

**Manuscript version: Author's Accepted Manuscript**

The version presented in WRAP is the author's accepted manuscript and may differ from the published version or Version of Record.

**Persistent WRAP URL:**

<http://wrap.warwick.ac.uk/117538>

**How to cite:**

Please refer to published version for the most recent bibliographic citation information. If a published version is known of, the repository item page linked to above, will contain details on accessing it.

**Copyright and reuse:**

The Warwick Research Archive Portal (WRAP) makes this work by researchers of the University of Warwick available open access under the following conditions.

Copyright © and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable the material made available in WRAP has been checked for eligibility before being made available.

Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

**Publisher's statement:**

Please refer to the repository item page, publisher's statement section, for further information.

For more information, please contact the WRAP Team at: [wrap@warwick.ac.uk](mailto:wrap@warwick.ac.uk).

**Corresponding author:**

Rikke Sand Andersen, Associate Professor, Research Unit for General Practice & Department of Anthropology, Aarhus University, DK

Bartholins Alle 2 – 8000-DK

[rsa@ph.au.dk](mailto:rsa@ph.au.dk)

**Authors:**

John McCartney, Senior Researcher, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Birgit H. Rasmussen, Professor, Department of Health Sciences, Lund University, Institute for Palliative Care, Region Skaane and Lund University, Sweden

Britt-Marie Bernhardson, Senior researcher, Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, Sweden

Senada Hajdarevic, Senior lecturer, Department of Nursing, Umeå University

Marlene Malmström, Senior researcher, Department of Clinical Sciences Lund, Institute for Palliative Care, Lund, Sweden

Sue Ziebland, Professor of Medical Sociology, Nuffield department of Primary Care Health Sciences, University of Oxford, UK

**Abstract**

Informal caregiving is increasingly considered a health care delivery-resource within the North European welfare states. While ‘informal’ often refers to non-professional, ‘caregiving’ connotes both affective concern (caring about) and practical action (caring for). This duality of meanings, however, often refers to the one direction in which care is given. Care, we suggest,

is relational and also requires that people receiving care are able to or wanting to share their needs. Informal caregiving thus requires sharing. Based on 155 semi-structured, narrative interviews with people with lung or bowel cancer, living in Denmark, Sweden or England, this paper explores how and with whom people ‘share’ when they fall ill. We approach sharing as a heuristic for reflecting on informal-caregiving, and illustrate how being *cared for* or *asking for care* are entangled with the management of social risks and notions of selfhood. We conclude that informal caregiving should explicitly be recognised as morally and sympathetically committed practices, which attend to the diversity of local moral worlds of patients, their needs and experiences.

**Keywords:** cancer, informal care-giving, sharing, illness experiences

## **Introduction**

In Denmark, England, and Sweden decades of neoliberal restructurings of the welfare states have moved the provision of healthcare from the margins of political attention to its centre. Across the three countries (with variable pace and impact) this has taken place in parallel with a retraction and change of traditional welfare programmes and a push for greater involvement of patients and their family in care practices. In line with other research, we suggest that such change equals – if not a reversal – then an alteration in existing politics of responsibility. In the welfare state the social responsibilities of the family, including those of caring and treatment, have been thoroughly organised and regulated through institutions (Wilkinson and Kleinman 2016) and part of what has been called a ‘faring well ideology’ (Langer and Hojlund 2011). According to Nikolas Rose and others (Rose 2007; Mikkelsen 2016), this is reflected in the way welfare states typically proliferate a politics of responsibility or a ‘responsibility contract’ building on the premise that the individual citizen takes optimal care of her own health, for which she in return may access highly specialised care and treatment when needed. For decades responsibility for care and treatment has therefore been placed in what Kleinman (1981) would call the professional sector and care practices have been considered a public or state responsibility. This development has naturally been supported by wider socio-political changes, such as women’s access to the labour market, and a shift towards increasing professionalization of care practices. As neoliberal restructurings of the welfare state represent, in many ways, a reversal of existing forms of social organisation, it is therefore highly relevant to explore the social practices that people engage in when they fall sick.

## **Calls for informal care-giving**

According to Johansson and colleagues, the family was ‘rediscovered as care-givers’ in Sweden in the late 1990s (2011: 342), and in many North European countries unpaid work by family and others, as well as a re-location of care practices to ‘the home’ is increasingly considered a necessary supplement to formal care provision (Pickard et al. 2000; Mattingly, Grøn, and Meinert 2011). English health policy experts have for example estimated a 40-60% increase in demand for informal care by the year 2031 (Pickard et al. 2007), and during the past decades various political incentives have been implemented to support the transition to more family based care. In Denmark, Sweden and England Leave of Care Acts were implemented as early

as the late 1980s and early 1990s and figures suggest that we may expect a steady increase in the prevalence of informal caregiving in all three countries (Verbakel et al. 2017; Beesley 2006). As indicated above, contemporary labour-market structures in Northern Europe, however, reflect a more traditional welfare-politics of responsibility, where the entitlements of the welfare system are based on the premise that citizens contribute through work. Also, the prevalence of single-households is increasing in all North European countries and people of pension age are twice as likely to live on their own as they were the 1960s (Beesley 2006; Eurostat 2018). Empirical studies thus suggest that contemporary family-structures and expectations may conflict with increasing demands for informal care and ongoing transitions in care-labour. Research continually indicates that the task of adapting to care-roles can be challenging, and in some local contexts it may be difficult to identify the necessary social or economic resources to carry increasing burdens of informal care (Romito et al. 2013; Broom et al. 2016; Nielsen et al. 2016; Mattingly, Grøn, and Meinert 2011) One Australian study, for example, describes contradictory understandings and tensions present in end of life care in hospital settings when carried out by close family members. Care is potentially a morally ambiguous social practice framed by positive connotations such as duty, gift and virtue, but often comprising experiences of failure, shame and suffering (Broom, Kirby, Kenny, MacArtney, & Good, 2016).

### **Care as an object of research**

Within anthropology, empirical philosophy and related disciplines, bodies of literature exploring care as a political and embodied, relational phenomenon have developed for the past two decades (Mol 2008; Wilkinson and Kleinman 2016; Yates-Doerr and Carney 2016). In this literature, care is often defined as acts of reciprocity that unfold within relations (Buch 2015) that are directed towards arranging, modulating or resolving needs (Mol, Moser, and Pols 2010). What is considered ‘good care’ may continuously be changing with context, and the need for empirically grounded explorations of care and care practices is emphasized. Rather than taking the contents of care for granted, this literature questions what constitutes care, for whom does it matter, what are considered needs, and into what politics do particular care strategies aim to interfere? (see e.g. Mol, Moser, and Pols 2010)

Since the 1970s, the concepts of dominance, subordination and biopower have become “a mainstay in within ethnographical inquiry” (Yates-Doerr and Carney 2016: 138). This is also evident in some of the theoretical conversations that have dominated care studies (Yates-Doerr and Carney 2016; Wilkinson and Kleinman 2016). This literature includes feminist writers who

criticize contemporary (Western) notions of care as socially engendered, devalued practices that are assigned to woman (Noddings 2013), but also more Foucauldian inspired scholars who point to the intimacies and affections that are mobilized through governance . In particular this literature has drawn attention to how the manifestation of biopower migrates outward toward people's homes and bodies through discourses of health and servitude. While power-perspectives have contributed important insights into the techniques through which bodies and selves are shaped, they rarely make visible the intersubjective dimensions such as affect, emotion or compassion in care (see e.g. Mol 2008 for more developed discussions on this).

Throughout the many interviews that we conducted as part of this study, we also came to see that a focus on biopower was insufficient for understanding the variety and differences in how our informants engaged with relatives or friends during cancer diagnostics and treatment. Our informants talked about their needs and their engagements with friends and family in terms of morality and empathy, and often they were more concerned with preserving stable social relations than attending to their health needs. Theoretically, this paper therefore locates care as a relational, social practice (Mol 2008; Wilkinson and Kleinman 2016). We follow recent theoretical conversations which highlight the intersubjective dimensions of care; and which focus on care as less a product of power, than as a social and moral practice, which is negotiated within complex biographical and cultural contexts of reciprocity and responsibility (Yates-Doerr 2012; Chattoo and Ahmad 2008; Mattingly, Grøn, and Meinert 2011).

This does not mean that power is not part of care. As indicated in the above, contemporary transitions of welfare produce new forms of social responsibility and forms of control that structure and define care-needs as well as the distribution of care-labour. Such transitions are indeed 'power-full', as they operate through what Foucault (1997) and Hacking (1999) would have called technologies of selves (e.g. it is 'good' to involve family in care) and classification (e.g. family members are transformed into 'relatives'). But to borrow from Mol, care does not *replicate* existing powers and it cannot be fixed within regulatory poles. It also follows its own logics (2008: 6-7). Care is not only the product of power, but it grows out of the very specific, intersubjective spaces or places in which it unfolds and are informed (but not determined!) by various cultural logics available. More specifically, we consider care as practices that attend to a variety of needs that are structured and identified through everyday socio-political engagements, and following Yates-Doerr "*that happens in the spaces of personal relationships, in linkages between formerly separated bodies and selves, and in the intimacies that form between one and another*" (2012: 139).

On this theoretical note and with reference to the socio-political back-drop of neoliberal landscapes of Denmark, Sweden and England which call for still greater involvement of family and friends in care, the aim of this paper is to explore cancer patients' illness narratives in order to understand how and with whom they engage when in need of care. As the socio-political structures of care-labour gradually makes informal care part of standard care, it becomes increasingly relevant to empirically turn to explore how people define and negotiate the moral boundaries around who can be involved in providing care (Chattoo and Ahmad 2008: 7).

### **The study**

The purpose of this project was to explore and compare cancer illness narratives across Sweden, Denmark and England, and identify potential system-related discrepancies in diagnostics and treatment. We recruited 155 people from Sweden, Denmark and England, seeking equal numbers of participants who were within six months of diagnosis of lung or bowel cancer (Malmström et al. 2018). Purposive sampling through hospital clinics in all three countries and through primary care, support organisations, snowballing and (in England and Denmark) social media, were used to achieve variation across gender, age, urban and rural locations, and pathway to diagnosis (primary care, screening programmes, emergency admission, investigations on other clinical pathways). Recruitment and interviewing took place concurrently in the three countries throughout 2015. A sociologist in England and an anthropologist in Denmark recruited and conducted all the interviews in their countries, while three nurse researchers collaborated in different parts of Sweden.

Interviews were conducted in participants' homes, unless they preferred another location. Interviews began with an open-ended question: "Could you start by telling me, in your own words and in as much detail as you want, about everything that has happened since you first started to suspect there might be a problem with your health?" The researcher then used a semi-structured topic guide based on relevant literature. Interviews were, however, not reduced to discussing specific topics, but looked to open-up reflections including those relevant to this paper, such as: experiences of talking to friends and family about falling sick; managing work obligations, engaging with children or close ones during illness, and experiences of the healthcare system.

*Analytical procedures and reflections on sharing as a heuristic for caring.*

Monthly teleconferences with the field research team were held throughout the recruitment, data collection and analysis phases. Interview accounts were analysed for narrative themes.

Researchers in each country conducted a separate thematic analysis using a coding frame developed through discussion in the teleconferences and based on the (anticipated) themes from the topic guide as well as emergent themes, which could be country specific. One two-day and one four-day analysis and writing workshops were held with the research teams from all three countries. Emerging analyses were iteratively tested with each country's dataset in ongoing dialogue with the international team, in light of existing knowledge and theoretical insights in the field. Selected Swedish and Danish interview extracts were translated by the bi-lingual researchers in preparation for this article.

Insights and questions for this contribution were formed as we increasingly became aware of the fact that family and friends played an essential role in making treatment trajectories doable. They helped patients to manage and execute their treatment schedules, handle everyday activities such as getting dressed or fed, and patients expressed different strategies and choices about accepting or negotiating this involvement. In particular, the cases where care was rejected or conflicting notions of personal integrity and boundaries were negotiated, turned our attention to the fact that sharing is a precondition of care-giving. Caregiving connotes, according to Buch (2015) both affective concern (caring about) and practical action (caring for). This duality of meanings, however, often refers to the one direction in which care is given. What was increasingly evident in our interviews was that informal caregiving involves practices of sharing. Involvement of family or friends in care requires not only that 'needs' are attended to, or defined. It also requires that people receiving care are able, or want, to *share* their emotions, or worries, as well the embodied intimacies of a potentially deteriorating disease. Sharing here is not a theoretical concept, but rather a heuristic analytic tool used to highlight particular kinds of practice or social forms of involvement that people engage in when managing serious disease.

In our material there was no clear pattern regarding with whom participants shared their worries, thoughts or experiences, nor were we able to identify distinct socio-political differences in sharing practices that could be associated with specific country contexts. Such differences may exist, however, as Denmark, England and Sweden (to some degree) have different healthcare systems, and neoliberal reforms have been implemented with different pace and impact. The retrospective interview accounts we collected do not provide sufficient detail on context to provide us with this kind of insight. Rather, the interviews provided first person narratives on how people managed cancer treatment. The three cases presented below, one from each country, were selected to contribute insights into the heterogeneous practices of sharing. The same points could probably have been made had we chosen three cases from a single



country, so case-choice also implies pragmatism and aesthetics. The cases presented illustrate the various strategies of sharing that most evidently stood out in the empirical material. By turning to these, we learn that care practices are moral acts that also tie into notions of social risks (Nichter 2003) and into ways of managing selfhood (Mead 1997; Chattoo and Ahmad 2008). By exploring how people share when they fall sick; what they share and with whom, we are reminded that practices of caring and being cared for unfold in the intersubjective space where people struggle to fulfil their commitments and adhere to social values. This intersubjective space does not easily lend (or bend) itself to meaningful forms of standardised care.

### **Case 1: Nigel**

Nigel is a 68 year old retired local bank manager who lives on his own in a semi-detached house in a suburban area in southern England. He has three sons from a former marriage and lives in close vicinity to his brother. Nigel has a long term condition that he has managed confidently, but now a bowel cancer has been added to his illness course. Fortunately, the cancer could be surgically removed, and Nigel's prognostic horizons are good, and overall Nigel seems at ease with his situation. There is thus no drama in the way he narrates 'having this small trace', as he calls it, surgically removed. The 'lack of drama' is also reflected in the wary outlook that Nigel has on the role of his family and friends during his cancer treatments. At the hospital Nigel was encouraged 'to bring someone as four ears hear better than two'. But despite this advice, Nigel went to all his appointments alone, and throughout the interview he repeatedly says that he 'did not want to impose on the family'. After his cancer surgery Nigel did spend a few days at his brother's house, but he keenly emphasised that he would have preferred to go straight home after surgery, as he felt embarrassed by not being able to take care of himself, "*I didn't want to stay too long. I didn't want to impose on them. And I'd rather be in my own place. ... without feeling embarrassed.*" Asked with whom he had shared his experiences Nigel accentuates the role of his neighbours:

My neighbours have been very good and everything like that. I've got very good neighbours here. Well obviously they are all very sympathetic. As I say, one of them, next door is a nurse or was, she's retired now, but she was a nurse. They both said, "y'know if it's only a trace [a small, operable tumor], don't worry about it. I'm sure there's no problems." Obviously, it did make me feel a little more at ease and hopeful.

Apart from the neighbours Nigel socialises with friends at his local golf club, and he was happy to be able to return to this leisure activity. Most centrally, the way that Nigel manages his situation speaks to his commitment to manage himself while sick. Whether Nigel's ways of sharing are due to the fact that his family situation leaves him with sparse access to intimacy, or whether Nigel considers it a risk to his social relations that he has fallen sick with cancer, is difficult to know. Nigel, however, repeats that 'not being a burden to anyone' is important to him, and it seems a dominant strategy in how he manages his life and illness. He tells his family how he is; but his ways of sharing reflect that he is hesitant to really engage them. The way he narrates his stay at his brother's house as well as his engagements at the golf club further accentuates this. Throughout the interview Nigel repeatedly tells us how, at the golf club, he actively distracts other people's attention from talk of cancer, by stating that 'he is doing great', or how 'fantastic, it is that it [the cancer] gone'. Nigel clearly prefers to exercise choice in managing the moral boundaries around who should be involved in his care.

Perspectives on care as relational practices, naturally take seat in embodied selves that are intersubjectively constituted (Mead 1997). Social relations (among other things) continue to shape us, and define us throughout our lifetime. Falling ill is an intersubjective experience, and as noted by Mark Nichter and others (Nichter 2003; Chattoo and Ahmad 2008) the threat of serious illness potentially endangers social relations. In situations of illness we are forced to manage both the risks to health and the risks to our social selves and our relationships. For Nigel, facing illness was not just a threat to his physical health, but also to his notion of selfhood, and how that hinges on his ability to meaningfully manage his social relations. Nigel's case, as well as dozens of other similar narratives in our material, thus bring to light some of the potential implications of ongoing transitions (or reversals) in care responsibilities in neoliberal landscapes. Nigel's care strategies embody the figure of the independent citizen, a morally competent person who does not rely on family in times of ill health.

## **Case 2: Hans**

Unlike Nigel, who lives alone, Hans, a Dane is married. Living with a partner is, however, not the only difference between the two. Hans is 66 years old and before he was diagnosed with lung cancer, he considered himself in good health. Hans is an academic and still working a few hours every week, keeping a busy life, as he says. His wife, Tove is an artist and Hans is interviewed in her studio in their middle class home situated in the suburbs of a large Danish town. Hans presents himself as socially and mentally resourceful, and his lung cancer as

something that came as a real shock to them. Hans' prognosis is poor and he was undergoing chemotherapy at the time of the interview.

Hans' wife Tove and their daughter, Line are actively involved in Hans' treatment journey. They took turns participating in the various consultations at the hospital, and throughout the interview Hans expresses gratitude for all the familial support that he has received. Asked whether he had talked to anyone else when he became ill Hans says:

I can't remember that I neither tried to talk to someone or tried to keep it a secret. Not at all. We did not have... we did not have anything to talk about at the time when it was just a pneumonia. There is no reason to talk about that for a long time. But at the time when I was told that I had a cancer, or at least something that required a bronchoscopy, then I talked. I have a very close friend who also had cancer for 1.5 years, and he is very sick. I have spent a lot of time with him during that time period. And here – where we live – in our neighbourhood – we have had a 'dinner-club' and for the last 5 or 7 years we have been sharing a meal together each Thursday. And one of them actually died from cancer five years ago. A brain tumour. We were all involved. So having cancer is something that we can talk about – it is natural to us.

Throughout 'his journey' Hans has written letters for friends and family. In the letters he, very bluntly and in detail, describes what he has gone through; the details of bodily distress (in one letter there is a section called 'the story of my lung'), the medical interventions that he has undergone, and the gratitude he feels because of the support he has received from friends and family. Hans' wife, Tove, their daughter and close friends have all engaged in planning of food, reading up on cancer management literature, and friends drop by to "lend an ear", as Hans says. Asked about the reasons for writing these letters he states that he did not want to burden himself nor his beloved ones with having to tell the same story over and over again, and it had a therapeutic effect; helping him accept what he calls 'the patient role', a role which he is seemingly hesitant to accept.

The sharing of illness experiences and the engagement of friends in specific care practices such as bringing food, lending an ear, helping to solve transportation problems etc., seems part of the reciprocity that glues together Hans' relations to his friends and family. During the interview Hans continually suggests that, had they chosen not to involve their friends, they might have seen it as a failure to acknowledge past favours and signs of confidence and caring.

Overall, and somewhat in contrast to Nigel, it is fair to say that Hans' sharing unfolds in a resourceful social milieu, but there *are* similarities to the way they approach life as a patient. From Hans' narrative we learn that he is keen to preserve meaningful (and reciprocal) social relations so that he is not reduced to 'a cancer patient'. Managing how and with whom to share takes form as distraction when, in his letters, Hans actively reminds his friends that he is still a socially and politically engaged person, and that he prefers that 'illness-talk' does not to colonialize their time and encounters. As noted by Moser, Pol and Mol (2010: 13), stories of care are often stories of ambivalence. While Hans' notion of selfhood (Mead 1997) implies strategies that prevent him from being reduced to 'a patient', he also actively engages both friends and family in his illness trajectory. Being engaged in care practices and knowing in detail about each other's lives, it is part of the social reciprocity – 'the social stuff' – that glues their relations together and imbues them with meaning. Thus the managing of illness does not unfold in separate social or material domains, and care practices are deeply embodied and relational practices.

### **Lena**

Our last example is Lena, who is 70 years old and lives a socially active life with outdoor leisure activities such as climbing and hiking in the country side in Sweden. Lena was interviewed two months after being diagnosed with a colon cancer. Luckily it could be surgically removed, and despite the operation Lena seemed fit and well during the interview. She was currently undergoing preventive chemotherapy 'just to make sure that it will not metastasize', as she said. Lena is married and has four grown-up children and several grandchildren. She ran her own company involving family members for many years before retirement. She lives with her husband (who is also retired), with siblings and other family members in their close vicinity. Throughout the interview Lena presents herself as a socially responsible and highly independent person, actively planning and reflecting on the next steps in her 'illness journey'. Overall, the manner in which she voices her expectations to the healthcare system and the role of her family is consistent with her account of how she has organized other parts of her life. The intricate relations between her former work-life and private life and the fact that she lives in close vicinity to many family members seemed to provide her with easy access to any social support she needed, and allowing her to be in control of things. When Lena identified traces of blood in her stools she told her husband, sister and daughter and followed their advice to take immediate action. She described taking great comfort from talking to them about what was up-and-down and that this outlet helped her to wait and stay calm. In particular, Lena was happy

that her daughter-in-law, who is a nurse at the nearby hospital, had insights and experiences that could guide her through her treatments. Lena mentions how her daughter-in-law played a supportive and caring role before she had her colonoscopy :

[...] she came and talked to me and explained ‘the medical stuff’ that I should go through. We talked ... and she described in great detail what should happen. And later they [she and my son] came here when I came home too and gave me accurate information, so I had of course no doubt about anything. I may be privileged; I find it easy to get information.

Acts of sharing care needs and expectations are deeply enmeshed in everyday relations (Chattoo and Ahmad 2008; Yates-Doerr 2012). To Lena, who enjoyed the company of a large family, and with easy access to health professionals, engagement seemed natural; she reaches out for advice and finds comfort in sharing her worries with her family. But like Hans and Nigel, Lena also reflected on *what* and *how* she shared, and with *whom*. Despite access to a seemingly resourceful social environment, Lena, for example, went to the hospital on her own and then sifted through the information she was given, to decide which parts to share with her husband and children respectively. According to Lena her husband was more confused and shocked by her cancer diagnosis than she was, and she felt that she could protect him if she did not ‘tell him everything’ and if he was less engaged in the practical matters such as providing food, or acting as a chauffeur. By contrast, Lena explains how she had asked the doctors ‘to tell her everything’; to let her know what her odds were.

In some ways, it seems that Lena’s ways of managing her illness embeds both a stereotypical commitment to a particular kind of selfhood formed by ideas of ‘motherhood’ (the carer of the family) and ‘business leader’ (taking charge). Her notions of selfhood, as well as her ways of managing her relations thus embody the figure of the caring mother, as well as the independent working woman. In some ways, Lena’s sensitivities, articulations and moral responses to managing her cancer journey thus reflect the socio-political landscape of the welfare society, which she has been familiar with throughout her life.

## **Concluding discussion**

“If care practices are not carefully attended to, there is a risk that they will be eroded. If they are only talked about in terms that are not appropriate to their

specificities, they will be submitted to rules and regulations that are alien to them” (Mol, Moser, and Pols 2010: 7).

Viewing care practices as embodied, relational practices, means moving care away from rationalist versions of human being, and acknowledging that care has more to do with being fragile than with mastering the world (Mol, Moser, and Pols 2010: 15). As illustrated in the case studies, in care situations (as in all parts of life) people bring with them a variety of social engagements and sometimes the disparities of living with a cancer disease can only be shared in the form of telling specific and concrete pieces of information, in other situations and social circumstance it allows for more intimate forms of engaging. The ways that Nigel, Hans and Lena shared, reflect how they found their ways into life as patients; and their practices of sharing were framed by moral invocations on how to manage moral notions of selfhood, as well as their social relations. This corresponds to the substantial literature illustrating how dealing with debilitating health or serious disease such as cancer, is not just related to the physical burden of disease, but also to changes in social relations and expectations that individuals experience when they are immersed in the process of recovery and adaptation (Seppola-Edvardsen, Andersen, and Risør 2016). A recently published ethnographic study on Norwegian ‘cancer survivors’ aptly suggests that, to people living in the aftermath of treatment, the managing of uncertainties about relapse are intricately related to the management of social risks. People, the authors suggest, continually:

[...] attempt to handle life with the risk and uncertainty in a way that prevents the state of uncertainty from dominating and having negative consequences for everyday life and social relations. Being and well-being in the social realm concern abstract, existential values and aspects of self that are important to us and others (Seppola-Edvardsen, Andersen, and Risør 2016: 370).

How does this tie into our reflections on informal care-giving? By attending to the social and individual diversity in the examples presented, and the various ways in which our informants shared their worries, discomforts as well as the more objectified pieces of illness information, we show that acts of receiving care require a commitment to involve oneself in difficult and sometimes emotional situations. As briefly stated above, some feminist writers have criticised contemporary forms of care-labour provision and ethics as reinforcing traditional stereotypes

of a 'good woman'. Care requires a recognition or attention to the needs of others, and such competences (or moral concerns) have been associated with the role of woman (Grimen 2009; Noddings 2013). In a similar form of critique, we warn that standardised calls for informal caregiving may co-produce moral connotations of what constitutes 'a good patient' who willingly and silently accepts new socio-politically enforced divisions of care-labour. Nigel, for various reasons, wished to manage on his own. This potentially places him in a vulnerable situation if his care needs increase or demands for family involvement become part of standard healthcare delivery. As is well established, attempts to classify, order and categorise 'intervenable populations' straddle neoliberal forms of care or contemporary biopolitics (Rose 2007; Foucault 1997). Attempts to order care practices in such ways, we suggest, may subject them to inappropriate rules and regulations.

As emphasised in our case studies, people's accounts are infused with acts of exercising choices in respect to whom they consider should be involved in their care. These are biographically situated choices (Mol 2008) made within a socially and morally bounded life. Nigel, Hans and Lena were all driven to take action to secure their process of treatment. But they acted, or they *chose* and *shared* differently, because they had different lives. If healthcare systems push for more reliance on informal care, this means that choice is restricted. While this may be troublesome for those like Nigel who live alone, it may also place social and moral challenges on people with wider social resources (such as Hans or Lena). They may need to share intimate details or worries with people who they prefer to protect, or keep at a distance (Chattoo and Ahmad 2008). Care may be directing towards relieving emotional and physical impairments of illness, but it also engage social domains of responsibility and relatedness (Wilkinson and Kleinman 2016: 161-63) and moral economies of duty or shame (Broom et al., 2016). Neither Lena nor Hans was vulnerable per se, but their experiences illustrate how shifting tensions during an individual life course *combined* with local sociopolitical changes entails shifting vulnerabilities (Buch 2015). Increasing calls for informal caregiving may be seen as a part transfer of care obligations onto the patient and his or her close relations. In many ways this stands as a contradiction to overall welfare state policies, in which care and treatment practices have been thoroughly organized and regulated through healthcare institutions. The illness narratives of Lena, Nigel and Hans in different ways embody the social and moral dissonances that may follow in the wake of care-labour transitions.

As aptly put by Pol, Moser and Mol (2010: 13) in their recent anthology on *care as practice*, stories of care carry ambivalence. We do not here wish to imply that increasing calls for informal caregiving is immoral or bad. As stated by Wilkinson and Kleinman care is also a

humanising practice, which may inspire empathy, love or respect, and which may “engage people in social relationships that are saturated with moral meaning” (2016: 162). But standardised or inflexible approaches to informal care-giving may have the opposite effect, if care is not carried out in respect for those involved, and if they are not provided social space to choose as expected of them. Care carries with it complex and particular connotations. Care is about more than care-giving, people in need of care are required to be able and willing to share and voice their needs. Hospitals, primary care and other care settings should be alert and responsive to individual preferences as well as their needs and have capacity in knowledge and time to manage diversity. Or, as stated by Mol and colleagues, good care is “persistent tinkering in a world full of complex ambivalence and shifting tensions” (2010: 14).

Acknowledgements: We wish to extend our thanks to all the informants as well as their families who made an effort to assist us with this research project. Also thanks to the advisory panel and wider project team members.

This publication presents independent research funded by The Research Centre for cancer diagnosis in primary care funded by The Danish Cancer Society and the Novo Nordic Foundation as part of a broader programme of work with partner countries. The views expressed in this publication are those of the authors, and not necessarily those of the funding partners.



## Literature:

- Beesley, Lusinda. 2006. 'Securing Good Care for Older People'. Kings Fund. London.
- Broom, Alex, Emma Kirby, Katherine Kenny, John MacArtney, and Phillip Good. 2016. 'Moral Ambivalence and Informal Care for the Dying', *The Sociological Review*, 64: 987-1004.
- Buch, Elana D. 2015. 'Anthropology of Aging and Care', *Annual Review of Anthropology*, 44: 277-93.
- Chattoo, Sangeeta, and Waqar I. U. Ahmad. 2008. 'The moral economy of selfhood and caring: negotiating boundaries of personal care as embodied moral practice', *Sociology of Health & Illness*, 30: 550-64.
- Foucault, Michel. 1997. *The birth of the clinic : an archaeology of medical perception* (Routledge: London).
- Eurostat. 2018 [https://ec.europa.eu/eurostat/statistics-explained/index.php/Household\\_composition\\_statistics](https://ec.europa.eu/eurostat/statistics-explained/index.php/Household_composition_statistics)'.
- Grimen, Harald. 2009. 'Power, Trust, and Risk: Some Reflections on an Absent Issue', *Medical Anthropology Quarterly*, 23: 16-33.
- Hacking, Ian. 1999. *The social construction of what?* (Harvard University Press: Cambridge Mass.).
- Johansson, L., H. Long, and M. G. Parker. 2011. 'Informal caregiving for elders in Sweden: an analysis of current policy developments', *Journal of aging & social policy*, 23: 335.
- Kleinman, Arthur. 1981. *Patients and healers in the context of culture : an exploration of the borderland between anthropology, medicine and psychiatry* (University of California Press: Berkeley).
- Langer, Susanne, and Susanne Hojlund. 2011. 'An Anthropology of Welfare: Journeying towards the Good Life', *Anthropology in Action*, 18: 1-9.
- Malmström, Marlene, Birgit H. Rasmussen, Britt-Marie Bernhardson, Senada Hajdarevic, Lars E. Eriksson, Rikke Sand Andersen, and John I. MacArtney. 2018. 'It is important that the process goes quickly, isn't it?' A qualitative multi-country study of colorectal or lung cancer patients' narratives of the timeliness of diagnosis and quality of care', *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, 34: 82.
- Mattingly, Cheryl, Lone Grøn, and Lotte Meinert. 2011. 'Chronic Homework in Emerging Borderlands of Healthcare', *An International Journal of Cross-Cultural Health Research*, 35: 347-75.
- Mead, George Herbert. 1997. *Mind, self, and society : from the standpoint of a social behaviorist* (The University of Chicago Press: Chicago).
- Mikkelsen, Henrik Hvenegaard. 2016. 'Unthinkable Solitude: Successful Aging in Denmark Through the Lacanian Real : UNTHINKABLE SOLITUDE', *Ethos*, 44: 448-63.
- Mol, Annemarie. 2008. *The logic of care : health and the problem of patient choice* (Routledge: London).
- Mol, Annemarie, Ingunn Moser, and Jeannette Pols. 2010. *Care in practice : on tinkering in clinics, homes and farms* (Transcript: Bielefeld).
- Nichter, Mark. 2003. 'Social risks of therapy management.' in Mark; Lock Nichter, Margaret (ed.), *New Horizons in Medical Anthropology. Essays in Honour of Charles Leslie* (Routledge: London).
- Nielsen, Mette Kjaergaard M. D. PhD, Mette Asbjørn M. D. PhD Neergaard, Anders Bonde M. D. PhD Jensen, Peter M. D. PhD Vedsted, Flemming G. P. PhD Bro, and Mai-Britt PhD Guldin. 2016. 'Predictors of complicated grief and depression in bereaved caregivers: a nationwide prospective cohort study', *Journal of Pain and Symptom Management*, 53: 540-50.
- Noddings, Nel. 2013. *Caring. A Relational Approach to Ethics and Moral Education* (University of California Press).

- Pickard, Linda, Raphael Wittenberg, Adelina Comas-Herrera, Bleddyn Davies, and Robin Darton. 2000. 'Relying on informal care in the new century? Informal care for elderly people in England to 2031', *Ageing and Society*, 20: 745-72.
- Pickard, Linda, Raphael Wittenberg, Adelina Comas-Herrera, Derek King, and Juliette Malley. 2007. 'Care by Spouses, Care by Children: Projections of Informal Care for Older People in England to 2031', *Social Policy and Society*, 6: 353-66.
- Romito, Francesca, Gil Goldzweig, Claudia Cormio, Mariët Hagedoorn, and Barbara L. Andersen. 2013. 'Informal caregiving for cancer patients : Informal Caregiving', *Cancer*, 119: 2160-69.
- Rose, Nikolas. 2007. *Politics of life itself : biomedicine, power and subjectivity in the twenty-first century* (Princeton University Press: Princeton, N.J.).
- Seppola-Edvardsen, Tone, Rikke Sand Andersen, and Mette Bech Risør. 2016. 'Sharing or not sharing? Balancing uncertainties after cancer in urban Norway', *Health, Risk & Society*, 18: 367-84.
- Verbakel, C. M. C., S. Tamlagsronning, L. Winstone, E. L. Fjaer, and T. A. Eikemo. 2017. 'Informal care in Europe: Findings from the European Social Survey (2014) special module on the social determinants of health', *European Journal of Public Health*, 27: 90-95.
- Wilkinson, Iain, and Arthur Kleinman. 2016. "A passion for society : how we think about human suffering." In *California series in public anthropology ; 35*. Oakland, California: University of California Press.
- Yates-Doerr, E. 2012. 'The weight of the self: care and compassion in Guatemalan dietary choices', *Medical Anthropology Quarterly*, 26: 136-58.
- Yates-Doerr, Emily, and Megan A. Carney. 2016. 'Demedicalizing Health: The Kitchen as a Site of Care', *Medical Anthropology*, 35: 305-21.