

**The personal is political yet again: Bringing struggles between gender equality  
and gendered next of kin onto the feminist agenda**

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### **Abstract**

In spite of feminist criticism of the welfare state, Norwegian society is frequently perceived as gender-equal. As a truism of public discourse, gender equality affirms a neoliberal understanding of individuals as able to act independently and to freely choose their course in life. This article disrupts that truism with an analysis of a transitional process that occurred to a seemingly free and gender-equal married woman whose everyday life took an unexpected turn at the age of 50 when her husband was diagnosed with Alzheimer's disease. Using an abductive method, we construct a narrative with this woman as the main character. We then use the narrative as an optical device for scrutinizing encounters between the notions "free and gender-equal woman" and "gendered next of kin", analysing the situated becoming of gender and understanding the encounters' potential for agency and resistance. The inquiry brings a pattern of gendered encounters into being, demonstrating how a seemingly free and gender-equal woman's strength and independence become subordinating weaknesses in encounters with the welfare state. This paradox raises questions about the politics of everyday life in a presumably gender-equal society, brings new

struggles onto the feminist agenda and demands that the personal becomes political yet again.

### **Keywords**

Feminist Politics, Struggles, Gender Equality, Next of Kin, Alzheimer's Disease.

### **Introduction**

It took four policemen to get him out of the house. Four. They took him to the emergency psychiatric clinic. What if she had been alone? What if the police had not come so quickly? What if...? It was so close. Who could have imagined such a scenario when promising, "... for better, for worse, in sickness and in health, until death do us part", as they had done more than 30 years ago? Death had nearly parted them that day. It was so close – and so unnecessary – if only someone earlier on had taken her fear seriously.

This critical episode, in which a woman narrowly escaped being killed by her husband, is the climax of the narrative unfolding in this article. The episode might represent an account of domestic violence as gendered homicide that demands to be explored, but it is also a place to begin an inquiry into everyday life in a society that is

proud of its state feminist heritage (Hernes, 1987; Tryggestad, 2014). Through the creation of a narrative about a white Norwegian heterosexual couple afflicted with Alzheimer's disease, this article takes the latter approach to make sense of the former. The main character in this narrative is a married woman we have called Sara. The point of departure for our research is a period in her life in which her otherwise gender-equal family life begins to crumble, and she struggles to make sense of what is happening. According to Dahl (2017), such struggles might be about who we are, or will be, but they are also about power and political processes, and are helpful tools for analysing change and for understanding the connections between the individual and society. By inquiring into Sara's everyday struggles, our endeavour has been to understand the specific extreme situation as more than an individualized event, but also more generally to develop an understanding of how similar personal struggles may be seen as political issues.

The narrative's main character, Sara, is modelled after a woman who told her story in two interviews that we conducted with her as part of a research project that analyses the everyday lives of younger families living with Alzheimer's disease. Sara was only 52 years old when her husband, whom we have called Paul, was diagnosed with the disease. In addition to the story that Sara's model told us, the narrative consists of fragments from the study's interviews with other families and healthcare professionals. To make Sara's model, her family, and their healthcare providers unrecognizable, we have altered some detailed characteristics of people and places.

Sara and Paul had full-time careers in addition to sharing the responsibility for three children. She worked in the public sector, he in the private business sector – a

typical segregation of occupation by sex in Norway (Håland & Daugstad, 2005). In spite of its clearly gender-segregated labour market, Norwegian society is considered highly gender-equal, with annual top rankings on the Global Gender Gap scale (World Economic Forum, 2015), and a dominant (pre-#MeToo) public discourse positioning women as equally free to choose lives of their own liking, and equally strong and independent in their choices. Such rhetoric of women's and families' freedom of choice has grown into a taken-for-granted good alongside the emergence of local manifestations of global neoliberal politics (Fraser, 2013). The welfare state, moving in a woman-friendly direction with immense importance for women's liberation, as Hernes (1987) observed in the 1980s, may be described in the 2010s as a neoliberal state embracing equal opportunities, individual rights and free choice, but also individual responsibility for one's own life (Liinason, 2018). Sara and Paul displayed this Norwegian neoliberal gender-equal ideal, living as an egalitarian, monogamous, heterosexual couple with children (Seeberg, 2012).

Then, through no choice of their own, they met Alzheimer's, and the disease afflicted their lives in specific gendered ways: he as the sick person and she as his wife.

Whilst the research literature has analysed and problematized the notions of "free and gender-equal woman" (e.g. Borchorst & Siim, 2008), and "gendered next of kin" (e.g. Bartlett et al., 2016) as two distinct categories, the encounters between them remain to be explored. The purpose of this article is, therefore, to use the narrative about Sara and Paul to scrutinize these encounters, analyse their potential for agency and resistance, and consider the need to bring new struggles onto the feminist agenda.

Hence, the encounters in which Sara's struggles appear are our units of analysis, and our approach is inspired by material feminisms. Material feminisms constitute a set of theoretical propositions within a shared onto-epistemology, rather than being one coherent, grand theory (Alaimo & Hekman (eds.), 2008; Barad, 2003; Van der Tuin, 2011). This set of propositions allows us to see beyond simplistic binaries towards understanding the world as consisting of ongoing intra-actions of becoming that must be inquired into as they unfold. The encounters are, therefore, intra-actions, not the actions of individuals, which also implies another understanding of individuals than that of the neoliberal rational and coherent individualized self. According to Barad (2007, p. IX), "[e]xistence is not an individual affair. Individuals do not preexist their interactions; rather, individuals emerge through and as part of their entangled intra-relating."

Being entangled means to lack independent, self-contained existence, and because "inter-action" means action between independent units, "intra-relating" and "intra-action" are more precise characteristics of the entanglements. Encounters are, therefore, entanglements of socio-material agents, such as people, policies, and things, producing order in everyday life. Translated into our narrative, this means that Sara's struggles appear in encounters that cease to produce meaning and order. Such encounters provide the point of departure for our research.

### **Creating the narrative**

The empirical material for our analysis of the encounters stems from a sociological research project on citizenship and families living with early-onset Alzheimer's disease – a disease that medically speaking is a brain disorder causing rapid cognitive decline. Alzheimer's disease is the most common form of dementia (AlzOrg, 2016). “Early onset” means that it appears before people are 65 years old, and “living with” implies an understanding of the disease as an agent among other socio-material agents shaping peoples' lives (Authors, 2018). In contrast to mainstream medical and caring approaches that are concerned with the brain, the individual with the disease, and sometimes family members as individualized entities, our approach highlights societal and political aspects of life with the disease through the connection of Alzheimer's disease to citizenship – hence, the disease is treated as a collective rather than an individual condition.

The rationale for early-onset Alzheimer's as a departure point is that those afflicted are usually active participants in society through paid labour, have children living at home, and are physically fit and healthy at the time the symptoms emerge. The changes in their everyday lives are, therefore, more dramatic than those of older people. Approximately five per cent of people with Alzheimer's disease have early-onset (World Alzheimer's Report, 2015), and an estimate for Norway is 1200 people below 65 years of age with this disease (Rosnes, Haugen, & Engedal, 2011).

Without giving any specification of identity markers as inclusion criteria, we asked key informants from the public healthcare system to assist us in the recruitment of families to the study and acquired 15 white, apparently heterosexual families. The sample consists of an even distribution of women and men. Family members with the

disease were included in our original design, but only two spouses agreed to consent for them. Therefore, but also because the unit of analysis was encounters rather than individuals, and because of our focus on societal processes of becoming rather than individuals' experiences of life with early-onset Alzheimer's disease, we redesigned the study without them being directly involved.

We interviewed 15 relatives of the younger persons with early-onset Alzheimer's disease (14 spouses and one daughter), 12 of them twice, 9–12 months apart. Depending on family members' preferences, we conducted the interviews at a convenient time in their homes, workplaces, or a rented space. Using an ethnographically oriented interview technique, we asked about everyday life situations: what happened, who and what was involved when, thoughts about living with a loved one with dementia, and changes in everyday life. Through these interviews, we generated a pool of potential professionals for the study but contacted them only if family members agreed. In total, 27 healthcare professionals from auxiliary care, respite care, home care, nursing homes, day-care centres, and provider offices agreed to be interviewed. As they represent the frontline of public healthcare policy, and gate-keepers to public healthcare services (Lipsky, 2010), their contributions became important for our analysis of the encounters between the individual and the state.

The main project employed a feminist citizenship approach (Lister, 2003), but without an explicit aim to understand gender or gendered processes. However, throughout the generation and analysis of the material, gender appeared repeatedly and in different ways as crucial for our understanding. Unlike the other publications

from the project (Author, 2017a; Author, 2017b; Authors, 2018), this article therefore privileges gender, and whilst the authors (2018) discuss different citizenship effects of intra-actions, this article demonstrates different gendered effects.

The entire interview material has informed this article's analysis, but one interview with a female next of kin particularly triggered our curiosity and urged us to delve into the gendered aspects of the material. She recalled a feeling of unease in an encounter with a healthcare professional who repeatedly mentioned the importance of the marriage contract for what to do in her situation. The relevance of this interview was not immediately obvious to us, but the mentioning of the marriage contract was an alert about potentially critical gendered processes requiring further investigation. Our close reading of that interview transcript launched the process of constructing the narrative we analyse here.

Through an abductive process of recursively shifting between interview material, available documentation and theoretical work (Alvesson & Skjöldberg, 2009), the narrative gradually took shape, and we began to see provocative connections between the individual woman, after whom Sara is modelled, and societal processes. In this way, the narrative became an optical device for diffracting critical inquiry into the production of gender and the effects thereof (Haraway, 1997). By following Sara's struggles, we became aware of encounters in which gender emerged as different and differentiating effects of entanglements of human and non-human agents. The patterns formed by these encounters facilitated an analysis of how seemingly private matters became political. As approximately two-thirds of primary caregivers for people with dementia are women (Alzheimer's Disease International,

2015), such gendered processes may potentially have relevance far beyond Sara's case.

A methodological consequence of our approach is a move away from mirroring reality to critically diffracting into the becoming of differences and their effects as they unfold. Mirroring reality as a target would have demanded the presence of the researcher during the events to observe what happened. However, seeing the emergence of differences and their effects as they unfold means that the researcher takes part in ongoing processes of becoming. Through our engagement with people in interviews, we took part in ongoing processes of becoming by asking them questions that stimulated their reflections about relevant events. The stories they told became the basis for inquiring into the differences. Hence, this approach denies that reality can be represented and that distinctions between reality, the told stories, and our analysis of them can be made objectively. As an alternative, the creation and analysis of the narrative enables us to see things differently, to see different things (Haraway, 1996), and raise new questions for both policy and research.

### **Love, connection, and duty – on becoming an informal carer**

Sara began to notice changes in Paul's behaviour long before he was 52 years old and received the diagnosis. He would come home from work earlier or later than normal, bring home the same items from the grocery store as the day before, lose concentration and interest in conversations, or repeat the same story from work one day after another. Annoying as this behaviour was, she confused it with a stressful job

situation. However, when he – an experienced traveller – asked her one day to help him book a flight, and another day asked her to assist him with financial issues at work, she realized that it had to be something else. This was too abnormal. She therefore encouraged Paul to visit his general practitioner (GP).

Paul went to his GP, but like many Norwegian men who do not easily talk about their health (Anderssen, 2008), he only told Sara “it’s fine!” As time went on, the situation at work and at home deteriorated. Via friends of theirs who were also his colleagues, she understood that he did not follow up on decisions and that the bank was concerned about the failure of his business to make payments. At home, anger often replaced his lively good mood and Sara became worried. What if it was something really serious, such as a brain tumour? She desperately needed an answer and decided to go with Paul to his GP. The encounter was not helpful for Sara. The GP did not see anything wrong in Paul’s behaviour and consequently did nothing to diagnose him. “Because he is young and good-looking, with a seemingly intelligent appearance, and manages to answer adequately even though he hasn’t understood a thing, the doctor trusts him, not me!” (Sara)

Sara felt that the GP’s treatment of her worries was very disrespectful to her. In retrospect, she came to think about how Paul had accused her of nagging when she talked about his health and mentioned her worries. Unlike many others with the same disease, he was still linguistically strong and used to tell not only Sara, but also friends and family, that she was such a nag who exaggerated the problem, because nothing was wrong with him. They tended to believe him, the successful

businessman. She thought that maybe he had told the GP not to worry about his nagging wife.

Eventually, Paul's GP was replaced with another GP who understood the situation differently and referred him to a specialist unit, a memory clinic, for medical assessment. Finally, a shocking diagnosis came: early-onset Alzheimer's disease. It did not make sense, but at the same time it made a lot of sense: he was too young and vital for a condition commonly understood as an old person's disease, but it explained so much. Life became comprehensible, but also very difficult because of the escalating progression of the disease.

Paul's behaviour changed, not only in the direction of forgetting, but also towards aggression and violence. The home-care situation became unbearable for Sara. Even though she had believed all along that she would manage, she had to admit that she no longer could. The GP and Sara applied for permanent nursing-home residency for Paul, but the application apparently did not present good enough evidence. The municipality needed to conduct a specific appraisal of Paul, implying observation of him in a nursing-home setting. The memory clinic took him to a nursing home – away from their home, the site of his aggression and violence – that made him do everyday tasks together with other people with dementia. He did fine. He behaved and managed to lay the table, and the application was turned down. They knew what his needs were: not nursing-home residency but stability and care in Sara and Paul's home.

Sara phoned the memory clinic and asked why they had given Paul such a positive score in spite of her testimony about the situation at home and the evidence from the CT scans of his brain. She was convinced that the healthcare system would rely on its own proof – why should they do those measurements if not? The CT scans clearly showed that “everything is gone!” as Sara put it. Instead, the professionals at the memory clinic reminded her that she had once signed a marriage contract with some duties she had to fulfil and that she had to stand by it, as she had vowed, “I do!” some 30 years earlier. She had thought a lot about just that issue, and felt that she had done her share, that it was not right to accept being eliminated as a person, or to let death actually part them as a result of him killing her. “I do not see being slain as my duty”, she said ironically.

The situation made Sara physically ill. She lived in constant fear of what Paul could potentially do to her, but she had to be strong and take care of him. She was thinking about quitting her job altogether but had second thoughts. If the situation improved and enabled her to work again, her age would very likely prove to be a serious barrier. Who would hire a woman in her fifties, who had been out of work due to health issues? The prospects were not good. She saw her GP, who gave her a medical certificate to go on sick leave. Paradoxically, she took leave from paid work – which had given her some relief – to be able to do unpaid care-work at home – which was what had originally made her sick.

The incident with the police was a door opener to permanent residency for Paul in a nursing home. His moving out was a relief for Sara but at the same time very sad, not least because of the way it had happened. She did not want to get rid of her

husband, but she could no longer handle the situation. She struggled. Then a municipal officer phoned Sara and humbly apologized for having turned down the application for permanent nursing-home space only a few months earlier. The officer told her that their instructions were to follow the advice of the memory clinic, in this case turning down her application. She then asked her GP why no one had taken her complaints and worries seriously before, whereupon he replied that she did not look like a suffering woman. Sara recalls saying, “but I’m crying in every meeting”, and the GP replied, “but even so, you look too strong and fit, more than strong enough to handle it”. (...) “So maybe they didn’t believe me, and thought I was lying – I don’t know!”

Finally, she said:

As soon as I feel strong enough I will ask for a meeting with the memory clinic. I need to know how far they find it reasonable to push the duties of a marriage contract. I don’t think any individual, or society for that matter, gains anything from a wife, or an entire family, succumbing. I hope no one will ever experience what I did. I felt absolutely betrayed.

Sara cared about Paul’s life, but also about her own life and their relationship. After all, she loved him, but gradually caring *about* their life became caring *for* Paul (Dahl, 2017). The entanglements of love, connection and duty made her take on the responsibility of becoming an informal carer – a transition that happened almost imperceptibly, but at the same time not without struggles. These struggles guide us to the gendered encounters of our analytical interest.

## **Gendered encounters**

The first encounter to which the narrative directs us is that of a presumably gender-equal family life. Like other middle-class couples, Sara and Paul enjoyed a relationship nurtured by Norwegian ideals of mutual respect for, and trust in, each other, enabling gender as heteronormative equality. However, the appearance of Alzheimer's disease – at this point in the narrative, an unknown intruder into the ideal family life – disrupted the once-established order. Gradually, the uncertainty to which this intruder gave rise turned what had been mutual respect and trust into the opposite. The new encounters, including those with family, friends, and Paul's GP, positioned Paul as trustworthy and respected, Sara as subordinate and wicked. Rather than expressing a wife's reasonable concern and right to know, her worries about his health condition and desperate need to know became merely those of an annoying, nagging wife.

Sara's insistence on going with Paul to his GP was an expression of her lack of trust in him – the mistrust was mutual. Convinced that the GP would listen to her, inquire into her concerns, and finally support her in a search for answers, Sara set out to use her strength and will to find out what was going on. However, her questions and worries met no resonance. Sara's agency was not in her power to decide but was an effect of the intra-actions of the encounter. Agency clearly emerged from the encounter, enabling Paul, not Sara. The GP's office emerged as an arena for the becoming of male superiority.

Because the professionals at the memory clinic approved of Sara's struggles and diagnosed Paul, this first memory-clinic encounter produced a new order. Now, the previously unknown intruder into their gender-equal family life got a name: early-onset Alzheimer's disease. Eventually, Paul lost his legal rights, and the diagnosis became an influential socio-material agent. This encounter enabled Sara to make decisions of importance, not only regarding their everyday life but also matters concerning Paul's working life. Again, gender relations shifted; now Sara became the trustworthy and strong party, whilst Paul was stripped of his responsibilities at work and at home. At the same time, her responsibility for maintaining his well-being increased immensely. In this encounter, we see Sara become a female-gendered next of kin.

When the disease progressed and interfered with this newly established order, gender relations shifted once more. Paul's aggressive and violent behaviour transformed their everyday life. Paul became a dominant, physically strong man, and their home a site of fear and violence. Sara worried about how much damage Paul might do to her but refused to accept being in such a state of gendered oppression. If he continued to live at home, she was afraid that she would either be eliminated as a person or be killed. She had reached the limits of her duty as a wife when she applied for permanent nursing-home residency for Paul. For her, it was obvious that such an assignment was the only permanent relief from her threatening everyday life situation.

It turned out that Sara's understanding of the situation was not shared by those concerned with municipal rules and regulations. Due to a shortage of nursing-home

spaces, and substantial costs related to them, the municipality needed proof from professional experts to assign a space and asked the memory clinic for help. However, this expertise seemed to have less influence on the assessments than the gate-keeping responsibility of controlling access to welfare goods. Here, the marriage contract became a convenient agent. Although CT scans of Paul's brain showed severe brain damage, the memory clinic did not accept that Sara's testimony necessitated a permanent nursing-home space for Paul. Instead, the professionals reminded her that she had vowed to care for him "in sickness and in health till death do [us] part", implying that as he had a wife he did not need a permanent space. The duty to care for Paul was Sara's, not the municipality's. In and through this encounter, Sara emerged as a whining woman trying to escape her obligations as a caring wife.

The expectations of Sara's contribution to Paul's care were considerably higher than those of male next of kin (Bartlett et al., 2016). Such gendered expectations are also recognized in other empirical fields, such as rehabilitation (Breimo, 2014). The memory clinic in our narrative was sympathetic to the needs of the male next of kin who came there with their wives. The memory clinic did not expect them to be able to deal with a situation similar to Sara's. Instead, the men emerged as helpless, in a pitiful state with a legitimate need for help. Indeed, according to the memory clinic staff, they were helped:

The reality is still that when a wife "allows herself" to become sick, then the husband deals with it badly, and much worse than the other way around. So, it's obvious... if the wife is here for medical assessment regarding dementia, it is likely that the husband needs help. I don't know if we use more resources

on husbands than wives in this situation but men certainly still need more help than women. We assess the situation and provide what they need.

Understandings of men as strong and independent, and women as weak and dependent, were again turned upside down – with negative effects for women. Rules, regulations, healthcare professionals, and the marriage contract all contributed to the becoming of female subordination in and through this encounter; paradoxically, in spite of the positioning of Sara as strong enough to carry the caring responsibilities.

According to Sara's GP, whom she described as being very supportive of her, it was due to her appearance as strong and independent that her struggles were not taken seriously. What she said and did produced little or no resonance with their expectations of a weak, suffering woman, in spite of her tears. She stood up for herself and was critical of what the healthcare system did to her and Paul, but such an appearance was not in accordance with the image of a woman in need of help. Unlike the women in a study on female caregivers, who considered care of their own lives to be less important than care of their husbands' (Eriksson, Sandberg, & Hellström, 2012), Sara stood up all along for her right to have a life and remain a free and independent individual. However, as a nonconformist in the municipal healthcare system, she struggled to make it happen. Convinced that she was right and had rights, she – the free and independent individual – would resume the fight and come to terms with the situation as soon as she felt strong enough.

Sara's perception of her potential agency mirrors a neoliberal understanding of individuals as able to act independently and freely choose their course in life.

However, our analysis of the gendered encounters in this case portrays agency and resistance differently, as enabled or disabled in and through the encounters. For Sara, sometimes agency, sometimes not, were the effects, depending on the entanglements of the human and non-human agents constituting the encounter. She was not free to choose. Paradoxically, her strength and independence, entangled with the marriage contract and other agents, disabled her agency in critical situations. We understand this paradox as one major effect of the encounter between the notion of “free and gender-equal woman” and “gendered next of kin”.

### **Societal effects of gendered encounters**

Taking the paradox back to the specific situation of life-threatening violence that introduced our narrative, we suggest an understanding of the near-homicide that goes beyond an incident in a married couple’s life. We also move beyond medical explanations about brain damage making Paul violent, despite the important fact that changes towards aggression and violent behaviours are more frequently found among men than women with Alzheimer’s disease (Cooper, Selwood, Blanchard, & Livingston, 2010; Eastley & Wilcock, 1997). Instead, to understand how such a crisis could take place at all, and will again, we suggest that it is an extreme expression of a gender-unequal Norwegian society. This paradox consequently raises general questions about the politics of everyday life in a presumably gender-equal society. From this perspective, we revisit the encounters constituting the narrative once more.

As the Norwegian GP system is a political construct framing the relationship between medical expertise and patients, the office of Paul's GP constitutes Sara's first encounter with the welfare state. The GP is constituted as the patient's advocate but also the gate-keeper to other healthcare services, and hence decisions made in the GP's office are consequential not only for the patient, but also for public healthcare budgets. The patient here is an independent individual with individualized rights, whereas the patient's spouse plays no role in this ideal dyadic relationship. The GP's rejection of Sara's worries is not one individual's act but an intra-action complying with the GP system's script, enabling the situated becoming of male superiority. The specific encounter at the GP's office that we have analysed should, therefore, be understood as an entanglement, not only of the people involved with their worries, attitudes and medical expertise, but also of the policies, rules and regulations forming the GP system.

One agent in these encounters, also active outside the healthcare system, is a gender hierarchy that positions certain masculinities on top in society (Connell & Messerschmidt, 2005). We find this agent active in the interpretation of Paul's complaints about Sara. To family and friends, and potentially also the GP, a nagging wife appears to be a credible interpretation of the situation – until Paul is diagnosed with early-onset Alzheimer's disease. Then he no longer complies with the masculinity that made him superior to Sara – a masculinity demanding complete cognitive abilities and control in life. With the diagnosis – in and by itself an intra-action – Paul lost his legal rights and consequently ceased to be a neoliberal individual.

The memory clinic, as a certified healthcare institution for providing a dementia diagnosis, is, like the GP, also a gate-keeper to public healthcare services and a distributed manager of welfare-state tasks. Even though Norway is an affluent society, concerns about the maintenance of adequate systems of care for the elderly in general, and for people with Alzheimer's disease in particular, are on the public agenda as an issue of budget savings. Therefore, Norwegian healthcare policy encourages more involvement of informal family carers, but at the same time underscores that such involvement should not affect women negatively (St. Meld. Nr. 29, 2012–13, p. 58). The gate-keeping role should be seen in this political light.

A diagnosis is necessary, but not sufficient for the assignment of services, such as permanent nursing-home residency. As gate-keeper, the clinic assesses the needs of the patient in accordance with Norwegian health and care policy. The policy is person-centred, and unsurprisingly the person in this policy is an individualized self (Bartlett & O'Connor, 2007), not an individual emerging "through and as part of their entangled intra-relating" (Barad, 2007, p. IX). Consequently, the memory clinic assessed Paul's needs according to such an individualized understanding of him, while Sara was given no space as a person in need. From a person-centred perspective, it is logical to assess a warm, caring home environment, when available, as best for Paul. Having a wife means by definition that Paul has a warm and caring home. Only when she resists this definition of the situation does the memory clinic constitute her as a woman who is trying to run away from her marital responsibilities and, in the same move, make her a resource for the management of welfare-state tasks. An in-principle gender-neutral task – assessing the need for permanent

residency in a nursing home – becomes a gendered and money-saving act interfering with Sara’s everyday life through a moral appeal.

In addition to being a contract between two individuals, under Norwegian law, the marriage contract regulates who can marry whom, financial issues between the spouses during marriage, and issues regarding the sharing of values. Hence, the contract is also between the individual and the state. The marriage contract demands a duty to provide for each other economically, including in these calculations unpaid work in the family, especially care for children. In case of divorce, the spouse who has earned less, and/or has had the main responsibility for childcare, may in principle take out as much value as the other. The law protects the rights of the financially weakest party, who most commonly is a woman, and secures her financial interests. These principles explain why a couple, like Sara and Paul, may be considered gender equal, in spite of major differences in income from paid labour. The marriage vow “to love and to care for each other in illness and in health” is not regulated by law, however. Bringing up the marriage contract in the encounter with Sara was consequently highly inappropriate and could potentially have led to a fatal outcome of violent abuse.

With Alzheimer’s disease in the family, the marriage contract no longer provides financial security, and the systematic pay gap between men and women produces gender inequalities and particular disadvantages for women whose husbands have Alzheimer’s disease. Firstly, because men in general earn more than women, the family loses the largest income source; secondly, the wife’s income diminishes when she is eventually unable to manage both paid work and unpaid care work at home.

Her earnings are not only reduced for the moment but also for life, as old-age pensions are calculated from years in paid labour. The contract between the individual and the state materializes as gendered, with negative financial effects for women.

Because of Sara's age, she potentially had many more active years in the labour market, but when the situation at home became more demanding, she found no other solution than to stop working. Her immediate thought was to quit her job altogether, but then a new agent entered the scene, this time the ideal worker (Acker, 1990), reminding her that a woman's value in the labour market decreases rapidly with age, and that a hole in the CV caused by caring for a husband would not be particularly helpful when she eventually returned to the labour market. Instead of letting the intra-relations of gender, age and health affect Sara negatively, her GP provided her with a medical certificate to go on paid sick leave and hence let the role of advocate for the patient overrule the role of gate-keeper for the welfare state.

The telephone call from the contrite municipal officer after the violent crisis in Sara and Paul's home expresses a gendered hierarchical relationship between the memory clinic and the municipality regulated by healthcare law. The municipality's office for providing healthcare services receives and treats applications from patients via GPs but, in cases in which dementia is suspected, the memory clinic is enrolled and has the final word. Whilst the municipal discourse is care-dominated, the memory clinic discourse is medicine-dominated, and the hierarchy between care and medicine, with medicine at the top, is as old as medicine itself, with clear feminine-care and masculine-medicine connotations (Sandelowski, 2000). Within this hierarchy, medical knowledge is privileged, but only in the hands of medics. Sara's use of the

CT scans to prove her case had no effect. Hence, medical knowledge does nothing in and by itself but only becomes powerful within certain entanglements, potentially producing consequential effects far beyond the medical domain into families' everyday lives.

The problematic assessments of Paul as weak, and Sara as strong, culminated in the violent crisis. In spite of common knowledge within the dementia field about behavioural, often aggressive, changes in people with dementia, Paul was always constituted as vulnerable and frail, and, therefore, in need of spousal care. Sara was constituted as strong enough to provide the care that Paul needed, in spite of her many attempts at communicating her feeling of frailty in certain situations. The shifting assessments of them as strong and weak also followed a pattern contrasting them with each other: one was always strong when the other was weak. Two strong or two weak persons at the same time seemed to be an impossibility, and so one was both strong and weak at the same time. Sara's appearance as a strong and independent woman thus did not fit with her desperate cry for help. Consequently, she did not get any help, and her strength became her weakness.

## **Conclusion**

Our inquiry into the encounters between the notions "free and gender-equal woman" and "gendered next of kin" has brought a pattern of gendered encounters into being, forming a gradual transition from a presumably free and equal woman in a personal relationship with her husband, to a subordinate and dependent next of kin in a public

relationship with the welfare state. Up to a certain point, every step on this route was her choice, but the choices were not free in the sense that she could have chosen not to take on the responsibility for her husband's life, as many men in a similar situation would do. The choices she made were rather effects of specific gendered interactions, and her personal struggles were effects of public policy. The potential for agency and resistance within this pattern of gendered encounters is, therefore, not to be found as a result of individuals' strength and will but as a result of making the personal political with demands for societal change rather than individual adjustments to a given situation. The pattern of gendered encounters raises a series of feminist questions, relevant not only to women, but to anyone in a similar situation, whether white heterosexual men, gay people, transgender people, or ethnic minorities.

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