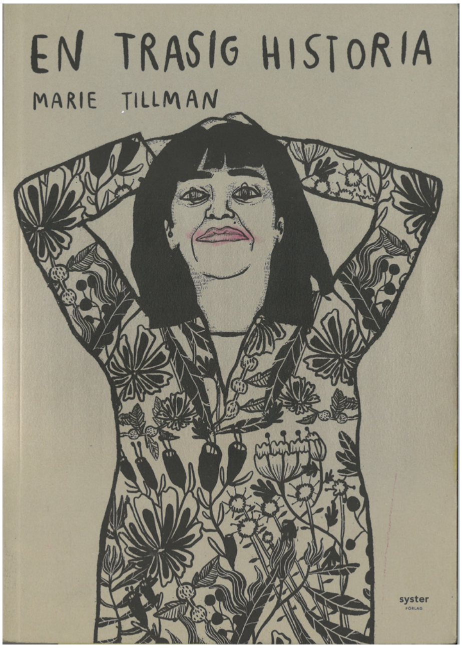

Figure 1. Mia's mother depicted on the cover of En trasig historia. *This and all successive illustrations come from* En trasig historia, *© Marie Tillman 2020. All images are reproduced with the permission of the artist.*

The focus of the story is Mia's mother. Her face is drawn in detail, most notably on the cover, where she is completely in focus (see fig. 1). The degree of realism continuously changes, depending on the mother's mood and illness. As her illness progresses, she becomes more out of focus and in a state of dissolution, which is especially noticeable in the drawing of her eyes (see fig. 2). These deviations from what James Phelan calls "the mimetic norm" or "baseline" in graphic narration underscore that we share Mia's perspective (Phelan 2023: 141–142).[13] The images foreground her experience of the mother rather than realistically portraying the outer reality.

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[12] Braiding is a term from comics studies, where separate frames are linked to each other through different means, for instance by the repetition of a motif, see Groeensten 2007: 145–158.

[13] Cf. Horstkotte & Pedri 2022: 60–61, on how shifts in style can work as focalization and make the reader adopt a particular perspective.

Figure 2. Mia's mother in a dissolved state (Tillman 2020: 186).

As a contrast to the way the mother is portrayed with singularity and expressiveness, Mia herself is throughout depicted as not fully formed, which stresses how there is not enough space for her in the relationship. The twisted arms and the almost invisible hands encourage associations to mutilation, a graphic trope which Nina Ernst shows can be used to indicate an instability of the self and a struggle with control (Ernst 2017: 107). The small mouth can be read as symbolizing her lack of voice and inability to speak up for herself. Throughout the story, Mia is drawn with small facial features and expressions, often seemingly genderless (see fig. 3). She is graphically stripped of individuality, and as the years in the story pass, she hardly changes. All individuality is placed in the drawings of the mother, while the child depicted could be any child. The portrayal emphasizes how Mia's development and subjectivity is impeded by caring for the mother.[14]

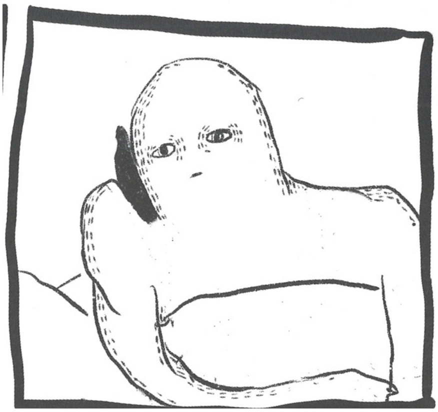

Figure 3. Mia is drawn with small facial features and expressions, graphically stripped of individuality (Tillman 2020: 136).

Whereas Tillman's fragmented graphic novel has an almost invisible narrator, *Natten* is a prose work consisting of short chapters written in second person, where the mother addresses her beloved and rebellious

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[14] Cf. Horskotte & Pedri 2022: 81–83, on how the graphic memoir is especially apt to portray the formation of subjectivity as social and identity as processual and interrelational.

daughter as “you”. The narration starts in the present tense and tells a coherent story, covering the time of less than a year while the daughter is a teenager. During this time, the daughter repeatedly runs away from home, the mother looks for her, and various care institutions are called upon for help. When that does not work, the daughter is sent off to two different institutions and is later allowed to return home. The present time is interlaced with pro- and analepses which cover a longer period, going back to the point when the narrator first became a mother, recounting how the family situation has changed over the years, and finally hinting at the peace and community that will come after the difficult time of adolescence. The narrator’s intimate address in second person creates a form similar to a letter, which emphasizes communication and community, and the rhythm of the narration, where the long sentences only separate their clauses with commas, captures the flow and insistence – and often desperation – of the thoughts.

The focus on relationships is emphasized by the fact that no one is given a name in the story – not only “I” and “you” are nameless, but the others are designated by how they relate to the daughter (“your brother”) or the narrator (“the man who would become my husband”).[15] This focus is also present in the mother’s thoughts not of her daughter, but of “them”, as having diabetes. This encapsulates how the illness affects the whole family, but it also underscores the heightened closeness between mother and daughter, a closeness the mother cannot help but push for: “co-dependency can appear in so many ways” (Gordan 2022: 44).[16]

Just as the brokenness of Tillman’s work is visible already in the title, the structuring metaphor of Gordan’s work is made explicit in the title’s use of the word “night”. This night is a relentless state that seems to have no end, a state of having no way to keep the daughter alive when she is out of reach, when she is “anywhere where I am not with my sandwiches and dextrose tablets, beyond my control” (Gordan 2022: 28).[17] The metaphor emphasizes the feeling of time standing still, except for the flow of worry she calls “variations of helplessness” (Gordan 2022: 96).[18] The narrator sees herself becoming a watch dog or a prison guard to

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[15] Swedish original: “din bror” and ”mannen som skulle bli min make”. A few are also designated by their nationality, like “the Frenchman” for the daughter’s father, perhaps an attempt to downplay his importance to both of them.

[16] Swedish original: ”medberoende kan se ut på så många sätt”.

[17] Swedish original: ”var som helst där jag inte är med mina smörgåsar och druvsockertabletter, bortanför min kontroll”.

[18] Swedish original: ”Hjälplöshetsvariationer”.

her daughter in an attempt to stop her from running away (Gordan 2022: 48, 81). Phrases as well as actions are repeated, coming back in variations. When the daughter is gone, the night includes a constant movement in search for her, as well as finally giving up, to simply wait:

> *It is the cape of the final night; it is four o'clock and there is nothing more to do than give up. […] There is a point when everything is done, and nothing is left except the night. You are alive or dead, I will not know until you are found or allow yourself to be found, and with this thought I must go to bed, nothing is in my hands.* (Gordan 2022: 8–9)[19]

The uncertainty and impossibility to control or even know what is happening shapes the desperation constantly swirling in the mother's head. The night as a metaphor captures the powerlessness of the immutable state created by the repetitions.

To summarize, the rat and the night are characteristic of the different flavors of desperation in the two works. In *En trasig historia* ambivalence is a key part of the desperation: the mother's unpredictability and inability to successfully parent means that Mia never knows what to expect or when acts of care will be needed. In *Natten* there is a consistency: the daughter rebels and moves away, the mother's desperation lies largely in her attempts to keep her child alive.

The subjectivity of the protagonists is intimately bound to the caregiving relationships. In *En trasig historia*, Mia's individuality is visually toned down and contrasted with the expressiveness of the mother, indicating the difficulty in developing a subjectivity beyond this relationship. In *Natten*, the mother's subjectivity is closely tied to the care for and the survival of her daughter. As the earliest point covered by the narration is the birth of her first child, the narrator is, in a sense, born as she becomes a mother. The ever-present fear of the daughter's death can thus be regarded as a threat to her identity as well. This relational directedness is a crucial part of the way these stories are narrated, and the caregiving does not only "shine a light on human conditions as inescapably interpersonal", as Arthur Kleinman has noted (Kleinman 2020: 238), but also on the formation of subjectivity, as the desperate caregiving deeply shapes the protagonists.

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[19] Swedish original: "Det är den yttersta nattens udde, klockan är fyra och det finns ingenting mer att göra än att ge upp. […] Det kommer en punkt där allt är gjort och ingenting finns kvar utom natten. Du lever eller är död, jag vet inte förrän du hittas eller låter dig hittas, det är med den tanken jag måste gå och lägga mig, ingenting är i mina händer".

The practices of desperate care

In stories of caregiving, it is not unusual that the stakes of the story mean confronting an imminent death i.e. caring for a loved one who is approaching the end.[20] In the works discussed here, the stakes are about caring for someone on a destructive trajectory, where they have to be saved from a possible death that could be either on purpose or the unintended consequence of recklessness.

It is worth noting that the question of mental versus somatic illness is not overly important here. The illnesses in the stories are bipolar disorder and diabetes respectively, but the dynamics of care are strikingly similar. A common feature is the struggle to keep the other alive against their own disinterest in their well-being. Both are stories of standing next to someone – a close next of kin – who moves away, fast and in the wrong direction, and not being able to stop them. In *Natten*, the narrator references a famous mother's story about a daughter with schizophrenia (Spungen 1996), and identifies the same rapid movement towards a metaphorical cliff in her own daughter: "this is a child I cannot manage, nothing I say or do affects her, her motor is already in full gear and headed towards the precipice" (Gordan 2022: 12).[21] The mother's movements and actions are strongly dependent on the daughter's: where she leads, the mother follows. In Tillman's work, Mia tries to match her mother's movements, and Mia's own movement, actions, and in a wider sense her whole identity, is shaped by her mother's illness. Mia is transformed from child to desperate caregiver, while in *Natten*, the parental care is heightened to desperate care. The metaphor of being caught up in, and dependent on, somebody else's movement is an apt metaphor for the experience of being next of kin in both works.

In our analysis, we identify three important building blocks as constitutive of desperate care. Here, we will explore how the works portray these building blocks: first, the worry and responsibility and the repetition they entail. Second, the hyper attentiveness and co-dependency of the protagonists, and third, the unsuccessful care and the turn to institutions as a last resort.

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[20] On the dynamics in these kinds of caregiving narratives, graphic and in prose, see for example DeFalco 2010.

[21] Swedish original: "det här är ett barn jag inte rår på, ingenting jag säger eller gör kan påverka henne, hennes motor är redan på fullt varv och riktad mot stupet".

Worry and responsibility

The mother in *Natten* is in an almost constant state of worry – the strongest emotion to exist within her state of night. She makes use of Schrödinger's cat as a metaphor, which emphasizes the pain of not knowing. As she tries to call her daughter, she only reaches the answering machine: "You are somewhere in one or another acute state or not, I have no way of knowing, *unfortunately I can't answer right now*. I'm thinking of Schrödinger's cat […] before the box is opened the cat is theoretically both dead and alive at the same time" (Gordan 2022: 98–99).[22]

The worry about death is also a constant for Mia. In a childhood episode, Mia hears an ambulance when she is out with a friend and immediately rushes home – the sound makes her fear for her mother. We follow the panic, the running, and Mia wondering what it will look like if her mother is dead (see fig. 4). The apartment isempty, and when the mother comes home, Mia hugs her hard. For a second, she can return to being the child, to be comforted by the mother – an illustration of how the protagonist oscillates between the roles of daughter and caregiver (Tillman 2020: 13–26). Later, she tells a friend that she feels it will be her fault if the mother dies (Tillman 2020: 119). The persistent imagining of the loved one being dead makes both Mia and the mother in *Natten* insist on their constant movement and search.

Figure 4. Mia running up the stairs in search of her mother after hearing an ambulance (Tillman 2020: 23).

One way this is shown is through the concept of ***the round***. Making a round entails repetitive searching and checking. As Mia searches the most likely places her mother can be, one checkbox is visible in each frame, and she finally, checking

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[22] Swedish original: "Du är någonstans i ett eller annat akut tillstånd eller inte, jag har inget sätt att få veta, *tyvärr kan jag inte svara just nu*. Jag tänker på Schrödingers katt. […] innan lådan öppnas är katten teoretiskt sett både död och levande samtidigt".

the same pub for a second time, finds her mother (see fig. 5). Gordan's narrator repeats her rounds almost like a mantra, every description of the repetition similarly phrased. She checks off her list both by making physical visits and by calling the same numbers over and over again:

> *I have called you a hundred times, I have called all your friends, I have sent angry, loving, threatening, and begging texts. I have talked to the field assistants, the after-school teen centers, the police and various emergency services, your photo is distributed to the employees in all the subway stations.* (Gordan 2022: 8)[23]

Figure 5. Mia making her round in search of the mother (Tillman 2020: 169).

Not only is the search portrayed as repetition in *Natten*. Further, repetition is shown to structure every activity of caregiving performed by the mother. Looking back at her earlier life, a similar repetition – parental caregiving interlaced with a large dose of medical caregiving – is presented:

> *Every afternoon, collect you at daycare, prick your finger, make dinner, dinner insulin, evening activities (bathtub, somersaults in the living room, different fairy tales), prick your finger, supplement with food or extra insulin, heart medicine, put you to bed, go out on the balcony, breathe. […] Put on an alarm in the night, wake up, prick your finger, give banana or extra insulin, morning again.* (Gordan 2022: 72)[24]

The desperate care is shown as a heightened version of the previous parental care – akin but intensified, twisted. Caregiving at the limit is a subset of what DeFalco calls "para-ordinary care", adjacent to the ordinary, but so demanding

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[23] Swedish original: "Jag har ringt dig hundra gånger, jag har ringt alla dina vänner, jag har skickat arga, kärleksfulla, hotfulla och bedjande sms. Jag har pratat med fältassistenterna, fritidsgårdarna, polisen och olika jourinstanser, ditt foto är distribuerat till personalen på alla tunnelbanestationer."

[24] Swedish original: "Varje eftermiddag, hämta er på dagis, ta stick, laga middag, middagsinsulin, kvällsaktiviteter (badkar, kullerbyttor i vardagsrummet, olika sagor), ta stick, komplettera med mat eller extra insulin, hjärtmedicin, natta er, ställa mig på balkongen, andas. […] Ställa larm till natten, vakna, ta stick, ge banan eller extra insulin, morgon igen […]."

that it is not understood as "ordinary", despite being quite common (DeFalco 2016: 7). The mother's care depicted by Gordan is closer to the ordinary, while Tillman portrays a reversal of roles as the young child is forced to care for the parent. The everyday repetition of parental care, and the security created by it, is missing here, and Mia's everyday life – like the rat's in the prologue – is instead characterized by unpredictability and uncertainty. In both cases, the worry, responsibility, and repetition exceed ordinary caregiving and brings the caregiving at the limit into a mode of desperation. DeFalco argues that care shaped by extreme dependency "recall the interrelationality of identity regardless of ability" and "conjures the inevitability and necessity of care for all embodied subjects" (DeFalco 2016: 53). This argument also applies to desperate care, which in its urgent mode – and in the different forms that the two works portray – has elements that are relevant in ordinary caregiving situations as well.

Hyper attentiveness: A fine-tuned calibration towards the other

In desperate care, the worry is linked to what we identify as the second building block, attentiveness, or rather hyper attentiveness, towards the other. The protagonists are watchfully observing, ad- justing their own lives due to the worry about the other, evaluating every situation. This is something that can be understood both in terms of responsibility and control – and the two are not always easy to separate in situations of desperate care. This hyper attentiveness is a result of co-dependency: the protagonist's whole existence is dominated

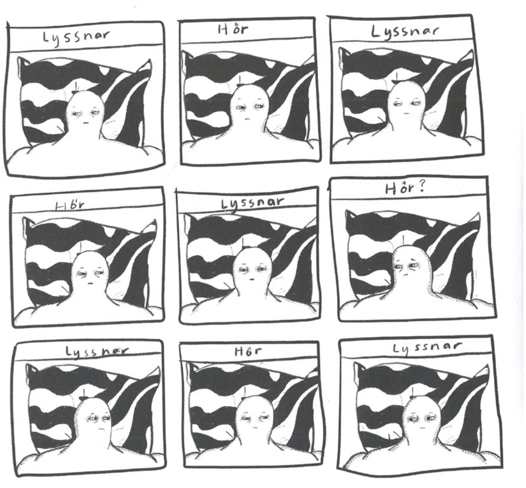

Figure 6. Mia lying in her bed, attentively listening after the mother. The caption switches between "listening" and "hearing" (Tillman 2020: 62).

by the sick family member.[25] The mother in *Natten* is setting her work and partly her other children aside, while Mia is afraid of moving out, fearing that her mother will not make it without her.

One example of this attentivness is Mia's listening from another room, afraid that she hears her mother drinking alcohol in the morning (Tillman 2020: 62–65). Mia's hyper attentiveness is portrayed by the juxtaposition of the words "listening" and "hearing" – two words ascribing slightly different meanings to the same activity (see fig. 6). The repetition of them over two spreads highlights the degree of Mia's attunement to listening to, guarding, and being there for the mother.

In Gordan's work, the mother is completely absorbed by watching out for the daughter: searching for her when she is away, looking for signs of flight when she is at home. No attention is left for anything else. About a dinner with friends, she writes:

> *Candles, low key conversations and mild laughter, often tjälknöl is served in these days between Christmas and New Year's Eve, but I have no memory of the food, the only thing I can think about is you. All of you children are here and I wander between the rooms like a shepherd dog, scared to death that you will run away* (Gordan 2022: 132–133)[26]

The shepherd dog, a variation on the metaphor of the watch dog, emphasizes the mother's guarding and observing presence. Her attentiveness and nigh-on absorption also dissolve the boundary between herself and the daughter. "What is the rest of the family doing? I do not know, I only have enough attention for you", she comments, and later adds: "[E]verything is about my daughter. When she feels better, I feel better. It is impossible to separate" (Gordan 2022: 47, 75).[27]

Gordan's mother cannot distinguish clearly between her own needs and the daughter's needs, defining everything by how it affects the daughter. Sometimes she mentions aspects of her own life like her work and writing, but the focus is incessantly on the daughter's well-being, life, and breathing.

Mia's well-being, or rather lack thereof, is also closely tied to her mother's. In one light-hearted episode, the mother tries to hand her a hamburger dressing, but it ends up in the potted plant instead. Despite the relative happiness of the

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[25] Cf. Nesby, who notes that in curographies, the healthy narrator's body is calibrated after the ill person's body. Nesby (2023: 220).

[26] Swedish original: "Levande ljus, lågmälda samtal och milda skratt, ofta serveras tjälknöl vid de här mellandagstillfällena men jag har inget minne av maten, allt jag kan tänka på är dig. Alla ni barn är med och jag irrar mellan rummen som en vallhund, livrädd att du ska dra".

[27] Swedish original: "Vad gör resten av familjen? Jag vet inte, min uppmärksamhet räcker bara till dig". "[A]llt handlar om min dotter. När hon mår bättre, mår jag bättre. Det går inte att skilja åt".

episode, which ends with them laughing together, Mia cannot allow herself to laugh until observing her mother laughing (Tillman 202a: 56–57). As Mia grows, she tries to emancipate herself. She moves out, and she does not always answer her mother's phone calls. But despite this, Mia's subjectivity remains dominated by the mother: ever present in repeated texts and phone calls where she seeks Mia to comfort her loneliness and in Mia's constant worry (see fig. 7).

Figure 7. Mia comforting her mother over the phone (Tillman 2020: 138).

The protagonists in the two stories thus continue to exist primarily in relation to the care recipient. Only secondarily do they exist in their own right. Discussing the construction of different selves in relation to caregiving, Eva Kittay highlights what she calls the idea of a *transparent self*, "a self through whom the needs of another are discerned, a self that, when it looks to gauge its own needs, sees first the needs of another" (Kittay 1999: 51). This idea is productive when considering the protagonists of the two stories, who in many ways see the needs of another first. At the same time, their selves are not transparent (i.e. invisible), rather the construction of their subjectivity is highly visible and messily intertwined with the care recipients'.

Unsuccessful care and the turn to institutions

The foregrounding of the mother-daughter pair in the two narratives underscores the intimate relationality of the desperate caregiving and places it within the context of family. This, however, is only part of the story. In a discussion on the ethics of care, Joan Tronto points out that care is never only dyadic or individualistic. Care encompasses much more than the emblematic caring of a mother for a child, and a focus on that relationship risks leading to a romanticization of care (Tronto 1993: 103). Even as depictions of dyadic care and mother-daughter relationships takes the centerstage in these narratives, there is nothing romantic or idealistic about the care performed. Furthermore, in the end, it is not successful, and the narratives show how this dyad cannot fulfil care on their own.

Both narratives are set in Sweden, a Nordic welfare state where a societal structure of institutions and social networks can offer help. In both works, the possibility to turn to these welfare institutions is shown as ethically ambivalent. It is simultaneously portrayed as a last resort and a rescue, as a way of giving up and asking for help when the next of kin caregiving is rendered impossible, and as a form of betrayal.

In Mia's case, reaching out to someone outside of the mother-daughter dyad is a difficult choice. She seems to have had no contact with any help before and has rather protected her mother from being spotted by others. When she, in the end, decides to contact the authorities, it is in the form of "the crisis team" (Tillman 2020a: 177).[28] On a single page, we see her call for help. The shrinking lettering, the unfinished sentence, and the way it continues through all the frames underscores Mia's hesitation: she can hardly bring herself to say the words (see fig. 8).

Figure 8. Mia calling the crisis team at the end of the graphic novel (Tillman 2020: 177).

When the police and the social workers arrive, we see them stand behind Mia as support while she is still in the foreground: she has brought these representatives of society into the home. The drawings of the mother's face are dissolved in a previously unprecedented way, and the same goes for the lettering in her speech bubbles (see fig. 9). Mia, in contrast, still looks very much like a child. Contrary to the mother's features, hers are still small, as are the lettering in her speech bubbles. The controlled depiction of her is a stark contrast to the disarray of the mother, but Mia is not portrayed as empowered, but as insecure and guilty.

In *Natten*, the societal help has always been there, through the mother's contacts with different teams and care institutions. Field assistants, after school teen centers, police, social service's emergency unit, hospitals – a whole range of helping community bodies have been invoked and contacted. Still, this does not work.

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[28] Swedish original: "Kristeamet".

Figure 9. Mia, the mother, and the crisis team. Note the mother's highly dissolved state (Tillman 2020: 185).

Here, the turn to the institution will instead result in the daughter becoming institutionalized – not just helped, but taken away, because the family is afraid that she might otherwise die. While the daughter is away, the mother on one hand feels lost without her, and on the other manages to slowly come back to her own life and work. In the end, a therapist helps to structure the care within the home, but she also emphasizes that the mother's action was a form of betrayal: even if it was to save her daughter's life, "it was still an abandonment" (Gordan 2022: 168).[29]

In both works, the turn to the institutions of society is thus portrayed as necessary but also as ambivalent for the characters - at the same time a betrayal and a lifesaving rescue, though in *En trasig historia* it is possibly as much a rescue of Mia as it is of the mother. For the mother in *Natten*, turning to the institutions means relinquishing part of her responsibility, whereas Mia needs to give up the whole responsibility and break the caregiving bond. The turn to the institutions also breaks up the dyadic structures and highlights their insufficiencies. Even though the institutions are not perfect, they are portrayed as the better choice when compared to the desperate care that has dominated the narratives up to this point.

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[29] Swedish original: ”det var ändå att överge.”

Aftermath: the (im)possibility of reconciliation

The turn to the institutions entails a breaking point in the caregiving relations in both works. What can be seen as a necessary betrayal has different repercussions for the two protagonists.

In *Natten*, the break offers a chance to find a new kind of relationship between mother and daughter. The narrator shows that in a close future – written as a prolepsis at the end – there is a prospect of reconciliation, where the daughter is a young adult and they both take their part of the blame. Gordan allows for the perspectives to not fully align, but without rivalry between them – she simply allows the story in its messiness to exist as it is. "Much later all this will be forgotten", she points out: "Much later all this will be over, I promise, and the only thing that remains is the story. And you will say, mummy, that was not the way it was, and I will answer, no, not for you" (Gordan 2022: 168).[30] This acceptance of the different stories may be the final proof that the mother has learned to, at least to some extent, hand over the agency to the daughter.

Another expression of the reconciliation is when the narrator clearly takes on the adult responsibility while they both scrutinize themselves, but the daughter replies: "I think we both did wacky things" (Gordan 2022: 174).[31] In all its

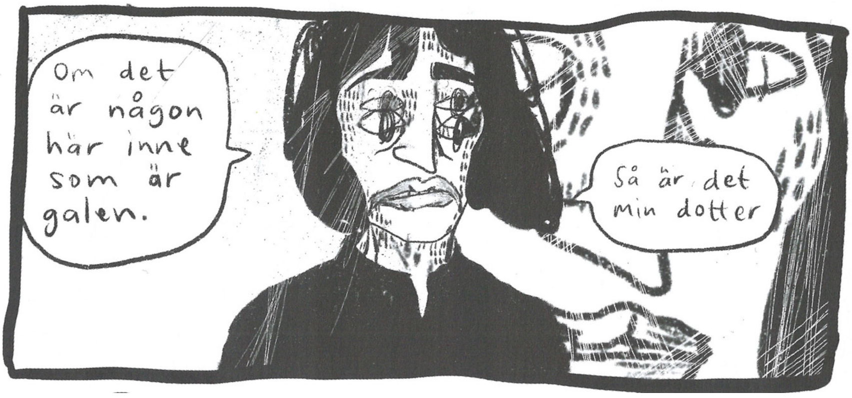

Figure 10. The mother calling Mia crazy. "If there's anyone in here who's crazy, it's my daughter" (Tillman 2020: 188).

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[30] Swedish original: "Långt senare ska allt det här vara glömt. (…) Långt senare ska det här vara över, jag lovar, och allt som finns kvar är berättelsen. Och du ska säga, mamma, det var inte så där det var, och jag ska svara, nej, inte för dig".

[31] Swedish original: "jag tycker att vi båda två gjorde knäppa saker". Cf. earlier when the mother notes about herself that she has been "a little crazy, or the mother from hell"; Swedish original: "Lite crazy, eller, morsan från helvetet" (Gordan 2020: 146).

simplicity, this summarizes the complicated repelling and attracting between the two main characters – as doing "wacky things". A hopeful and conciliatory view on their relationship, even the most difficult parts of it.

In Tillman's work, there is no reconciliation, no meeting beyond the disintegration of the caregiving bond between mother and daughter. The mother tries to brand her daughter as the crazy one to the policeman: "If there's anyone in here who's crazy, it's my daughter. She's really fucking crazy. If anyone should be locked up, it's her!" (See fig. 10. Tillman 2020: 188).[32]

From the mother's point of view, the turn to the authorities is a betrayal, even though it is ultimately a result of her initial failure to fulfil the parenting role. In the very last panel of the fragmented chronological story, Mia stands alone, framed as if by a spotlight (see fig. 11). She still has the same small facial features, her neutrally set mouth subtly betraying her sadness. Throughout the story, she has moved out and started her own adult life, but there is still not room for her to be grown, have strong emotions, and be her own person.

The narrative does not end here. This final disaster is followed by an earlier memory, where the mother makes a joke – the same joke as she makes in the first episode – that Mia as a small child does not understand. The very last panel has the exchange: "What do you mean, mommy?" "Yes, what do I mean, Mia" (Tillman 2020: 191).[33] This could possibly be seen as a way of softening the end, but most acutely, it emphasizes the lack of understanding between mother and

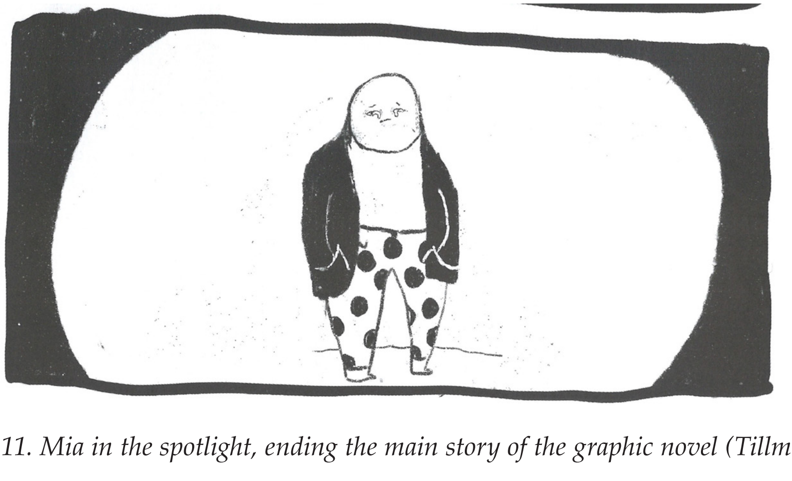

Figure 11. Mia in the spotlight, ending the main story of the graphic novel (Tillman 2020: 189).

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[32] Swedish original: "Om det är någon här inne som är galen. Så är det min dotter. Riktigt jävla galen är hon. Om det är någon som ska spärras in så är det hon!"

[33] Swedish original: "Vad menar du, mamma?" "Ja, vad menar jag, Mia."

daughter. The mother talks over Mia's head, and the enigma of the mother takes the central stage. The braiding of the first episode and the last creates a sense of repetition and circularity: has anything changed at all? There is no real contact in this epilogue – the mother does not meet her daughter's eyes, the daughter poses a question she does not get an answer to, as it is only answered by another question.

The mother in *Natten* finds a way to hand over some of the responsibility to her daughter and tone down her caregiver role, strengthening the mother-daughter relationship. The position of caregiver can be rehabilitated as a functioning part of everyday life, and the relationship returns to more normal parental care. In *En trasig historia*, this is not possible. Mia's toning down the caregiver relationship can only happen by handing over responsibility to the authorities. The only act of care possible – both with regards to the mother and to Mia herself – is to turn to the institutions of the welfare state. There may not be reconciliation, but in a sense, Mia learns to care not only for her mother but also for herself.

Concluding remarks: The ethics of narrating desperate care

Through the analysis of the narration and practices of desperate care in *Natten* and *En trasig historia*, we have shown how both the narration and the building blocks of care underscore the desperation, the strong interdependency and responsibility, and the dyadic construction of subjectivity at play in these works. To further the discussion theoretically, we want to consider the ethical questions raised by these kinds of messily relational, auto/biographical narratives of desperate care.

Both Gordan and Tillman address ethical questions posed by these kinds of narratives. What happens when I cannot tell my own story without, to some extent, telling that of another? The metafictional reflections in *Natten* address the question of authenticity and perspective. The narrator emphasizes that the story would look different from the daughter's perspective. In an interview, Gordan has also stated that all family members have approved the story before publication (Andersson 2023). Similarly, Tillman has addressed the issue on her blog, where she writes about the hesitation to narrate her experiences, "when my life has been so completely influenced by somebody else". She emphasizes that this poses an ethical conundrum: her mother does not want to be exposed, but if she cannot tell her mother's story, that would result in "her then owning my story" (Tillman

2021b).[34] Both Gordan and Tillman have also chosen to label their stories as a novel and graphic novel respectively, avoiding the stronger truth claim of the out-right autobiography. From this perspective, auto/biographies of desperate care can be considered as ethically challenging, running the risk of imposing on the story of another whilst telling one's own.

Without disregarding this perspective, we want to suggest that these works also invite a somewhat different discussion on ethics: of narration as a way of amending desperation and as an ethical care practice in itself. One fundamental similarity between *Natten* and *En trasig historia* is that 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. Their life stories become "irrevocably intertwined, interdependent and mutually constitutive" (DeFalco 2016: 53). From a feminist standpoint, Kelly Oliver re-evaluates dependence, often thought of as opposed to autonomy, as a necessary condition for subjectivity. She emphasizes the formation of subjectivity as dialogical, shaped both by one's contextually situated subject position and by responding to and addressing others and, through self-reflexivity, oneself. "Subjectivity, in fact, is responsibility, respons-ability, and ethical responsibility" (Oliver 2002: 327).[35] In the works of Gordan and Tillman, the dialogical process of responsibility and the formations of subjectivity are warped in two main ways. Firstly, one other – the care recipient – takes precedence over all others in shaping the protagonist's subjectivities. Caught up in a dyad of desperate care, through worry and hyper attentiveness, they respond (or try to respond) only to the other half of the dyad, not to any others or to themselves. Speaking on a societal level, Oliver points out that one's subject position can limit the sense of subjective agency (Oliver 2002: 326–327).[36] Here, we primarily view this limitation in the context of family; the subject position as next of kin can, in these narratives, be described as a factor that limits the protagonist's subjective sense of agency.

Secondly, the response-ability in these works becomes lopsided, aimed mainly one way, from caregiver to recipient. The position as next of kin is reinforced by the desperate mode of the care that the protagonists perform. Oliver uses the term

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[34] Swedish original: "Jag har tänk mycket på det här att berätta vad jag varit med om. Hur gör man det på ett okej sätt när mitt liv har varit så totalt influerad av någon annan?" and "Att hon då äger min historia".

[35] Cf. Tronto 1993: 127 on attentiveness, responsibility, competence, and responsiveness as the four ethical elements of care.

[36] On this societal level, Oliver talks about subject positions as oppressed or marginalized in the dominant culture, for example by race or gender.

affective attunement to describe the processual ability to respond and attune to others' signals and affective energy (Oliver 2002: 329). What happens in these works can, with this framework, be described as a circulation of desperation. The daughter desperately tries to break free in *Natten*; in *En trasig historia* the unpredictable mother desperately calls on her daughter for comfort whilst simultaneously evading the care. Lacking other kinds of response from the care recipients, the caregivers attune to the affect of desperation, to the motor – in Gordan's phrasing – being "in full gear and headed towards the precipice" (Gordan 2022: 12).

Oliver emphasizes that at the heart of subjectivity is the ethical obligation to promote the health and well-being of others through "loving attention" (Oliver 2002: 330). With the subject position as next of kin limiting agency, and the lopsidedness in responsibility and respons-ability, the loving attention in these works is overshadowed by desperate, urgent and anxious attention. The promotion of the other's well-being is both unsuccessful and excessive, and the protagonists fail to address and respond to themselves. Both the turn to institutions and the decision to narrate their stories can be described as attempts to remedy the ethical deficiency born out of desperate care – attempts that in the works have different resolutions, demonstrating the breadth of the concept. In both narratives, turning to the authorities is a way of breaking up the dyadic dynamic and the circulation of desperation. Likewise, the narration itself constitutes a new way of responding – both to the care recipient beyond the mode of desperation and to oneself.

In the end, however, these narratives do not promote an illusionistic ideal of autonomous, independent subjects (cf. Feder & Kittay 2002: 4–5). Rather, breaking up the desperate, dyadic dynamic between mother and daughter enables constructions of subjectivity within a wider social context: the mother in *Natten* is able to respond to the rest of the family and to her work, and Mia no longer responds only to her mother. Thus, breaking up the dyadic dynamic is not a rejection of dependency, but makes less destructive dependencies and a plurality of responses possible.

The self-reflexivity lost in desperate care is also regained through the act of narration, used as a practice of care for the self, especially the past self: Tillman retrospectively cares for herself as a child; Gordan remains faithful to the desperate mother. Arthur Kleinman writes that care does not stop with death; it continues in the caring for the memories (Kleinman 2019: 3). In a parallel way, these stories show how desperate care continues even after the relationship has been transformed, through either normalization, as in *Natten*, or a break, as in *En trasig historia*. When it continues as narration, the care performed is no longer desperate but takes the shape of stories of desperate times.

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Originalartikel

"To be able to live among the dead"

On empathetic images of death and dying in Harald Voetmann's *Amduat. An Oxygen Machine*

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The Danish author Harald Voetmann's father died at an old age of pneumonia at the regional hospital; shortly thereafter, the author published a book with printed handwriting as an epitaph to his father with the title Amduat. An Oxygen Machine. *In ancient Egypt, the Amduat was a night journey of twelve hours in the afterlife of a pharaoh accompanied by the sun god. Voetmann uses this old mythology as a palimpsest for his representation of the last hours of his father's life in the hospital. Death is and has always been a condition of human life; what has changed in the history of modern medicine is the way health care is delivered to dying patients. I read* Amduat. An Oxygen Machine *as an attempt to restore the dignity of his father's life in a medical setting. The handwritten texts are often parodic in style rather than pathetic, even though the subject matter is deeply emotional, and the author's advanced use of form invites a complex way of attaining empathic identification. The book is a significant contribution to the growing body of literary illness narratives dedicated to the next-of-kin perspective.*

Writing of loss in an advanced form and as a ritual

In her classic book *On Death and Dying* (1969), medical doctor Elisabeth Kübler-Ross reminds us that death is and has always been a condition of human life; what has changed in the history of modern medicine is the way health care is delivered to dying patients. When people die in the hospital instead of at home, they often suffer as a result of medical treatment aimed at prolonging life rather than increasing comfort. As an important supplement to case studies like Kübler-Ross' qualitative interviews, literature can offer imaginative stories about death and dying that represent experiences and at the same time create a reality in the reader. Narrative medicine argues that literature creates the empathetic conditions for a deeper understanding of research findings from medical case studies and interviews (Charon 2001, Goyal et al. 2008). An interdisciplinary approach that combines ethnographic fieldwork and literary analysis is needed to improve the care of dying patients in hospitals.

Apart from a few noticeable exceptions in literary fiction, among them Lev Tolstoy's short novel *The Death of Ivan Ilyich* (1886), the process of dying is described in the mode of fictionalized autobiography by a next-of-kin figure. The Danish author Harald Voetmann (b. 1978) published a literary work on his father's death entitled *Amduat. En iltmaskine* (2018, Amduat. An Oxygen Machine) whose aesthetic features are unparalleled in Danish literature. Before illuminating the stylistic, formal and intertextual singularity of this book, I will contextualize the book's affiliation to literary stories about illness and thereafter compare the explicit intention of the book with the typical expectations of such literature. Key words for my initial characterization of this rare book are parody in style instead of pathos and writing as a ritual instead of a therapeutic work.

Voetmann's *Amduat* can be categorized within the rapidly growing body of literature of what Anne Hunsaker Hawkins (1998) labelled "literary pathographies", in recent years extended by next-of-kin literature as studied by Amalie DeFalco (2023). At a thematic level, Voetmann writes about his father's death from pneumonia in the hospital. In Danish literature, literary texts about the death of a relative, often a parent's death, yet sometimes also the loss of a child or partner, have been published by well-established authors such as Pia Tafdrup (2006), Peer Hultberg (2009), Naja Marie Aidt (2017), Helle Helle (2018), and most recently Madame Nielsen (2022). Voetmann's book deals with a death that was expected – and relatively undramatic from a clinical perspective – as the father passed away at an old age at the regional hospital in Holbæk with family members around him. In this case, the family members are three sons, Harald Voetmann being one of them.

In order to understand Voetmann's unusual choice of parodic style and narrative features, I find it illuminating to compare him with Roland Barthes, who wrote about the death of his old mother at their home in 1977; the mother died peacefully. The day after his mother's death, Barthes began a diary that he continued for almost two years; however, the writing was presumably never intended for publication. The title of his daily notes was *The Mourning Diary*. Barthes' mother had lived with him throughout his adulthood, and consequently her death – the loss of his closest confidant and friend – had a destabilizing effect on his life. As his mourning progresses, Barthes slowly learns to live by himself without his mother's presence and to cope with the complete loneliness he feels, despite the sympathy of those around him. Occasionally, he contemplates his own imminent death in the diary:

> *To think, to know that maman is dead* forever, completely*, is to think, letter by letter, that I too will die* forever *and* completely*. There is then, in mourning, a radical and new domestication of death; for previously, it was only a borrowed knowledge, but now it is* my *knowledge. It can* hardly *do me any more harm than my mourning.* (Barthes 2011, p. 119)

As is widely known, Barthes was a pioneering figure of French structuralist and narrative theory, and his more general reflections on the structure of language and the discourse of dying in literature reverberate through the otherwise personal diary.

Compared to Voetmann's *Amduat*, also a kind of diary, yet much more complex in form, Barthes' style is pathetic, whereas Voetmann uses parody as a rhetorical figure when describing his father. The subtitle, *An Oxygen Machine*, even indicates a satiric distance to the modern highly technological hospital as the oxygen "mask" is exchanged for a "machine" which is associated with the dehumanized medical industry. The concepts of parody and satire will be defined in the following. One more aspect differentiates Voetmann from Barthes' and the typical autobiographical mode of pathography writing. The "I" narrator is often the son sitting at the bedside, but sometimes the "I" narrator is the father dying of pneumonia; a sudden shift which creates an intended confusion in the reader. A confusion that mirrors the confusion and bewilderment in the old, dying father. This dynamic of utterance position is a narrative feature that, according to Dorrit Cohn (1999), draws an autobiographical text into the realm of fiction.

Writing about a relative's death has presumably been therapeutic for many authors in next-of-kin literature. Arthur W. Frank's argument in his book *King Lear: Shakespeare's Dark Consolations* (2022) is that everyone who suffers has a need not only to tell, but also to hear stories about a suffering that are not theirs. He introduces the methodological concept of a "vulnerable reader" as a supplement to his famous "wounded storyteller", introduced in the book of that title from the 1990s: "The figure whom I call the vulnerable reader is another side of the wounded storyteller; to be one requires being the other" (Frank 2022, p. 3). Frank's primary reason for presenting a so-called vulnerable reading of Shakespeare's classical drama *King Lear* was the expected death of his own father – and his relation to his two daughters is also touched upon. *King Lear* is a family tragedy centered around an old father and his three grown-up daughters. Frank is quite explicit about this personal context in his presentation of the reading strategy and the chosen work of literature: "Vulnerable reading most often begins by seeing how a story mirrors our own suffering" (ibid., p. 6). This is indeed a risky strategy of reading: if a vulnerable reading only centers on this mirroring of one's own suffering, it risks becoming a narcissistic project. On the other hand, reading a literary text as if it does not on any level mirror one's own life represents the kind of academic detachment that Rita Felski (2020) and others have criticized in recent years. Inspired by Frank and Felski, I will present a "vulnerable" and an "attached" reading in the following and discuss this new strategy of reading.

The idea of literature's therapeutic power is dominant in the growing field of bibliotherapy and expressive writing, as introduced in the Nordic region by, for example, Cecilia Petterson (2020) and the edited volume *Skrivning og sundhed* (2021, Writing and Health). Yet, in contrast to the therapeutic use of literature, exemplified by Frank's reading of *King Lear* and by Barthes' writing a diary in the wake of his mother's death, Voetmann's intention is explicitly non-therapeutic. If therapy involves repeatedly returning to a wound to heal it, a ritual aims to move on from the loss once and for all. In a public speech, quoted in a newspaper article, Voetmann stated the following intention with his *Amduat*:

> *The book should be a ritual that is completed. I do not write to achieve catharsis or get rid of something. Several of my books have been written during depressive periods, where I was brooding over something and couldn't move on until the form was completed and the work was created. So perhaps it is rather the opposite of therapy: the work contributes to creating problems for me.* (Voetmann in Turner 2018)[1]

Rather atypically for next-of-kin literature and in contrast to bibliotherapy and expressive writing, Voetmann seems skeptical towards the idea that he as an author can achieve a therapeutic purification of uncomfortable emotions through

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[1] 1. Quotes by Harald Voetmann in the newspaper article and from *Amduat. En iltmaskine* were translated from Danish to English by Anders Juhl Rasmussen.

the creative process. By his own admission, he did not write the *Amduat* to ease his sorrow over losing his father; rather, his act of writing is explained as constituting what anthropological theorists since Victor Turner have called a ritual (Turner 1969). The meaning of a ritual – a well-known practice in various religions and cultures – signifies a transition from one stage in life to another. Voetmann has come to terms with this transition and his loss through the ritual of writing the book. All the texts printed in the *Amduat* are written by hand in what appears to be a first draft, so writing every single page in the book may have taken on the character of a ritual. Consequently, Voetmann mentions in the same above-quoted speech that he does not intend to read the book aloud more than once.

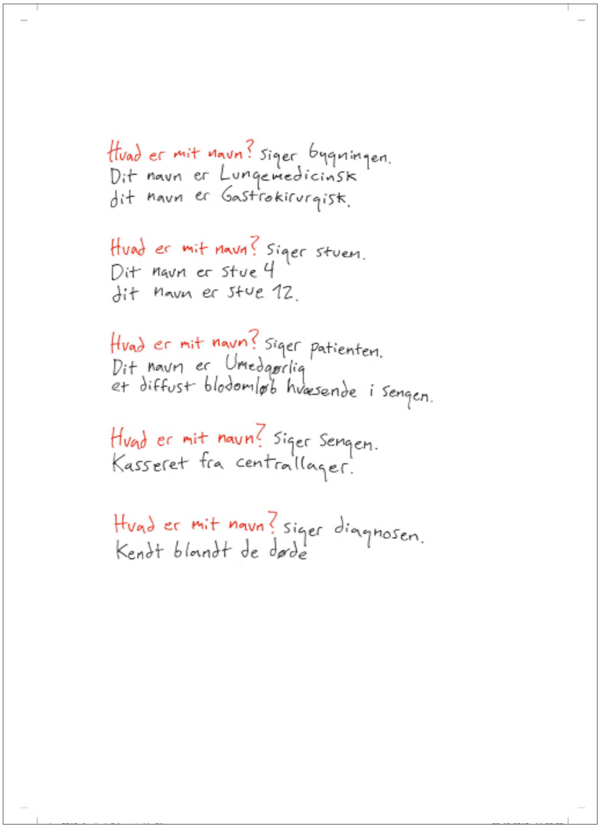
The ritualized conception of artwork can be contrasted to Sigmund Freud's idea of therapy, where through repeated conversations, the patient reveals a hidden trauma. Having outlined the indisputable differences between therapy and ritual, one could argue that the contrast in attitudes between Frank and Voetmann towards the purpose of next-of-kin literature is not a strict dichotomy. In his explanation of why reading Shakespeare can be helpful on a personal level, Frank prefers the metaphor of literature as a "companion", echoing literary critic Wayne C. Booth that: "Good companions do more than commiserate; they complicate who we think we are" (Frank 2022, p. 7). As we can see from the quote above, Voetmann's attitude is not very different: "the work contributes to creating problems for me".

The merged stories of dying in present-day Denmark and ancient Egypt

Against this background, I will turn to the formal and intertextual singularity of Harald Voetmann's book. The author adds two elements to his otherwise rather ordinary story of loss in *Amduat* that makes the project truly unique, and these elements are closely connected. Firstly, he places his father's death in the highly technological hospital within a historical framework of the Egyptian burial chamber, where all pharaohs were buried 5,000-8,000 years ago. In such burial chambers, signs and images depicted the story of an underground journey through the realm of the dead towards the so-called "heart weighing", where it would be decided if the pharaoh could have eternal life or not. If the pharaoh's conscience was clear, meaning the heart was as light as a feather, then access to eternity was granted. According to one myth, called the Egyptian Amduat (Apt and Hornung, 2007), the journey in the underworld towards the heart weighing took twelve hours from sunset to sunrise. Hour by hour, the pharaoh encounters enemies and helpers, monsters and gods, in the company of the sun god Ra. It is the god's task to safely transport the pharaoh to the heart weighing, which is the ultimate trial. Similarly, in his *Amduat*, Voetmann provides a description of his father's final hours, alternating between the fictional space of a burial chamber with depictions of Egyptian gods and a technological hospital room with modern medical equipment and physicians doing their rounds.

The author adds another element to this intertextual description of the hospital room as a burial chamber in that the book's 99 short one-page texts are written by hand. In addition, the book cover is a drawing depicting Egyptian gods as in a burial chamber, but partly transformed into a modern hospital setting. Only the colophon page at the very end of the book is typewritten. Occasionally, it is possible to encounter books in contemporary literature where handwritten fonts are simulated in machine-produced typography. In Voetmann's case, however, the handwriting is no illusion, and its authenticity is revealed by the fact that the font varies in size, appearance, and inclination, which is common for handwriting. Voetmann thereby creates a hybrid between the machine-distributed handwriting as used in contemporary graphic novels and the manuscript culture of actual handwriting on paper found in modern literary archives.

The choice to incorporate Egyptian mythology as a historical framework for the death of Voetmann's father and the decision to have his own handwriting printed in a book are apparently closely related. On the walls of Egyptian burial chambers, the story of the pharaoh and the sun god's journey through the underworld was engraved on the chamber's four walls. Voetmann's handwriting can thus be interpreted as an engraving on paper, or better, an inscription. The book's handwritten pages – the inscriptions – are consequently not numbered with page numbers. Back then, there were no other writing tools; today, authors have many options, yet there is probably no instrument so closely connected to the living human body as handwriting. The Egyptians often left headings in red and generally wrote with black, a graphic variation also know from medieval manuscripts in Europe. Voetmann adopts this principle, with the headings written in red, while the texts are written with a black pen (Illustration 1: see below).



Hvad er mit navn? siger bygningen.
Dit navn er Lungemedicinsk
dit navn er Gastrokirurgisk.

Hvad er mit navn? siger stuen.
Dit navn er stue 4
dit navn er stue 12.

Hvad er mit navn? siger patienten.
Dit navn er Umedgørlig
et diffust blodomløb hvæsende i sengen.

Hvad er mit navn? siger Sengen.
Kasseret fra centrallager.

Hvad er mit navn? siger diagnosen.
Kendt blandt de døde

Illustration 1. A handwritten page in two colors from the book.

The Egyptian Amduat can be traced back to Thutmose III's tomb in the Valley of the Kings. Later the Egyptologists began to transcribe and copy it, and much later, it was portrayed in translated publications like *The Egyptian Amduat. The Book of the Hidden Chamber* (2007). Likewise, the reader of Voetmann's *Amduat* gets an intimate sense of reading something that could have been written in the hospital room by a son in the final days and hours of his father's life. With its narrative of the journey through the underworld and a father's death, Voetmann highlights the temporal organization of a process that involves past, present, and future. Simultaneously, the author makes use of the spatial aspect by outlining the burial chamber in a drawing printed on the opposite page to the table of contents. The twelve-hour journey through the underworld is told chronologically in the Egyptian Amduat, but Voetmann's drawing of the burial chamber as a space and the non-linear story told in the 99 short texts produces a fragmented experience of chronology and a narrative plot.

What I have attempted to describe here is succinctly explained by the author on the back of the book cover in simple words addressed to the reader (first sentence) and the father (second sentence):

> *When my father died, I was reminded of the period after my mother's death, when he took me on a journey to Egypt. I thought, well, when you also are dying now, and if I cannot help you, I will take you to Egypt.*

Obviously, the book is meant as an epitaph to the father. On the book's title page, the author makes another brief statement about the two, merged narratives in the form of a poem:

The journey of the Sun through
the underworld's countries
as described in
Tuthmosis III's tomb
in the Valley of the Kings
and father's death at Holbæk
hospital

These merged stories from ancient Egypt and the present remind me of Kübler-Ross's conclusion in her famous book that death is and has always been a condition of human life. Here, the Egyptian gods have been replaced by physicians administering medication and using advanced technology: religiosity has been replaced by science. Yet, the intimate relationship between a dying father and a grieving son is unchanged and part of the human condition.

Parodic style and genre hybridity

As touched upon in my comparison with Barthes' mourning diary, Voetmann's *Amduat* is unusual in that it portrays the loss of a beloved father through the style of parody, i.e. exaggeration and distortion of the usually sincere discourse of pathographies. Most, if not all, literary works on the suffering and death of relatives that I know of are characterized by pathos, seeking the reader's compassion through identification with their own grief. No one loses a beloved family member without mourning, and Voetmann presumably does not mourn any less than does, for example, Barthes over the loss of a parent. As already stated, his book is an attempt to restore the dignity of his father's life in the medical, dehumanized setting.

However, since his debut novel, Voetmann has explored parody and satire as stylistic devices, and he recently translated the old Roman satirical poets *Sulpicia* (2016) and *Juvenal* (2020). He obviously finds the parodic modus and the moral satire more fitting than sincerity and pathos to present the deeply personal emotions affiliated with his own father's death. The Greek *parodia* means "counter-song" and is often understood as ridiculing a background text or discourse. Linda Hutcheon's has clarified the concept, and in her account the modern use of parody does not necessarily aim at ridicule, whereas satire is decidedly moral in its intent (1978). In my view, Voetmann's *Amduat* is a parody of the sincere pathography discourse, the "mourning" diaries, and satirical towards a medical system that fails to meet the fundamental need for dignity.

An excerpt from the book's table of contents can illustrate Voetmann's exaggerated and distorted style. When mastered, this parodic style evokes bodily reactions of laughter and tears at the same time:

> *"She who smashes the foreheads of the sun's enemies"*
>
> *"She who repels the evil and slaughters Dreadface"*
>
> *"The furious one who slaughters him-with-the-low-heart"*

"Smashes the foreheads", "slaughters" and "the furious" are hyperbolic adjectives describing the battle between good and evil, and this reference to the perilous journey in the ancient afterworld is obviously in complete contrast to the final quiet hours of the father's life in a modern hospital. As a further example of this, a nurse carefully massages cream into his father's nose, but the scene is parodically represented with labelling the nose a "bill", and for variation "the hawk's bill" (p. 41). From a modern point of view, the Egyptian Amduat uses the same kind of distortion: the many animal-like monsters encountered by the pharaoh and the sun god in their journey are strange, distorted figures, such as humans with animal heads, for example Anubis with his jackal head. Parody of the sincere pathography discourse is for Voetmann also an imitation of the Egyptian Amduat. Furthermore, a dialogue in Voetmann's book between his father and a nurse about dinner is witnessed by the son and recounted like an absurd comedy: (father) "I want sausage on bread", (nurse) "You can have potato soup" (father to son) "Must I have sausage soup? Why must I have sausage soup?" (p. 53).

A final aspect of the book's formal exceptionalities is the blend of formal genres. Here the three major literary genres, epic, dramatic, and lyrical, are mixed in the book as a whole and even in the individual texts. The first text in the book, starting with the question "Where are you?" and continuing with the answer "I am at home", fits nicely into the dramatic genre. Presumably, it's the son who asks, and the father who answers. The son continues: “You are not at home”. Later someone asks the question, “Where am I?”, which in fact could come from either the son or the father. It is a parodic dialogue spanning four pages, addressing the question of where the father is located: in his own fuzzy perception of where he is and in the son’s equally disturbed perception of the situation. The death of his father is an unreal experience for the son. Thematically, it introduces the notion that the father is no longer in his home but in a hospital, bedridden, confused, and bewildered, and the son is together with him in an imaginary world as well as in reality. Being “at home” for a dying patient and his relative can also mean finding rest in death. In this sense, the father is not at home in this first text, as the book is an imaginary journey undertaken by father and son through the twelve hours of afterlife until permanent rest is found.

If the first text is a dramatic, rather absurd dialogue printed on the page as a poem, then the next text, entitled (in red pen): “To be able to die among the living”, is an epic text that begins:

> *In the time after his death, Dad kept getting up from the grave. He couldn’t grasp that he was dead and had to stay lying down. Just as he had lacked awareness of his illness at times, he now lacked awareness of death.* (p. 5)

It is clearly a grotesque description of unnatural conditions: if the father is dead, he cannot literally get up from the grave, again and again! Awareness of illness is a commonly used medical term, and physicians often recognize a lack of awareness of illness in patients when entering the terminal phase. The quoted metaphor “awareness of death” is Voetmann’s playful invention, and it probably means that it is the relatives, not the father, who have difficulty accepting the loss of their father. The text takes up no more than one page, and like the dramatic dialogue, it deals with the issue of finding rest, both for the dying person and for the relatives.

The third text in the book is lyrical and consists of some lines of verse, with each line written on a separate page. Thus, the following four pages of the book read as follows, with line breaks marked “/” and page breaks marked “//”:

> *A door is a knife //*
> *A knife is an hour //*
> *A door is a knife/a knife is an hour //*
> *A look is a wound/and a wound is a feather.* (p. 6-9)

The lyrical verses and short poems slowly build up from simple and seemingly unpoetic words, which, through their juxtaposition, take on poetic qualities. Read literally, the sentences make no sense. A door is *not* a knife, a knife is *not* an hour.

Symbolically, these verse lines point to the hospital room, time approaching the cessation of time for the father, the knife, as what can separate the father from his surroundings, the eye contact that still exists between them, the wound as a metonymy for death, and finally, the feather that could evoke associations to Egyptian mythology. As mentioned previously, the journey through the underworld ends with the weighing of the pharaoh's heart; if the heart is as light as a feather, access to eternity is granted.

This almost programmatic blending of genres in the first pages of Voetmann's *Amduat* could be perceived as a true *Gesamtkunstwerk* as the idea existed in German Romanticism around 1800, where Friedrich Schlegel in particular defined the visionary, romantic literature as a fusion of epic, dramatic, and lyrical genres (2014). The juxtaposition of dramatic, epic, and lyrical texts in Voetmann's book takes another turn when individual texts blend dramatic and epic, or epic and lyrical, elements within the same text. An example of an indeterminate dramatic and epic text is "Not to end in loneliness", where the son engages in a dialogue with his father in an epic form:

> *"Do you know where you are"? And the father answers "I am at home. I am at Bøgebakken". "No dad, you are in Holbæk Hospital. You have severe pneumonia. And you have probably had a stroke again." "Is it you", the father asks. "How nice to see you. Is that your mom outside the window?" "No, mom has been dead for 25 years now. This is an oxygen mask, it will help you to breathe. No, you need to keep it on your face, you need to keep it on, dad. Take my hand or the bed guard. We are all here with you."* (p. 38)

"Bøgebakken" refers to the house in the town of Birkerød where the family lived when the children were growing up. The father hallucinates about being at home with his wife and three sons, but this illusion of place and time is being contested by the fact that his son and his brothers are sitting next to their father's bed. The title of the text suggests that being there with the father in the hospital is intended to alleviate the fear of him facing death alone and in isolation.

Another text lies somewhere between the epic and lyrical genres and is also one of the very few non-parodic texts in the book – apart from the first line written in red and which twists a previous (quoted) heading:

To be able to live among the dead.

I adjusted your mask.

Your head had fallen from the pillow.

Immensely skinny and damaged to look at.
Mother showed me that one can die young.
You showed me how old one can become.
In my face I see yours.In yours I see my children. (p. 62)

The lyrical form is fused with epic qualities through a short narrative, within which the author gives a shockingly personal reflection on mortality. The death of a parent often prompts grown-up children to contemplate how long they themselves might live. In this case, Voetmann's mother lived a relatively short life while his father lived much longer, and therefore it is an open question as to whether he and his own children will enjoy a long or a short life. This text reminds us of Barthes' reflection on his own mortality from his mourning diary: "To think, to know that maman is dead *forever, completely*, is to think, letter by letter, that I too will die *forever* and *completely*."

Complex empathetic identification

At this point, I would like to discuss a point made by Arthur Frank and quoted previously. To what extent can a book like Harald Voetmann's *Amduat* be read as a mirroring of one's own suffering, in this case one's own grief following the death of a relative? In Rita Felski's chapter on the notion of identification between the reader and a literary work from *Hooked: Art and Attachment* (2020), she argues that these ties between reader and work can take many forms. Her book explores how readers feel connected to aesthetic works such as literature and film, and she examines the theoretical and analytical aspects of the affective relationship between the reader and the work. One of the categories explored is identification, which has for a long time been considered an unacademic – or more precisely pre-academic – approach to literature. However, Felski argues that identification in its fundamental form is simply unavoidable even for the most critical and self-aware reader. Furthermore, she suggests that identification should not be perceived solely as a naive connection between the reader and the narrator or character. Identification, in her terms, is not synonymous with sameness, and it is neither sentimental nor unreflective (Felski 2020, p. 84-85).

When it comes to literary stories about illness, whether this is a literary pathography or next-of-kin literature, it is useful to examine the type of identification characterized by empathy as the sharing of feelings. According to Felski, empathy with the narrator or a character in a novel is one of four types of identification, and she adds "alignment", "allegiance", and "recognition" to the empathic relation (see also Jurecic 2012):

> Alignment *refers to the formal means by which texts shape a reader's or viewer's access to character.* Allegiance *speaks to the question of how ethical or political values – that is, acts of evaluating – draw audiences closer to some figures rather than others (p. 96) …* Recognition *names an experience of coming to know; of being struck by some kind of insight about the self (p. 101) …* Empathy*: sharing someone's feelings and responding with concern to these feelings. (…) To refer to someone as empathic is to imply not just that they are aware of others' feelings but also that they respond to these feelings in a compassionate manner.* (ibid., p. 105)

The definition of empathy 4), as compassion for the suffering of others, is differentiated from the other three types of identification which lean towards 1) narrative techniques, 2) ethical and political values, and 3) recognition in terms of self-awareness. Most books and films about relatives will generate compassion for the person witnessing a loved one's illness or death. The question then is whether the reader – in casu *me* as reader – develops empathy towards the relative sitting at his father's bedside in Voetmann's *Amduat*. I will argue that certain aspects of the book pull me in one direction, while others draw me in another, and this tension creates a rare and ambiguous experience. The fact that the book's style is mainly parodic, and that the overarching historical intertext is ancient Egyptian mythology, do not instill in me any immediate feelings of *alignment* and *allegiance* with the relative and his loss. On the other hand, the dynamic utterance situation that the narrator "I" is often the son, but sometimes also the father, creates a strong *recognition* of the close relationship between the two men, and a strong *recognition* of the intimate relationship between reality and illusion. This feature arguably increases the reader's – here *my* – sense of being close to the rare experience of dying: the reader does not merely listen to a dying patient, but actually is the dying patient for a moment through the power of imagination. I do not only recognize the intimate relationship between the son and the father on a textual level. On a personal level, I also identify with this complex relation as I am both a grown-up son (born in 1979, so similar in age to Voetmann) to an old father and a father to two young children. Thus, by means of the advanced form used, and not least through the handwritten texts, the voice and the story touch my heart and foster *empathy*.

The verbal, the visual and the auditive modalities

In a final attempt to highlight the book's effectiveness in provoking empathetic images, one can argue that Voetmann not only merges stories of dying in present-day Denmark and ancient Egypt, he also seeks to merge verbal and visual modalities, resulting in what has been called *graphic medicine* (Williams et al. 2015, Phelan 2023) as an extension of the established field of *narrative medicine* (Charon 2006, Rasmussen et al. 2022). In addition to the use of handwriting as described above, the book has drawings (mediated or generated by a computer program) of gods and animals on the front and back covers as well as on the two flaps. All the approximately 20 gods and five animals in the book's four paratexts are presumably drawn following instructions from Voetmann and copied from the Egyptian Amduat. The gods and animals are combined in a very specific way that must have required the expertise of an Egyptologist (Illustration 2: see below).

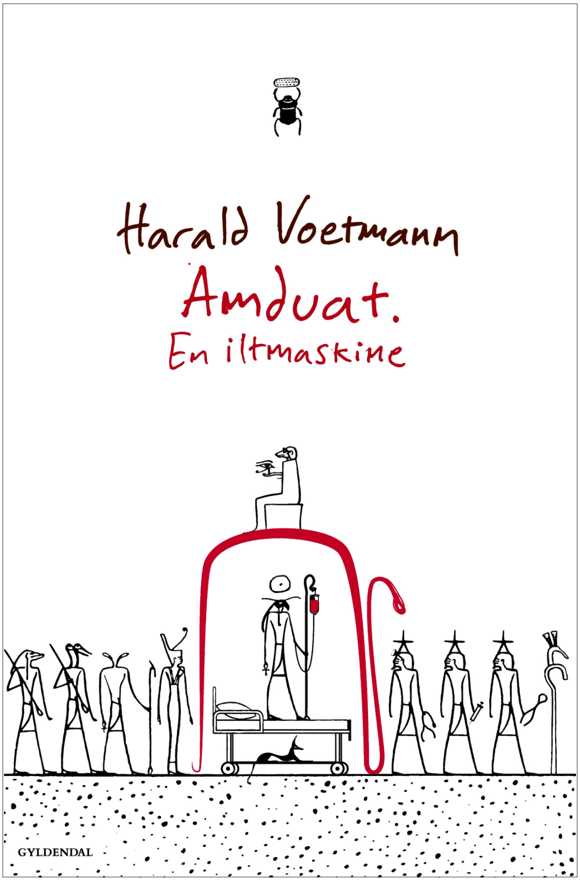


Illustration 2. The book cover.

Most of the gods on Voetmann's cover are direct copies from the burial chamber's narrative. However, the drawing on the front cover of the sun god Ra standing on a hospital bed clearly has a drip on his arm, and the three gods on his right have been equipped with a stethoscope, a syringe, and a pair of forceps, respectively. Thus, the sun god Ra on the cover is associated with the father, who, in the texts, lies in bed with an oxygen mask to breathe, and the Egyptian gods, here from the 7th hour of the Egyptian Amduat, are associated with modern physicians. As mentioned previously, the gods were tasked with helping the pharaoh on the perilous journey through the underworld where they had to pass the serpent Apep, which is depicted in Voetmann's *Amduat* on the book's first inner flap. In addition to the sun god Ra on the front cover, Apep also appears alongside Horus on the same first inner flap, and Anubis on the second inner flap; these gods are also named in the handwritten texts. Above the author's name on the front cover is a scarab, an ancient Egyptian religious symbol of life and rebirth, which was associated with the early morning sun, Khepri.

In his book *Narrative Medicine* (2023), James Phelan, one of the leading scholars in the field of narratology, recently applied a rhetorical approach to narrative defined by attention to narrative as communication between an author and an audience. The communication situation is defined thus: somebody telling somebody else on some occasion and for some purpose(s) that something happened (Phelan 2023, p. 4). What happened in the case of Voetmann is that his father died. The occasion is therefore simply the death of his father, whereas the purpose of him telling the story is what this article is trying to nail. The most important consequence of the rhetorical approach to literary narratives is that it involves the author paying particular attention to the reader's cognition, affect, and ethics, as well as to the interactions between these layers. Phelan does not only include literary narratives in his book, he also includes a chapter on graphic novels about health and thereby attempts to analyze both the verbal and the visual aspects of this upcoming genre that intersects the medium of comics and the discourse of healthcare. Whether Voetmann's Amudat should be categorized as a graphic novel or a printed manuscript is less important than to recognize that this multimodal expression of drawings and handwriting fulfills its purpose better when perceived as a physical book rather than an e-book.

The graphic choice Voetmann makes in printing his own handwriting supports his assumed intention to present human life – across thousands of years – as something to wonder at. In Walter Benjamin's famous essay "The work of Art in the age of Mechanical Reproduction" from 1935, it was noted that:

> *Even the most perfect reproduction of a work of art is lacking in one element: its presence in time and space, its unique existence at the place where it happens to be.* (Benjamin 1969, p. 3)

The reproduction of the Egyptian Amduat from Tuthmosis III's tomb in a printed book about the ancient chamber will always lack the here-and-now character of human perception in the tomb. Additionally, for the Egyptians, the creation of writings and paintings was more than merely a way of keeping a record. Word and image contained magical powers which could make extraordinary things happen – for example help souls in their hazardous passage from death to afterlife. One could argue that with his *Amduat*, Voetmann is taking the question of the mechanical reproduction of books to its limit in a performative gesture: this rare book in Danish literature not only merges the present and the past, the verbal and the visual, but also merges the handwritten manuscript and the mechanically reproduced book in an examination of a liminal human experience: the loss of a father.

In addition to the graphic modalities of the work, I previously mentioned that the text was read aloud to an audience only once, during the reception of a literary prize; together with the audiobook, which is read aloud by the author, these factors all add something to the essential idea of considering this particular artwork as a ritual rather than therapy. Typically, when a book is read aloud, minor misreadings have been corrected in an edited recording. In this case, Voetmann seems to have completed the reading in one take, and the listener can therefore sense from his quite remarkable shifting tone of the voice when the author is moved emotionally by reading his own texts.

Conclusion

Wrapping up this article, Voetmann's *Amduat* begs the delicate question as to who are perceived as gods in present-day society? The ancient Egyptians were typically dead by the age of 35, they had a strong belief in their many gods, and they expected that death was followed by rebirth. Their cyclical view of life and death was supported by the recurring patterns of natural phenomena like the movement of the sun. Death was no more and no less than a transition: the entering of a new phase of being-in-the-world (Apt and Hornung, 2007). In the present-day Nordic region, people are living much longer than ever before: these days, men die on average around 80 years old, and most of the – native – population is completely secularized. If the ancient Egyptians had a short life and believed in eternity, modern Scandinavians will typically live a relatively long life and believe that death is a definitive ending. The answer to the question of who the new gods in our society are may be the physicians prolonging human lives in their highly technological hospitals. Another question is to what extent modern humans can replace their metaphysical need for understanding the full spectrum of human life with medical knowledge of the biological body? The answers to this question may be found in an identificatory reading of artworks like Harald Voetmann's *Amduat. An Oxygen Machine*.

To follow up on the opening argument made in narrative medicine, what literature does – in supplementing medical case studies and qualitative interviews like Kübler-Ross' *On Death and Dying* – is to offer imaginative stories on death and dying. These stories create a reality in the reader that is formed from empathetically identifying with the dying person. Without acknowledging these stories, medical research tends to neglect the personal, intimate side of human experience, which covers emotions and sensations as well as metaphysical beliefs. What makes Voetmann's *Amduat* constitute such a significant contribution to the illness narrative, and more specifically to the growing body of next-of-kin literature, is the unusual stylistic use of parody instead of the typical pathos of pathographies and the moral satire of a highly technological medical hospital. To create a sense of distance – but not detachment – from intimate feelings, the text employs genre hybridity blending lyric, epic and drama, along with the use of fictional features in the enunciation. These features result in the reader's confusion over "who speaks?" mirroring the father's confusion in his final hours before death. In contrast to most bibliotherapy and expressive writing in health, Voetmann has the explicit aim of perceiving writing – and reading aloud – as a ritual instead of a therapeutic work. This ritual work about the loss of his father has been carried out not only two, but three times in various media fora: when writing the texts by hand without editing, when reading the book aloud once in public, and finally when reading the texts aloud in a recording studio in presumably one take.

A so-called vulnerable or post-critical reading of Voetmann's *Amduat*, inspired by Arthur Frank and Rita Felski, invites the reader to reflect personally on their own situation, in casu *my* own relations to my old father and to my young daughters to whom I am a father. Everyone who reads the book will find it inspires their own personal reflections on family relationships, ageing, and dying. For me, the lasting impact of reading the book is a reminder of a powerful medical system, where physicians act as gods prolonging life, yet fail to meet the fundamental need for patient dignity, and the recognition of life as a vibrant mystery when faced with death as the unknown territory.

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Originalartikel

Shared stories:

Co-authorship and relational perspectives in two breast cancer memoirs

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The essay examines two breast cancer memoirs from a literary perspective: Cancer in Two Voices *by Sandra Butler and Barbara Rosenblum (1991), and* The Use of Photography *by Annie Ernaux and Marc Marie (2005). The comparative analysis of the two texts aims to explore the dual perspective that characterises both works, shedding light on how the notion of kinship acts and is interpreted within them. Furthermore, the inquiry investigates the ethical implications of these collaborative literary projects, ascertaining the presence of different narrative authorities and determining what values and functions are associated with storytelling when a couple experiencing illness decides to write about it. What emerges from the comparison is an extended notion of kinship that gives rise to narratives 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.*

Introduction

Among the authors of illness memoirs, or pathographies,[1] we find caregivers belonging to the family circle and partners acting as compassionate witnesses, thus foregrounding the concept of kinship and rejecting the sick person's subjectivity as the only dominant principle of the narrative. The change of perspective is further accentuated in those memoirs written by two closely related authors. This is the case of the texts at the centre of this essay, written by pairs of lovers and from different geographical areas; *Cancer in Two Voices* by Sandra Butler and Barbara Rosenblum (USA, 1991) and *L'usage de la photo* (*The Use of Photography*) by Annie Ernaux and Marc Marie (France, 2005).[2]

By considering the impact of the diagnosis in a couple and community dimension, this article aims to establish how the notion of kinship is interpreted within these two co-authored works and influences the very structure of the text. Indeed, in both stories the sick person elects her partner as her closest companion and participant in the illness, questioning both the meaning of kinship and that of caregiver. At the same time, she encourages the other to give voice to his or her own experience of living with someone diagnosed with cancer. This subdivision of the narrative, however, does not only entail a thematisation of the bonds privileged by the authors, their importance and their limits, but also a shaping of the text that bears the traces of the tensions and negotiations associated with the notion of kinship.

To explore these representations of kinship and how they influence both form and content in the two memoirs, I will rely on close reading. This literary approach allows me to identify and highlight the narrative strategies through which the authors present, navigate, and challenge notions of kinship in and through their collaborative writing projects. Emphasis is placed on the selected memoirs, *Cancer in Two Voices* and *The Use of Photography*, covering the two decades leading up to and following the millennial shift. The works have in common that they are exceptional cases in which it is precisely the plurality of subjectivities at stake, starting from the dual authorship, that determines atypical textual configurations. While Butler and Rosenblum's memoir stands out for being «[t]he only published breast cancer narrative written collaboratively by a lesbian couple» (DeShazer, 2005, p. 232), *The Use of Photography*, despite its heterosexual belonging, is also an isolated case, since co-authored writing projects are a rarity in the general

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[1] The term is used by Anne Hunsaker Hawkins to define «a book-length narrative about the author's illness» (Hawkins 1999, p.xiv).

[2] The first English translation of *L'usage de la photo* came out in October 2024. However, as this article was written earlier, all translations from the original French text are mine.

autobiographical landscape.[3] Moreover, in the two works dialogicity is intensified using various genres of discourse, as Butler and Rosenblum do by combining the writing of a collaborative diary with letters and essays, and by including in the text a series of photographic images, as is the case in *The Use of Photography*. As I will observe, however, even if both works are hybrid and co-authored texts, and the same disease is the motive of the narrative act, their literary responses are quite distinct and lend themselves to wide-ranging reflections prompted by the notion of kinship in the context of illness and writing. For example, it cannot be excluded that the equal relationship between the two authorial subjectivities may be strengthened or denied by the difficulties and tensions that illness introduces into the couple's life.

Comparing breast cancer memoirs

Before delving into the selected works, a few words need to be said about the inclination of breast cancer memoirs towards a communitarian vision that is reflected in the textual composition. This aspect derives from the historical-cultural conditions that, since the 1970s,[4] produced such publications. Furthermore, the strong gender connotation of the disease explains, in part, the desire of female authors to be the spokesperson for a community in danger to which they belong, as is the case with *Cancer in Two Voices* and *The Use of Photography*.

Since even a diagnosis of breast cancer can entail painful encounters with cultural preconceptions and dynamics of oppression in the biomedical context, choosing to write publicly about this pathology from a personal perspective is in line, patently or implicitly, with principles in defense of women's health and independence. Similar motivations persist over time and although in France there has not been the pathographic flowering that took place in the United States, Annie Ernaux (born in 1940) and Barbara Rosenblum (1943) and Sandra Butler (1938)

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[3] Two further exceptions, where the disease in question is not breast cancer, are the Italian memoir *La cura* (*The Therapy*) by Salvatore Iaconesi and Oriana Persico (2017), and *A Matter of Death and Life* by Irvin D. Yalom and Marilyn Yalom (2021).

[4] In the same period, the women's health movement took hold (which has its analogue in France in the *Mouvement de Libération des femmes*), determined to make women regain control over their bodies, by freeing them from the prevarications of institutions such as the law and medicine, which through reification and paternalism have led to a negative connotation of gynaecological phenomena and practices in particular. The organization of consciousness-raising groups and self-help clinics encouraged women to share their experiences and to play an active role in the therapeutic processes, so that they would not succumb under the potentially oppressive weight of medical knowledge and more generally of male domination (see Diedrich 2007, pp. 37-38).

witnessed and lived through the same years of social change. The French writer has also repeatedly described those years in her autobiographical works, dwelling on female sexuality and recounting the clandestine abortion she suffered when she was a student (see her memoir *Happening*, 2001).

In spite of their individual peculiarities, breast cancer memoirs are defined by certain general traits and implications of the disease that are emphasised in the narratives: since breast cancer is an extremely common pathology among women, all are at risk and therefore involved in the story of those who have been diagnosed with cancer; as it is prone to recurrence, it impacts an entire life; as it affects a specific female organ, with cultural and social meanings, it influences a person's identity. Although inevitably absorbed by the severity of their illness, especially when narrated while it is ongoing, the authors turn to the other to increase her chances of survival and support her through her own experience, thus expressing the political mission of these texts (cf. Couser 1997, pp. 37-38). While this claim can be made about pathographies in general, where «the need to *tell* others so often becomes the wish to *help* others» (Hawkins 1999, p. 25), in breast cancer memoirs this desire to affect and possibly change the external reality is particularly pronounced and urgent due to the prevalence and high mortality of the disease, which currently remains the most common cancer among adults. It is not surprising, therefore, that the personal dimension of her partner's illness is promptly transcended by Sandra Butler in the introduction to *Cancer in Two Voices*, in which, although relying on 1990 statistics, she defines breast cancer as «a shared epidemic – a collective experience» (Butler and Rosenblum, 1996, p. iv). Consequently, far from diminishing, breast cancer memoirs continue to exist in the West and represent one of the most significant contributions – not only in numerical terms – to pathographic writing.[5]

It is undeniable, then, that there is a political matrix, which unites the breast cancer memoirs, limiting an exclusively self-referential function of the narrative act in favor of a collective cause. Such a vocation is recognisable in both *Cancer in Two Voices* and *The Use of Photography*. If Butler and Rosenblum explicitly conceive their book as a text serving and defending the female population threatened by breast cancer, Ernaux participates in the same project, even though the statements of intent are kept to a minimum and are not reiterated. The work's political value is inherent in the existence of the text itself, whose dialogical component lies not only in the collaborative writing of two authors. If anything, Ernaux, for whom

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[5] By way of example, I recall, for their political strength, the seminal *The Cancer Journals* by Audre Lorde (1980) and the recent *The Undying* by Anne Boyer (2019), which has contributed greatly to renewing the tradition of breast cancer memoirs.

feminism is not an option, but her natural way of being (see Ernaux and Marie 2005, pp. 157-158), addresses a reader to whom she wants to make visible the women affected by breast cancer, starting with the unveiling of her own experience:

> *In France, 11% of women have had or have breast cancer. More than three million women. Three million breasts sewn, scanned, marked with red and blue drawings, irradiated, reconstructed, hidden under blouses and T-shirts, invisible. We will have to dare to show them one day, indeed. [Writing on mine is part of this unveiling.]* (Ernaux and Marie 2005, pp. 112-113)

Meticulously describing her completely hairless body and the device implanted under the skin for the infusion of drugs, Ernaux exposes aspects of cancer that the public does not know, and that she, too, ignored before she fell ill (see Ernaux and Marie 2005, pp. 23-24). This sharing of knowledge acquired through experience is a task that the French author and Barbara Rosenblum share, even if they are distant in time and space: both are the first, in their circle, to have breast cancer, but they know that they will not be the last. As Rosenblum writes: «There will be others. […] Such a weighty responsibility, to be the first, yet it gave me a purpose. I am trying to live self-consciously (and perhaps die self-consciously) in an exemplary manner. Many of my friends will see their future in the way I handle mine» (Butler and Rosenblum 1996, p. 13). And Ernaux, similarly: «The feeling that breast cancer was going to happen to me like all things that only happen to women. Even though neither my mother, nor my grandmother, nor my aunts, nor my cousins, ever had one, that I am the first, as I was when I chose higher education, that I inaugurate» (Ernaux and Marie 2005, p. 33).

Of course, there are also many differences between the two memoirs. To understand the discordant plot developments that I will discuss later and that illness also brings to light as disparities on the level of narrative authority, it is necessary to keep in mind the works' specific starting relationships. Regarding *Cancer in Two Voices*, Butler and Rosenblum are a longstanding couple, composed of two defined and independent personalities sharing important affinities (both Jewish, in their forties, lesbians, feminists, intellectuals). Moreover they are equal from a professional point of view that contributes to legitimising their narrative: both together and individually they have already authored other publications (essays) and readers might not feel any imbalance between the relevance of the activity of Butler (who is a consultant for women victims of violence) and Rosenblum (who is a sociologist and an academic), an ideal situation for collaborative writing. Things are different in *The Use of Photography*, since cancer is diagnosed at the same time as the beginning of the relationship between a man and a woman who, driven by erotic passion, decide to write about it. While Annie Ernaux is an internationally renowned writer, Marc Marie is a journalist, 22 years her junior and not in the public eye; furthermore, as readers, we perceive that his admiration for Ernaux surpasses, in the text, the one she may feel for him.

These preliminary observations immediately suggest a first notable element of the collaborative writing undertaken with the next of kin of choice. Importantly in this context, a negotiation of narrative authority is necessarily taking place in pathographies when a kinship member shifts from the role of character to that of narrator, from object to subject of the telling, from the periphery to the centre of illness. It is not an innocent transition, firstly because with regard to the person who has been diagnosed with the disease, the other, being healthy, is certainly privileged and her experience is intrinsically different from that of the patient. The latter, however, holds an irreducible narrative authority provided by the direct experience of illness and, in extreme cases, of the proximity to death.

In addition to *Cancer in Two Voices* and *The Use of Photography*, this shift of roles is acknowledged, more or less explicitly, in other illness memoirs that stick to the conventional single narrator. Public sharing may imply that is not the sick person who has chosen to reveal his or her story by taking responsibility for it directly: this is what happens in David Rieff's *Swimming in a Sea of Death*, in which the author recalls the fatal leukemia of his mother Susan Sontag, who notoriously never wanted to write a pathography. Instead, in *In Love* by Amy Bloom, who accounts for supporting her husband after his decision to apply for assisted suicide, inaugurates the memoir with this sentence used as an epigraph: «"Please write about this", my husband said». Nevertheless, these 'narrative mandates', whether tacit, explicit or stolen from the ill or deceased person without his or her consent («the dead instantly lose their entitlement to privacy»; Miller 2000, p. 13), force us to question the boundaries between one's own experience and that of others, as well as the authorisation to tell that being a kinship member would seem to entail automatically.

Therefore, the doubts that these narratives raise are close to those that Nancy K. Miller investigates in her essay *Bequest and Betrayal,* valid even if they refer to the death of a parent: «whose story is it? […] If not explicitly, the memoirs devoted to a dead parent are almost always meditations on a writer's authority, her right to tell this story, the path she followed to telling it» (Miller 2000, p. 13); «Is the biography of another ever a story separate from ourselves? Is autobiography ever a story separate from the significant others – parents, lovers – with whom we continually make and remake our selves?» (p. 123). These same issues lead David B. Morris, who in *Eros and Illness* combines theoretical inquiry with the story of his care for his wife Ruth, an Alzheimer's patient, to attempt to set boundaries, however fluid, between his role as a caregiver and as a scholar who has to unveil private family facts:

> *First, on ethics: Ruth's story belongs to Ruth, and I need to respect her privacy as far as our joint experience allows. Second, on method: as caregiver, I am a paramedical figure, with rights and responsibilities at the bedside, but my role is more complex than duties and privileges suggest. Family caregivers cannot put aside the interlaced social and emotional filaments that bind them to the patient, which infiltrate my account in ways that prevent me from dividing subjective experience and critical inquiry into separate compartments* (Morris 2017, p. 26).

Rights, responsabilities, duties, privilegies, social and emotional filaments: all these aspects also belong to Sandra Butler's part of *Cancer in Two Voices*, since she takes a triple role, as caregiver, co-author and co-protagonist. On the other hand, regarding Marc Marie, despite his central role in *The Use of Photography*, I will argue that he does not fulfil a traditional caregiver function. As far as the plot is concerned, the two memoirs show divergences related to the same specific disease that inspired them, but whose prognosis and progress are dramatically different, leading to two opposing narrative arcs. While for Annie Ernaux, the therapies are successful and the memoir ends with a restored health, Barbara Rosenblum faces a diagnosis that is immediately declared to have little chance of recovery.

Significantly, regardless of the different prognosis of Rosenblum and Ernaux, the thanatographic component, manifested in *Cancer in Two Voices*, is also present in *The Use of Photography*. Despite the prospects of recovery, the diagnosis is welcomed by Ernaux as a *memento mori* that forces her to come to terms with her own finitude and to question the idea of the future. Instead, as the metastasis spreads, Rosenblum longs to live the remaining time to the full, and finally to embark on a path of preparation for death. According to the classification proposed by Arthur Frank in *The Wounded Storyteller*, it is therefore recognisable in *The Use of Photography* a restitution narrative, which highlights the favourable outcome of treatment, and in *Cancer in Two Voices* a quest narrative, which considers illness as an opportunity for personal growth.

In the following close readings, the analysis of the dialogical structure of the text and the role that the notion of kinship, rethought in a personal manner, plays within it, will help to bring out the originality of these two memoirs and open up to different interpretations of relationality arising from dual authorship.

Cancer in Two Voices: «A window to see out of and to allow others to see into»

In *Cancer in Two Voices* the breast cancer story traces the plot set up by the disease, generally characterised by the discovery of a lump, followed by diagnosis, treatment with heavy side effects and an epilogue, given by recovery (permanent or temporary) or, as is the case in *Cancer in Two Voices*, the death of the patient. However, the text by Butler and Rosenblum does not merely account for this storyline and indeed falls within the category of multicultural narratives identified by Mary K. DeShazer, in which the political and communitarian aspects of the patient's experience stand out (see DeShazer 2005, pp. 219-220, 233). More precisely, *Cancer in Two Voices* foregrounds lesbian feminism, class inequalities, the Jewish identity shared by the two authors and criticism of the American health system (Rosenblum is the victim of an initial misdiagnosis that prevents her from immediately treating the cancer, which remained undetected for a year). All these facets contribute to composing the circumstances in which the illness takes place and reflect the values and principles at the heart of Butler and Rosenblum's response to the diagnosis. While these premises exist before cancer, its onset then offers an opportunity to test them, question them and finally confirm who one is. *Cancer in Two Voices* certainly coincides with a path of personal development through illness, of self-discovery and inclusion of the unexpected in one's life, but mostly, for Butler and Rosenblum, it is a matter of consolidating and reaffirming who they have been up to that point. Hence, the political dimension coexists with the individual approach and inner growth expected in personal narratives of breast cancer (see DeShazer 2005, pp. 223, 234), which the memoir also adheres to.

Cancer in Two Voices is mainly composed of the shared diary that Butler and Rosenblum decide to write when Rosenblum's soon-to-be terminal breast cancer breaks into their relationship. Thus, the authors' voices alternate, offering two distinct perspectives on the day-to-day course of the disease and relying on writing as a regular exercise in introspection to account for the effects of illness on their lives. Moreover, the work contains personal essays in which the two authorial voices merge; letters signed by Rosenblum, including those addressed to the collective recipient represented by her circle of female friends, and one, also written by Rosenblum, addressed as a bequest to her nephew. Finally, the memoir is opened and closed by the sections written by Butler to complete the narrative and contextualise it after the death of her partner, whom she does not hesitate to address directly.[6] The interweaving of genres of discourse and differentiated

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[6] My analysis is based on the second expanded edition of 1996.

recipients contributes to the structurally relational character of *Cancer in Two Voices*, in which an extended notion of kinship appears embedded in the textual fabric that includes the partner, family, friends, and the vast readership, composed primarily of women and patients, to whom the work as a whole is addressed. Each part of the memoir, then, highlights the relevance of these connections: if the diary coincides with self-analysis, it is also open to reciprocal reading within the couple, while the letters enhance the relationship with the other women and with the family. Since Butler and Rosenblum's bond has always valued the autonomy and subjectivity of the individual, and, at the same time, the constant exchange with the other, this approach is naturally reflected in the way the couple deals with the illness and conceives its narrative. Hence, for Butler the pronoun «us» underlying *Cancer in Two Voices* has a precise meaning:

> *The loneliness that had been our oldest companion lifted and the partnership – the "us" – replaced it. […] We retained our separate friends, our own priorities, our own political emphases. That is what made the "us" work so well. Even after Barbara became ill […] the pattern we had established remained constant. […] There was much air and space and movement in our "us". […] This book is filled with the words of the "us" that began with Barbara's diagnosis and ended with her death* (Butler and Rosenblum 1996, pp. iii-iv).

From Rosenblum's point of view, isolation and participation coexist in the disease:

> *Each day is filled with a wide-ranging richness, from really deep laughter to inexpressible, inconsolable isolation. From connectedness with others to the beauty of perceiving the inner design and structure of all things. […] I am filled with a sense of being here, being moved, being touched and both connected and alone in my life, my journey, my odyssey* (pp. 42-43).

Given these premises, it is clear that each author has in mind a double direction of her writing around the journey undertaken after Rosenblum's diagnosis: towards herself and towards all the people she cares about. In this regard, it is significant that after going to see an exhibit of an AIDS quilt, Butler asks Rosenblum what panel she would have wanted for herself and she answers: «A window to show I wasn't a monad. A window to see out of and to allow others to see into. I would want all my friends to sign it so it would reflect the connectedness of my life. Then I would want it to have a message from you. Something about us» (Butler and Rosenblum 1996, p. 182). On the one hand, the metaphor of the window encapsulates the unceasing exchange between interiority and the external world that both Rosenblum and Butler have constantly practised. On the other hand, the window may be associated with glass, a transparent surface that, while allowing the reciprocity of the gaze, establishes both a separation between the subjects, who remain distinct, and the possibility of self-reflection on the part of the beholder, thus emphasising and encouraging self-consciousness.

Cancer in Two Voices also adheres to this framework through a rhetorical strategy that pervades the text and is based on the authors' longing for clarity, understanding and knowledge with respect to what is happening and how one feels about it, which must be made intelligible to one's own eyes and those of others. Hence the analytical inclination of the text, which insists on explanations and justifications even, and indeed especially, when their proximity to the truth makes them unpleasant and painful. This dynamic is matched by the rapid sharing of the diagnosis with Rosenblum's expanded kinship:

> *Exactly one week and three hours after I learned I had cancer, I had a meeting in our house of twenty women who would be involved in my healing and caretaking. It was a conscious and deliberate choice to mobilize a battalion of friends to help and assist me in every phase of fighting my disease* (Butler and Rosenblum 1996, p. 12).

Rosenblum's female friends, who are also involved in collective alternative medicine practices in her favour, become part of a therapeutic alliance, suggested by the use of the war lexicon that proves empowering for both authors. The functional role of the group, however, does not obscure the individual subjectivities that compose it, which are also affected by their friend's illness. Rosenblum is willing to welcome them together with the inspiring words, once spoken by herself, that this virtuous circle gives back to her:

> *They spoke of their feelings and their love for me, of their commitment to the shared struggle of winning the battle against the cancer growing in my body, and of their dedication to whatever was needed to win that battle. That night changed the way I spoke. Since then, many friends have reminded me of my own words* (p. 13).

The empathy shown in this circumstance is instead expressed through a partial communication, marked by omissions, towards Rosenblum's elderly parents, who belong to the core of the more traditional and, in this case, vulnerable kinship of biological family. Far from being conflictual, the relationship with their daughter becomes the object of problematisation, in terms of unveiling the diagnosis and sharing the care with Butler, since their frailty requires that they must first of all be protected from the gravity of the situation.

Undoubtedly, the fact that Rosenblum, exhausted by the disease, still manages to make such a sense of consideration for her family prevail, supported by Butler, underlines her extraordinary moral strength: «In my living, and even now in my dying, still protecting and taking care of» (Butler and Rosenblum 1996, p. 34). If in this observation emerges the pride of those who manage to remain faithful to themselves even when death is approaching, Rosenblum's words may also hint at a certain weariness due to the additional effort, in the midst of illness, that this altruism requires, where perhaps it would be less demanding, for the sick person, to indulge her own needs to the detriment of those of others. Rosenblum is aware of this inner conflict, which she formulates without reticence elsewhere in reference to Butler:

> *I have fewer boundaries now. Our needs seem out of sync and out of proportion. Sandy has never seemed more independent, more separate, and I have never been so needy. My sense of time is urgent. Hers seems scattered all over the place. We can't align our priorities, it seems. […] I'm jealous of her enormous energy* (Butler and Rosenblum 1996, p. 39).

As I outlined in the previous section, co-authorship necessitates a negotiation of narrative authority. For her part, Butler, as the primary caregiver and co-author of the memoir, does not overlook the tensions and issues that arise from making kinship a meaningful part of an experience, and story, of illness. Hence, her contribution to the story is not ancillary, because she is at the centre of a personal journey that is indivisible and at the same time different from the one marked by her partner's illness, but equally significant and worthy of being told. Butler's account is complementary and symmetrical because it reveals the other side of the story of illness, that of someone who witnesses the suffering of her loved one, is terrified by the prospect of life without her and must be able to manage her care without losing her own identity.

If Rosenblum is prey to the unpredictability of a body deeply affected by illness and therapy, struggling to maintain a positive spirit, Butler is no less unstable on an emotional level, admitting feelings that are as unpleasant as they are human and disclosing a complex psychological landscape:

> *My moods are wide-ranging and unpredictable. I marvel at her. I marvel at me. And sometimes I want her to tell me she's sorry for getting cancer and ruining our lives together. And sometimes I'm angry at her for getting it. I want to tell her that I am sorry for letting her get cancer and not making her go to a better doctor. And most of the time, I lie in her arms grateful for the life we have together* (Butler and Rosenblum 1996, p. 15).

Sometimes, Butler expresses an ambivalent position towards the very idea of kinship, for example when she is irritated because she is not the only beneficiary of the gifts derived from the conspicuous compensation received by Rosenblum for her misdiagnosis; or when she struggles to accept other caregivers, even if she quickly recognises that it is precisely the network of contacts on which the couple can rely that allows her to maintain her own independent life and story:

> *Her parents will arrive next week. I feel displaced and jealous of her intimacy with them. All the old rough and unresolved places of our relationship resurface. All the tangled threads of her specific history that exclude me. But at the same time, I am released. Reprieved. Able to be in my own life for a week or so. To remember myself* (Butler and Rosenblum 1996, p. 33).

Indeed, it is by opening the experience of illness to a circle of sympathetic and supportive presences that Butler can carry on her own single narrative, the possible thinning of which worries her from the moment of Rosenblum's diagnosis: «How will her cancer force me to engage with the choices of being both in my life and in hers as well – and still keep my balance?» (Butler and Rosenblum 1996, p. 19).

Finally, Butler must also recognise that, as the stage of her partner's disease becomes advanced, Rosenblum moves further and further away from her. Mutual understanding fails and even looking at oneself in the mirror offered by the other is now unbearable:

> *Seeing her vulnerability forces me to face my own. But mostly I turn away from it to tend to her and grow burdensome. She goes so far away when she is in pain: […] she cannot speak. I am alone, outside, and am, for the moment, temporarily bereft. Her fear parallels my own, and we cannot do more than hold each other and cry. I whisper to her […]. She reaches towards me, touches my face, but her eyes seem inward now, the reflex an automatic one* (Butler and Rosenblum 1996, p. 152).

An ultimate change in the balance of narrative authorities in the text is given by Rosenblum's death, which incurs the transition of the voice to Butler alone. She is responsible for the completion of her partner's story, the end of which can only be told by the other. Butler is also in charge of assembling, refining and clarifying the work in line with the intentions shared with Rosenblum, with whom the project was conceived and carried out until death interrupted it. The overall impression remains, however, that *Cancer in Two Voices* presents us with two subjectivities enlightened by illness and by the presence of the other, with respect to which both authors continue to position themselves. This includes highlighting moments of differentiation that Rosenblum identifies from the initial stage of the disease: «I went alone today to see Dr. Grant for my post-chemotherapy visit. This painful disentangling is necessary for both of us. The truth is that it is not our cancer but mine. I have to find my way alone now» (Butler and Rosenblum 1996, p. 17). Keeping the window open proves rewarding, but neither Butler nor Rosenblum downplay the limits and difficulties of such an ambitious collaborative writing project.

The Use of Photography: « He makes me live *above* cancer»

Annie Ernaux and Marc Marie are co-authors of *The Use of Photography*, a text enhanced by 14 photos, taken by the couple, which depict the clothes confusedly abandoned on the ground before having sex. Ernaux and Marie decided to write a piece inspired by each snapshot, autonomously, freely and without agreeing or sharing the content with the other, to be offered to read only once completed. In this circumstance, photography and writing are primarily conceived as a divertissement and a component of the erotic game, outlining a project that at first glance is very different, because it appears to belong exclusively to the intimate sphere, from the didactic unveiling of Sandra Butler and Barbara Rosenblum. Although in *Cancer in Two Voices* the erotic dimension linked to collaborative writing is not overlooked, it operates as a substitute element, albeit of enormous value, for a sexual activity made impracticable by the ferocious effects of illness and therapy: «Together we have developed a new form that can accommodate our individual and unique voices into a dialogue. We write about things that are important to us. We make love at the typewriter, not in the bedroom» (Butler and Rosenblum 1996, p. 159). As for Ernaux, whose therapies are successful and who, unlike Rosenblum, does not undergo a mastectomy or develop metastases (to this day the French writer is still healthy), sex is not precluded at all, since she can rely on a body altered by medical treatments, but not debilitated or deprived of desire.

The Use of Photography is driven by a literary motive that Ernaux declares at the beginning of the work, relating it to the poetics that distinguishes her entire production, already considerable in those years: the author aims to grasp the flow and elusiveness of life, here represented by eros, fixing them in visual and written traces. Therefore, compared to *Cancer in Two Voices*, *The Use of Photography* is characterised by a less ominous diagnosis and a greater literary ambition, but also by an interpretation of kinship that coincides only with Ernaux's partner, Marie, and does not extend to a wider network of meaningful relationships. Above all, the couple flaunts an attempt to belittle cancer and suggests, in a latent way, a disparity between the narrative voices that is not consistently observable in *Cancer in Two Voices*. Both elements can be identified from the first pages of the French text.

It is Ernaux alone who takes charge of the introduction of the work, where cancer is mentioned almost at the end, as a random fact of secondary importance:

> *When we started taking pictures, I was being treated for breast cancer. As I was writing, I immediately felt the need to evoke "the other scene", the one that was taking place in my body, absent from the negatives, the uncertain, astonishing fight — "is it to me, really to me, that this is happening?" — between life and death. I shared it with M. Not even he could hide this fact, which was essential in our relationship for months. It is the only time we have spoken of the content of our "compositions", a spontaneous, provisional name of our project, corresponding to what they were, in both senses of the term, for us* (Ernaux and Marie 2005, pp. 16-17).

While cancer is thus first evoked as something other, «the other scene», Ernaux immediately discusses her illness in the following section (again without sharing this part of the text with Marie). This further contextualises the collection of pictures and written pieces by providing its backstory. Here, Ernaux recalls the first evening spent with Marie, when the writer casually informs the man that she cannot meet him the next day because she has a medical appointment as she is being treated for breast cancer. The scene repeats the mode of the introduction, where the illness was mentioned last, and the tone of her dialogue with Marie appears equally and intentionally nonchalant. The informative, descriptive purpose, in line with the flat, rigorous and denotative style of Ernaux's writing, aims, by the author's own admission, to upset the other without giving him the time to prepare for the shocking news:

> *Now I have the impression that I have said to M. "I have breast cancer" in the same brutal way in which, in the sixties, I had said to a Catholic boy "I am pregnant and I want to have an abortion", in order to force him, without having time to take precautions and assume an expression, to look at an unbearable reality* (Ernaux and Marie 2005, p. 22).

Ernaux's bold imperturbability, however, cracks in acknowledging, precisely, that this reality is unsustainable. Subsequently, in this first text that is associated with a photo, the apprehension brought by illness has free rein in the words of Ernaux.

Ernaux and Marie carry out a strategy of resistance to clichés and to narrative conventions that distinguish respectively the expectations of healthy people and the stories of other patients. From the point of view of the illness plot, the omissions stand out: the diagnostic moment, hospitalisations and caregivers are absent; apart from Marie, no one else from Ernaux's circle enters the narrative (according to the extratextual biographical information about Ernaux, she has two adult children from her ex-husband, but there is no mention of them), also because the author preferred to confide her condition only to a few people to preserve the integrity of her identity: «I didn't want any compassion that, every time it was shown, failed to mask this fact: for people, I had become someone else» (Ernaux and Marie 2005, pp. 75-76). This reaction is the opposite of the one that produced *Cancer in Two Voices*: while Rosenblum and Butler choose to share the diagnosis with a large number of people, Ernaux announces it only to a few (without naming them in the text). Similarly, although collaborative, the writing of *The Use of Photography* coincides with a strict delimitation of interferences in the experience of illness, which is made public only with the release of the work and when cancer has become an event of the past. While *Cancer in Two Voices* is based on a trusting openness to a wide community, which has a positive effect on the couple's life with illness, since Ernaux has encountered only disheartening looks, she leans towards a protective closure. Given her general diffidence, the relationship and collaboration with Marie take on even more importance. The writer implies that her partner has the strength and empathy to bear the weight of her diagnosis, respecting an identity that Ernaux does not want to be changed by illness. Her partner's male gaze – «I think she looks fine. [...] Her hair is brand new because of the chemo, I love to caress it» (Ernaux and Marie 2005, p. 55) – seems to confirm and flatter this identity.

The personal growth usually associated with Arthur Frank's quest narrative is also missing in *The Use of Photography*, which sticks to the restitution pattern. For Ernaux, the most remarkable inner alteration following the diagnosis is the different perception of time, which has shrunk and is subject to a sudden acceleration. However, even this discovery is greeted with calm astonishment:

> *In the underground, at the bank, I looked at old women, their deep wrinkles, their drooping eyelids, and I said to myself «I'll never be old». It wasn't a sad thought, just a surprising one. I'd never had it before.*
>
> *The most striking thing was the simplicity of it all* (Ernaux and Marie, 2005, p. 36).[7]

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[7] It is worth noting, to highlight the subjectivity and relativity of Ernaux's perspective, that the author was already 62 years old at the time of diagnosis.

Atypical is also the invariably positive connotation of the words related to the Institut Curie, defined by Ernaux as an «ideal place» (Ernaux and Marie 2005, p. 36) where human beings are cared for with attention and delicacy: «My stay at the Institut Curie for the operation [...] was very sweet. [...] In my diary I wrote that I felt immensely happy» (pp. 24-25).[8] After some time, Marie, who used to visit Ernaux every day while she was hospitalised, remembers that period as the «happy days of the Institut Curie» (p. 152).

Certainly, the approach of *The Use of Photography* suggests a shift in perspective and an enrichment of the illness plot (which here is not the main storyline, as the erotic narrative arc is equally foregrounded). This might be expected from the evolution of the genre, since «it is symptomatic of the maturing of the breast cancer narrative that new ones evince the need for a new angle; once the genre has been established, the experience of cancer is not necessarily sufficient to justify a narrative» (Couser 1997, p. 70). After all, Ernaux and Marie wrote *The Use of Photography* at the beginning of the 2000s, when breast cancer narratives included previously unexplored motifs in their plots. Ernaux and Marie, apparently unconsciously, participate in this transformation, even though the originality of their contribution is such that it does not fit into any of the prevailing tendencies in English-speaking areas.[9] This can be explained by the fact that *The Use of Photography* is a French work and may be susceptible to other influences and discourses, or that its authors have not viewed their work as a breast cancer memoir. Ernaux does give an impression of unfamiliarity with this genre when she feels the need to consult a biography of the French writer Violette Leduc, who died in 1972, to find out how long she had survived her breast cancer diagnosis.

The aspects of the work that make it a counter-narrative of breast cancer may also be seen as the result of the isolation of the couple through eros, in which illness, rather than being integrated, is consciously dominated and downgraded. In *The Use of Photography* there are recurring signs that refer to a mise-en-scène carefully opposed to the troubling presence of cancer. As Marie observes:

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[8] In *The Use of Photography* both authors mention their diaries as a source they occasionally rely on to retrieve information or clarify details about the period in which the photo they are writing about was taken. The diary, anyway, remains a textual form external to the collaborative work and not a constitutive element as it appears to be for *Cancer in Two Voices*.

[9] In the new millennium, breast cancer narratives written in English have been enriched with new elements compared to their twentieth-century counterparts: more cultural diversity is included; mainstream cancer culture (consumer-oriented, based on pink iconography, promoting philanthropy instead of activism) is considerably criticised; the environmental causes of the disease are discussed; the memory of those who did not survive is extensively honoured; medical practice aiming more at detection than prevention is contested; genetic testing and prophylactic mastectomy become part of the plots (see DeShazer 2013, pp. 1-2; 8-11).

> *[the table] where we have dinner when we've chosen not to go out. Part of the ritual, once again, in so far as we have divided time from the first night. As if our days were numbered. As if to create a series of perfect moments [...], little bubbles in which the tragedy of the events of our respective lives would be both trivialised and forbidden to stay. From bubble to bubble, death finally let go* (Ernaux and Marie 2005, pp. 102-103).

The couple takes refuge in their relationship to escape the dramatic circumstances of their respective lives in which they happened to meet: illness for Ernaux, while for Marie the death of his mother, a breakup and a dismissal from work. It is not surprising, then, that the relationship between Ernaux and Marie is marked by lightness and that the occasional tensions that emerge between them are simply part of the dynamics of seduction (jealousy, lack of attention for the other). So, after an argument with Marie, although Ernaux is in the meantime waiting to know if she will have to undergo a mastectomy, the upset caused by their quarrels seems more relevant to her: «I told myself that the pain caused by M. was worse at that moment than not yet knowing if I was doomed or not» (Ernaux and Marie 2005, p. 88). Nevertheless, the fact that erotic semantics punctually prevail over the discourse of illness alludes to the need to exorcise the latter and, in particular, that persistent association between cancer and death to which not even Ernaux is immune. In fact, she confesses that for years, prior to her diagnosis, when she had to go to a library near the Institut Curie, she used to change sidewalks before arriving at the height of the building, as if she were avoiding danger (see Ernaux and Marie 2005, p. 33).

The use of photography, here primarily encouraged as erotic ritual, has a further implication in this context, which refers to death. The link is inevitable if it is true that, as Susan Sontag states, all photographs remind us of human finitude as they «state the innocence, the vulnerability of lives heading toward their own destruction and this link between photography and death haunts all photographs of all people» (Sontag 1977, p. 3). However, the pictures taken by Ernaux and Marie only represent objects, which is also in contrast to the tendency towards (self)portrait in connection with breast cancer, focusing on the detail of bodies modified by treatment (see Bolaki 2016, pp. 26-50). Since the late 1990s, breast cancer narratives have relied on this expressive medium, occasionally resorting to memorial photographs of what remains, i.e. objects belonging to those who did not survive or places emptied of their presence (see DeShazer 2013, pp. 11-12). Ernaux and Marie's compositions partly correspond to this second type of images, but the French writer is alive at the time of the shots and thus there is no memorial intent in the couple's project. On the one hand, the two authors cannot help but acknowledge the deadly fascination inherent in each photo and identified by Sontag; on the other hand, the uncertainty of Ernaux's prognosis accentuates the shadow of the end and forces the couple to anticipate the confrontation with it: «When I look at our photos, it's the disappearance of my body that I see. [...] M.'s statement last year "You've always wanted to write as if you're going to die afterwards, well, you've got there, my cocotte!"» (Ernaux and Marie 2005, p. 146).

Marie is not assigned any role as a caregiver in *The Use of Photography* and his figure is not as defined and central as that of Ernaux within the text. A closer look reveals an asymmetry concerning the voices of Ernaux and Marie, indicating that they do not carry the same weight. In fact, the French writer's narrative authority predominates: she is responsible for the introductory sections of the work, as well as the epilogue in which she declares that her cancer has gone away with treatment; her perspective and needs are also placed in the foreground in Marie's parts; Ernaux's house is where most of the photos were taken and all the reflections on writing belong to her. The fact that the relationship is recent and that the couple does not have a shared past life contributes to the sense of a distance to be bridged, which Marie compensates with what he has learned about the writer through her books, as it happens when he and Ernaux visit the house where she grew up: « There I found details that she had mentioned in her books. Somewhere, we could feel like we were on an equal footing by now» (Ernaux and Marie 2005, p. 128). Nevertheless, between the lines Marie shows an inferiority complex towards Ernaux, expressing insecurities ranging from the woman's greater height (she is also older, therefore arguably more experienced) to her talent and fame as a writer.

Particularly revealing of these feelings of inferiority is a passage in which the couple, while having sex, throws on the ground the objects on the desk where Ernaux usually composes her works: Marie confesses that he has taken pleasure in desecrating her «sanctuary» and being put before «what she is socially recognised for» (Ernaux and Marie, 2005, p. 91). Marie also recalls the day when, in the absence of his partner, he sat at Ernaux's desk, as if to rehearse her role as a writer. As for Ernaux, with regard to sex in her studio, the momentary oblivion is twofold, since she sets aside both her literary activity and illness, thanks to Marie's ability to make her «live above cancer» (Ernaux and Marie 2005, p. 87). It is always Ernaux, however, who fears that there is an unconscious textual strategy at work on her part aimed at not really making room for Marie's writing: «Sometimes that scares me. To open up your writing space is more violent than to open up your sex. What an unconscious strategy, perhaps already at work, to make no room for him» (Ernaux and Marie 2005, p. 62). It is possible that illness, for a writer like Ernaux, entails the fear of no longer being able to master her own story. Unlike the presence of two actual co-protagonists in *Cancer in Two Voices*, then, Annie Ernaux emerges as the true heroine of the story in *The Use of Photography*, and not only because of her illness, but also because of her posture as a writer highlighted in the text. In addition, this is allowed by the fact that death acts as a vague threat in the text, without having the more defined contours of the imminent and announced end which Barbara Rosenblum must face, eventually being forced to surrender her story into the safe and loving hands of her partner.

The story goes on

While this article is focused on the act of collaborative writing, it is worth adding a few final observations on how the reading, at all levels, of their work is conceived by the authors, and how it expands the relationality of both memoirs to include a broader public. As we shall see shortly, in Ernaux's case this implies overcoming Marie's role both as the primary recipient of her text and as the exclusive representative of her kinship during her illness. Similarly, I will show how Rosenblum openly questions her readership and how, as she approaches death, this reflection has to do with the idea of legacy.

In the epilogue to *The Use of Photography* Ernaux confesses that she did not write thinking Marie would read her texts and that she was afraid, in exchanging their pieces, of discovering his otherness, wondering whether writing separates or reunites. We do not know the outcome of the couple's reading of each other's texts, but having had access to the complete work, we may see a certain distance persisting between the authors despite and throughout their co-authorship. Ernaux's introduction serves to shorten the gap between the text and its readers, who are responsible for bringing it to life and enriching it with their own experience: «The highest degree of reality, however, will only be attained if these written photos are changed into other scenes in the memory or imagination of the readers» (Ernaux and Marie 2005, p. 17). Noting how Ernaux also writes to make public her own breast cancer story, positioning herself in an unbroken chain of sick women, an important part of the audience the author refers to is therefore likely to be female. This bond with other women, who perhaps represent the actual kinship for Ernaux in her work, establishes a continuity both in the past, given by those who have experienced illness before, and with those who will read her work and come after her.

Even if *Cancer in Two Voices* and *The Use of Photography* have clear narrative closures (death for Rosenblum, recounted by her partner; recovery for Ernaux), the authors of both works call on their readers to continue their stories in the form of testimony. In the imminence or fear of death, the preoccupation with one's role within a continuity through writing and reading appears more accentuated in the absence of children to whom the story of a life can be passed on. As Nancy K. Miller points out: «What happens to our legacy if there is no next of kin? […] Who will witness your death? Visit your grave? Tell your story?» (Miller 2000, p. 11); «To be a childless adult (and to be straight) represents a peculiar form of marginality in a culture dependent on identities of generation» (p. 65). For Rosenblum, this problem does not arise, as she is able to count on a kinship whose value is not diminished by the absence of children. *Cancer in Two Voices* includes a letter to this effect, addressed to her nephew Asher who is still a child. His aunt has made sure to leave 13 letters to give him for as many birthdays when she will no longer be there. The letters contain moral teachings based on Rosenblum's life (the one included in the work, for example, focuses on the theme of fullness) and are recognised as an «ethical will» by the rabbi with whom she is preparing to die according to Jewish tradition, tracing her act back to a practice with a long history (see Butler and Rosenblum 1996, p. 192). Consequently, Rosenblum's trajectory, made even more meaningful by the narrative of and through illness, is rooted in a long-term continuity that honors her identity as a woman and a Jew and projects herself into the future. Readership therefore allows one's own story not to end completely and to establish bonds that go far beyond the private circle. This aspect, albeit with some differences, can also be found in Ernaux's text and reinforces the relational nature of both works examined.

My comparative analysis of *Cancer in Two Voices* and *The Use of Photography* shows that although starting from similar premises, namely a collaborative writing project based on a diagnosis of breast cancer, the narrative outcomes can be significantly different in terms of content and form. Affinities and divergences have emerged by adopting the specific relationship between the two authors of each memoir as a key. Firstly, I noted that, even if kinship is primarily made to coincide with one's partner, who has absolute prominence in the relational dimension of both sick authors, it does not overlap with the role of caregiver. While Sandra Butler does take on this role, Marc Marie does not. Secondly, I observed that the notion of kinship is more extended in *Cancer in Two Voices*, where friends and other family members appear significantly, while in *The Use of Photography* the couple is the only relevant bond to be involved in the experience of illness. In any case, the texts analysed, both devoted to introspection, problematise these same bonds, which are strengthened but also complicated by the appearance of breast cancer, since the diagnosis brings to light the strengths, limits, nuances, and contradictions within the couple's life. Ethical dilemmas and ambivalent connotations thus arise, given that a partner and/or a caregiver can be both a reassuring and intrusive presence.

Despite the premise of a writing project equally divided between each memoir's authors, narrative authority will, more or less intentionally, become unbalanced or unevenly distributed in a co-authorship between a patient and their next of kin. The article has explored this dynamic by taking into account the authors' biographies, the specificity of their relationship, and the inextinguishable opposition between the healthy and the sick. Nonetheless, in both works breast cancer is considered an experience capable of establishing a sort of blood bond with all women, whether known or never met, connected and united through writing. What emerges is a shared and further reinterpretation of the notion of kinship that extends towards a wider readership.

Finally, the multilayered and collaborative narratives I have examined are supported by the idea that choosing to show ourselves to others means making ourselves visible and intelligible to ourselves. This is a central task for autobiographical writing that the concomitance of illness further complicates because it forces us to deal with our vulnerable and mortal nature. The plurality of voices and perspectives which enriches *Cancer in Two Voices* and *The Use of Photography* allows these intimate texts to transcend the private and individual dimension, honoring the closest ties, but also building extraordinary bridges with people and realities distant in time and space. In conclusion, this is one of the powers of literature that the co-authored stories discussed here express in an exemplary way: «We need a language and stories for an exchange between generations that bypasses the body and the family: bonds of paper, not only bonds of blood. We are also connected by books and the friendships that grow out of them» (Miller 2000, p. xii).

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- inddragelse af antropologi/medicin, humaniora/sundhedsvidenskab
- inddragelse af relevant eksisterende litteratur
- sikker sammenhæng mellem metode, analyse og fortolkning, herunder overbevisende argumentation for/diskussion af forskerens valg og konklusioner.

Omfang: Max 9000 ord inkl. dansk og engelsk abstract (max 250 ord hver), noter, referenceliste

Oversigtsartikler

Vi publicerer oversigtsartikler, der med baggrund i et præcist defineret emne formidler et fyldestgørende overblik baseret på en kritisk gennemgang af eksisterende viden samt peger på fornøden ny forskning. Der lægges vægt på:

- bidragets velafgrænsede fokus og betydning

- inddragelse af antropologi/medicin, humaniora/sundhedsvidenskab

- en systematisk, kritisk inddragelse af eksisterende viden

- klar faglig positionering af forfatter

- begrundelse af valg for oversigtsvinkel (historisk, metodisk, begrebsafklarende, teoretisk, m.v.)

Omfang: Max 12000 ord inkl. dansk og engelsk abstract (max 250 ord hver), noter, referenceliste

Essays

Vi publicerer essays, der formidler et emne, hvor forfatterens faglige indsigt har givet anledning til at give udtryk for en ræsonnerende holdning til et emne. Der lægges vægt på:

- at teksten er afrundet og relevant

- betydningen for ny tænkning og nye ideer

- fascinerer og udfordrer læseren med overraskende formuleringer, sammenstillinger og synspunkter

Omfang: 3000 ord inkl. noter og referencer. Abstract er ikke nødvendigt til essays.

Anmeldelser

Herudover modtager vi gerne relevante anmeldelser af bøger mv. Disse må i omfang ikke overstige 1500 ord.

Udformning af et manuskript

Sprog

Manuskriptet skal følge gængs retskrivning på et af de skandinaviske sprog. Vi antager undtagelsesvist manuskripter på engelsk, og kun hvis der foreligger en rimelig grund hertil (f.eks. ph.d.-artikel, der skal skrives på engelsk; engelsksproget forfatter). Ved engelsk manuskript påhviler professionel sprogrevidering og korrekturlæsning forfatter. Redaktionen har desuden ikke kapacitet til at korrekturlæse norsk eller svensk, og det er derfor også forfatters ansvar, at der er læst korrektur på norske eller svenske manuskripter. Vi vægter et klart, præcist sprog.

Opsætning

Manuskripter skal indsendes som word filer og sættes op med skrifttypen Times New Roman str. 12 og halvanden linjeafstand. Kortere citater (under 3 linjer) anbringes i teksten i "citationstegn". Er de længere (mere end 3 linjer) anbringes de som selvstændige afsnit indrykket fra både venstre- og højrekant.

Indhold i indsendelser

Manuskriptet indsendes elektronisk via tidsskriftets website. På websitet opretter man sig selv som 'author' og følger dernæst anvisningerne for submission.

Artiklerne skal være udformet efter denne standard og indsendes i følgende dokumenter:

1. Dokument: forside med forfatter (e), titel (både på originalsprog og på engelsk) og korresponderende forfatter

2. Dokument: artikeltekst med dansk og engelsk abstract, brødtekst forsynet med mellemrubrikker, citater, litteraturhenvisninger, referenceliste inkl. doi-numre samt eventuelle noter (slutnoter) og eventuelle illustrationer, tabeller og figurer med forklarende tekst og kildeangivelse.

3. Dokument: Kort forfatterbeskrivelse, som angiver uddannelse, ansættelse og forskningsområde (max 50 ord)

Herudover indtastes følgende informationer under punktet 'metadata':

1. Titel
2. Forfattere
3. Abstract
4. Referenceliste inkl. doi-numre

Referencer

Angivelser af referencer følger principperne for APA outputstyle. Det er forfatterens ansvar, at referencelisten er korrekt opstillet. På alle referencer som har et DOI skal DOI-nummer anføres og referencelisten/litteraturlisten skal både sættes ind i 'metadata' ved indsendelse af manus samt i dokumentet med artikelteksten.

Ved angivelse af sidetal i forbindelse med citationer markeres sidetal med komma (Efternavn 1998, 207) eller med s' (Efternavn, 2000, s. 207). Valget mellem de to skal være konsistent igennem hele artiklen.

Se eksempler herunder:

Bog: Bourdieu, P. (1977). Outline of a theory of practice. Cambridge, UK: Cambridge University Press.

Bogkapitel: Macintyre, S., & Ellaway, A. (2000). Ecological approaches: Rediscovering the role of the physical and social environment. In: Berkman, L.F. & Kawachi, I. (eds.), Social Epidemiology (pp. 332-348). New York: Oxford University Press.

Artikel: Cheek, J. (2004). At the Margins? Discourse analysis and qualitative research. Qualitative Health Research, 14, 1140–1150. doi: 10.1177/1049732304266820.

Web-referencer skal angives med fuld URL (web-adresse) samt angivelse af hvornår web-stedet blev besøgt. Derudover angives også oplysninger om forfatter, når dette er muligt. Web-referencer bør om muligt indsættes på samme måde som øvrige referencer.

Noter anbringes efter teksten og notenummeret anbringes i teksten i løftet petitskrift. Indskriv notereferencerne manuelt (undgå tekstbehandlingsprogrammers fod- og slutnotefunktioner).

Proces

Tidsskriftet påtager sig den endelige redigering, korrekturlæsning og sætning. Kommasætningen vil blive rettet efter sprognævnets anbefalinger.

Tidsskriftet forpligter sig ikke på forhånd til at trykke artikler, hverken opfordrede eller uopfordrede. Egnede manuskripter bliver sendt i peer review. Efter peer review og revidering af manuskript kan redaktionen vurdere 1) at manus er klar til korrektur og trykning, eller 2) at manus går til en yderligere revisionsrunde på baggrund af redaktionens kommentarer.