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Paper to be presented in 'Innovation and Sustainability' Third Transforming Care Conference, 26-28 June 2017, Milan, Italy

Thematic Panel 10, 'The transformative power of care'

Slipping into 'that nurse's dress': caring as affective practice in couples' relationships

Abstract

This chapter explores caring as an affective practice in the everyday lives of elderly couples, drawing from interviews with elderly care-givers whose partners have fallen permanently ill. I interpret the care-givers' narratives as communicating personal, sentient, thinking and feeling involvement in the affective practice of caring. Simultaneously, though, the process of caring operates on the level of normative expectations concerning how partners ought to treat each other. The chapter focuses on the early phase of care, exploring the kinds of activities and tensions involved in the process of the couple's relationship becoming a care relationship. The care-givers' narratives of the early phase of care unfold around the central tension between the idea of two equal adults and the requirements of the new circumstances in which one partner depends on the other's care. Assuming the position of a care-giver is a process in which different forms of knowledge (such as sentient and discursive) and ambivalences of power are central to the caring practice itself and must be continually resolved. The paper argues that the concept of affective practice is especially useful in capturing the ambivalences (of power) inherent in the caring practice and everyday lives of elderly couples.

Introduction

Sometimes—like in that photograph of our morning—when he’s still asleep, and I’m reading, then I sometimes kiss and cuddle him. But that nurse’s dress—I start wearing it immediately after we get out of the bed.

In this quotation, Kristiina, an interviewee in the study reported in this chapter, describes a moment in bed before rising and starting the day. Her partner suffers from advanced Alzheimer’s disease. One some days, he recognises Kristiina, and on other days, he does not. He could not manage living at home without her constant care.

What initially caught my attention in Kristiina’s account was the metaphor of the *nurse’s dress*. In many ways, this metaphor captures what it means to give care to one’s partner at home on a daily and nightly basis. Wearing the nurse’s dress points to the embodied dimension of having responsibility for one’s partner’s care while simultaneously simply living together at home. The metaphor implies wearing a uniform that hides something deeply personal associated with nakedness (not having clothing at all) and wearing one’s own clothes (free expression of one’s personality). The metaphor of the nurse’s dress refers to the management of emotional expression to produce desired emotional outcomes in the partner who needs care. This kind of activity can, and has been, analysed as emotion work (Hochschild 1983; James 1992; Thomas et al. 2003; Twigg 2000).

In this chapter, however, I explore caring as affective practice (Wetherell 2012, 2013) and suggest that it offers a useful conceptual tool to broaden our understanding of care in intimate relationships. Firstly, the concept allows conceiving of caring as an activity that entails personal, sentient, thinking and feeling involvement without assuming that these feelings and sentiments are the individual possessions or characteristics of those who engage in them. Secondly, the concept brings together the sentient/embodied and the discursive without assuming that either precedes the other. Thirdly, conceiving of caring as an affective practice enables grasping how caring for another person involves acting

in a power relationship. As I elaborate on the idea of caring as affective practice throughout the paper, I have these three points in mind.

The chapter proceeds in the following manner. I first elaborate the idea of caring as affective practice drawing from care research and Margaret Wetherell's concept of affective practice. I next present the methodology of this study. The following three sections are empirical and focus on the activities and tensions related to the process in which a couple relationship turns into a care relationship. Finally, I present the main conclusions and suggestions for future research.

Caring as affective practice

In this section, I discuss caring as a practice drawing from Wetherell's (2012) concept of affective practice but differ from her in one area: instead of analysing caring practice in interactions, I approach caring practice through personal narratives. Despite this significant difference, I find Wetherell's concept useful for exploring how elderly persons who become care-givers to their partners perceive and give meaning to their changing lives and circumstances.

The concept of practice is well established in the social sciences (Schatzki, Knorr-Cetina & Savigny 2001), but surprisingly little has been written about caring as a practice in the sociological approaches to care (see, however, Benner & Gordon 1996). I suggest that the concept of affective practice (Wetherell 2012) offers a useful tool for examining care for several reasons. Firstly, this concept directly addresses issues of power. Power is understood as constitutive of care relationship in even early care research (Wærness 1984), but power dynamics and the consequences nevertheless are neglected in empirical research on informal care. The imbalance of power in the care relationship arises from dependency: without another person's help, the partner who needs care would not survive. To need another person to fulfil one's basic needs makes one vulnerable (Wærness 1984). Julia Twigg (2000) explores vulnerability as the source of this unequal balance of power, using bathing as an example: whereas the one needing care is exposed and naked, the care-giver can protect themselves, for example, by using rubber gloves

or clothes. The one giving care (whether a professional or informal carer) occupies a more powerful position in relation to the one needing care as the care-giver is more capable physically, mentally and socially. The care relationship thus is an inherently unbalanced power relationship. In this chapter, I shed light on how caring in intimate relationships inevitably deals with power in those relationships.

Secondly, Wetherell's concept of affective practice enables grasping the constant interplay between sentient and discursive knowledge concerning the appropriate, desired and required ways of being together in the context of care. Early care researchers pointed out that the activity of providing care for a person involves a particular kind of knowledge that arises from the care-giver's personal engagement in the activity of caring (Graham 1983; Wærness 1984). Care researchers have emphasised the importance of embodied and situated knowledge rooted in relationships and caring practice (Benner & Gordon 1996, 45; Hamington 2004; Lynch & Lyons 2009, 77; Mason 1996; Wærness 1984). Norwegian sociologist Kari Wærness (1984) developed what she called the rationality of caring, the idea that caring for dependent persons involves a particular kind of rationality to which the actor as a sentient being is integral. Later, sociologists such as Jennifer Mason (1996) constructed concepts to understand the sentient dimension of caring. Mason (1996), in particular, aimed to shift from a conception of feeling and thinking as individual states of mind towards an understanding of feelings as action embedded in relations between people. While Mason (1996) stressed thinking and feelings as activities, she did not further elaborate what she meant by activity. Wetherell's (2012: 23) concept of affective practice does so while perceiving affect as relational instead of individual.

This chapter traces care as affective practice that emerges in the relationship between partners and in the interface of discursive, embodied and personal knowledge. In defining this concept, Wetherell (2012: 82–83) explains that feelings and emotions do not emerge unexpectedly but have a history or context, and that through affective practice, 'the other person's status is being accomplished, performed and continued'. In the chapter, I treat caring as an affective practice embedded in the life history of the couple, however long or brief it is (Bowlby et al. 2012). While these 'cycles of affective practice' have different

durations (Wetherell 2012: 12), affective practice persists over a relatively long period of time and is entangled with the couple's history. Older couples share years of joint history that persist as memories and as habits of being together even when one partner begins to need care (cf. Smart 2007).

As Wetherell (2012) did not define the concept of practice as such, I turn to Benner and Gordon (1996: 43–4) who stated that 'a practice differs from discrete behaviors, strategies, or techniques in that it is a culturally constituted, socially embedded way of being in a situation and with others'. In my understanding, social embeddedness implies discursive knowledge concerning the appropriate ways of being together and the meaning of caring, as well as the personal histories embedded in the ways of being together (Wetherell 2012: 121).

Sensory methodology of the research

This chapter is based on interviews with 15 elderly persons who give care to their partners at home on a long-term basis. The interviewees, recruited primarily through advertisements in free local newspapers, are between 59–82 years old. Their partners suffer from either advanced dementia or severe physical incapacities caused by stroke. They all need constant care, assistance and attention, for which the interviewees had responsibility at the time of the interviews.

The methodological approach of this study draws upon sensory methodology (Mason & Davis 2009: 587), a research strategy 'attuned to the complex ways in which the senses are tangled with other forms of experience or ways of knowing'. Attuning to the sensory has ontological ('what is there to know for the social sciences') and epistemological ('how it can be known') implications for this research strategy (Mason & Davis 2009: 587). For this study, including the sensory in the social reality means reading the interviewees' narratives as told by sentient beings about their concrete surroundings. In analysing the transformation of a couple relationship into a care relationship, I pay attention to the mundane aspects of being together at home and living as a couple whose lives have been upended

by illness and need of care. Becoming a care-giver for a partner is situated in the ‘affective textures and activities of everyday life’ (Wetherell 2012: 4).

Epistemologically, the sensory is included in the data collection in this research strategy. Drawing from the idea that photographs can elicit sentient description (e.g. Harper 2002; Mason & Davies 2009), I aim to capture data with thick sentient description. For this purpose, I suggested that, if possible, the interviewees take photographs of their everyday lives and use them to tell me what they find important in their daily lives of care. Seven interviewees took photographs, while the rest found it too difficult or ethically problematic in the circumstances. Photographing was not possible for all participants, so I remained open to other sensitising elements introduced by the setting of the interviews in the participants’ homes or shared by the interviewees, such as poems they wrote.

In the analysis, I focus on seven interviews describing care needs that emerge gradually. I read these interviews as personal narratives communicating changes in how the partners relate to each other. I focus on the activities and tensions involved in the process in which the couples’ relationships become care relationships. Through analysis of the carers’ narratives, I suggest that a central tension arises between the idea of two equal adults and the requirements of the new circumstances in which one partner depends on the other for care. I further suggest that this tension—and its constant resolution in everyday encounters with the partner—remains central to the affective practice of caring.

Becoming unsettled: emerging awareness of care needs

As the interviewees look back on the time they later perceive as the early phase of care, they describe a period of gradually growing confusion, irritation, worry, frustration and anger regarding their partners. Ulla, a 66-year-old woman whose partner suffers advanced dementia, tells a representative story. She recalls that her partner gradually stopped taking care of what had been ‘his duties’ at home, such as renovating the house. In addition, he sometimes did things that deeply upset her. For example, once while gardening, he cut flowers very dear to Ulla. At the time, she thought he intentionally aimed to upset her.

The stories of the early phase of care convey a sense of becoming unsettled in two aspects. The *first* concerns *habitual ways of being together*. A couple who lives together for years, sometimes decades, accumulates knowledge of each other's characters, habits, personality and ways of doing things. In addition, they establish conventions and rules for how things are done in the household and how partners may treat each other (Crossley 2011: 36–37; Smart & Neale 1999: 69).

The interviewees' narratives reflect the breakdown of habitual ways of being and living together is reflected in various ways. Kaarina, for example, describes how she, in addition to paying attention to what she calls 'small oddities', notices how her partner began to 'vanish'. She refers to his changing embodied appearance: 'it was very rare that he had any expression on his face anymore', she recalls. For Helena, the most upsetting disruption is her partner's changing personality:

He got angry more often than before, and he was easily irritated. And, of course, I didn't know that he was sick, he hadn't been diagnosed yet, so I yelled and gave him orders and threw tantrums: 'why did you do this thing like this?'

The interviewees' narratives express growing puzzlement and distress they sometimes sense in their bodies. Ulla, for example, tells how she used to—and still sometimes does—experience palpitations if her partner does not follow her instructions.

Secondly, the *balance of power within the couple's relationship* becomes unsettled. The power balance is challenged by the partner's care need which is not yet perceived as a *care* need. Awareness arises as a feeling of worry or irritation over the partner's actions or appearance. Soile recalls those early days:

It was about that time I first got nervous [shows a photo of a middle-aged man with an expressionless face]. I guess we both thought that he had cancer because he had begun to lose weight. (...) I didn't notice it because he had always eaten in the evening, and I had eaten in the morning. And we were both in mature age when we got together, so there was no reason to change our habits. So it took a while until it dawned on me that he was losing weight because he had stopped

eating. We went to the grocery store together, but I didn't always pay attention to what he bought.

Soile's story illustrates how the need for care disrupts the couple's status quo. Needing help to fulfil basic needs (such as eating) implies dependence on another person to fulfil those needs (Wærness 1984), unbalancing the relationship between the one who needs care and the one who provides care (Twigg 2000; Wærness 1984). The interviewees' accounts reflect the tension arising from this condition. For Soile to become aware of her partner's care need, she has to pay attention to him in ways that can be regarded as intrusive, for example, by looking at what he buys in the grocery store.

In this section, I describe how the interviewees make sense of what is happening in their lives as they slowly become aware of the partner's illness and need for care. To an extent, even becoming aware of the partner's care need implies a shift in power between them and creates tension in their everyday dealings. Those tensions intensify when the care-giving partner begins to act to help.

Settling into the affective practice of caring

The narratives next reflect on the difficulties after the care-giving partner becomes aware that the partner is, in fact, sick and in need of help. At this point, they attempt to interfere in the partner's personal matters in various ways. David Conradson (2003:508) suggested that caring is the care-giver's movement towards the one needing care in response to the care need. In the light of this idea, I interpret interfering in the partner's personal matters as attempts to move towards the partner. However, at this point, these efforts are hesitant and illegitimate as they question the partner's authority as an independent adult. As Soile puts it: 'I'm not used to tending to adults, but when I noticed the situation, I tried to begin to tend'.

This phase of the story reflects the difficulties in altering the habits and conventions of a couple relationship. The inability to move generates frustration. Pentti describes this situation:

She has changed little by little, but she resists and says, 'I don't have this disease. I don't want to have this disease!' Then you get this terrible feeling. ... How will we manage and live with this thing?

Frustration is among the feelings most commonly shared by the interviewees. The resistance Pentti describes is his partner's unwillingness to comply with the identity of a person with a fatal illness, which appears frequently in the interviewees' stories. Pentti illustrates that becoming aware of the partner's need for care is not only a matter of a change in the caregiving partner's mind-set: responding to the care need requires that the partner consent to the sick role in everyday dealings and interactions. Complying with the sick role is threatening for several reasons. Most significantly, chronic illnesses, especially dementia, threaten authority over one's own life. The early stage of dementia can be a confusing and frightening experience as one slowly loses control over mundane and self-evident matters.

The difficulties in moving towards the partner's care need do not arise exclusively from the partner's resistance. Also interfering in decision-making about eating, sleeping and visiting the doctor is the cultural understanding that adults independently perform these activities. Normative expectations stipulate what two adults, even those who share an intimate relationship, should do for each other (Parker 1993). These discursive expectations are engraved in the couple's habitual ways of being together. The partner's care need questions these normative expectations as needing care inevitably means that one is, to an extent, incapable of caring independently for oneself in matters usually understood as each adult's own responsibility (Isaksen 2002; Twigg 2000). Dementia, in particular, entails loss of meanings and social conventions (Schillmeier 2009). Memory loss ultimately threatens the well-being and safety of the person suffering dementia. Care, therefore, is needed to ensure that the person who suffers from dementia still eats, drinks, and is safe both physically and emotionally.

To become a care-giver to one's partner, one must cross the boundaries of acceptable treatment of one's partner. In the interviewees' accounts, the negotiation of the new balance often culminates in attempts to get the partner to agree to go to the doctor. For example, when Kristiina, whose partner suffers from

Alzheimer's disease, first suggests going to the doctor and having a memory test, her partner becomes angry and accuses her of calling him crazy.

Attempting to interfere in the partner's matters is questionable in the context of a couple relationship. Once the care-giving partners perceive their partners in the context of care relationships, however, they find it easier to make decisions and act in certain ways in relation to the partner. Helena's reflection illustrates this transition:

There was a time when I said to him that because you're so mean, and you do all these nasty things, I do not want to grow old with you. You can live your life as you will, and I will leave and be on my own. I did feel sad that it would all end like that. But then fortunately, he got the diagnosis that he had dementia. (...) You should not get stuck on thinking that you have a spouse. You shouldn't insist on having a spouse. You won't cope that way. I wouldn't have coped that way. (...) I have somehow managed, right from the diagnosis, to think that all that we had, and all that we still hoped that there would be, were gone. From now on, it is a care relationship.

Perceiving a caring relationship enables not expecting the partner to comply with the ideal of how spouses treat each other. Perceiving the partner as in need of care enables undertaking activities (morally) questionable in the context of a couple relationship. Perceiving the relationship as a care relationship enables responding to the partner in ways useful for caring purposes. Kristiina, for example, states that she tells 'white lies' to keep her partner calm. She states that it is acceptable to lie now that the partner is sick, whereas earlier in the relationship, the need to not tell lie to each other was self-evident.

Getting in and out of the nurse's dress

I analyse the interviewees' narratives of how they come to care for their partners at home. These narratives communicate a change in the interviewees' understanding of their partners, themselves and their relationship. In many ways,

the change entails letting go of the expectations and conventions of a couple relationship. Through the care-givers' narratives, I illustrate how this change is necessary to assume responsibility for the partner's care. However, the shift from a couple relationship to a care relationship does not necessarily include a transformation into a fulltime care-giver who consistently holds the partner's care need as the determining element in what to feel and how to express one's feelings. Even if the interviewees eventually do come to terms with the partner's constant need for monitoring and care, they still struggle with feelings of sadness, irritation and anger in relation and relating to their partners. This tension is precisely why it makes sense to conceive of caring as a *practice* through which certain affective states are constantly pursued. The shift to a care relationship does not mean a complete break from the life as a couple. Here, we return to the metaphor of the nurse's dress, which I interpret to express different aspects of embodied care, including tone of voice, facial expressions and ways of touching and gesturing. This dress is not clothing a person always wears but, instead, slips in and out of.

Helena, who attended a course on how to interact with a person suffering from dementia, talks about importance of her voice:

It's [the tone of voice] one of the most important things. If I'm tired, and I say something with a snappy tone of voice, he flinches. So irritation is really contagious. That's something that's really worth trying to rehearse away from yourself.

Similarly, Kristiina tells that she tries to 'keep [her] face shut', while Oili attempts to 'swallow the anger'. Some interviewees need to remind themselves to recognise their partners as sick and in need of care. Doing so requires effort:

I talked to the doctor as I tend to lose my temper, and then I curse and shout. Because the thing is that he looks outside as if he's okay. It's hard to get it in your head that he's sick. Then you just act out against it, and to him [ask]: *don't you get it?* I don't know how to get inside the thought that he really isn't all right as he looks all right. I think it would be easier if he had something more visible. (Kristiina)

So far, I have considered the shifting power balance in the relationship as if a couple relationship is a relationship of two equals. That, of course, is not always—if ever—the case. For example, Oili, an 82-year-old woman, describes suffering mental abuse from her husband throughout her marriage. She has stayed in the marriage out of a sense of duty and attachment that has, despite the abusive elements, deepened over the years. She reflects that her husband's dementia has turned the power balance upside down. Finally, she is the one capable of hurting her husband who is now helpless and dependent on her:

I: I've thought about how this ambivalence in our marriage might be reflected in the caring relationship. This is what I have been thinking. We have all these difficulties, and they can be reflected in the caring work. But I don't know—I have tried being patient with him, but still I'm afraid that it might be reflected.

R: What do you mean, that they could be reflected?

I: Well, I mean that I would never—I'm afraid that if I sometimes flare up so badly, I might do something, hurt him. This is what I'm afraid of. But I haven't flared up. (Oili)

Oili's story illustrates that the past is woven into the affective practice of care in complex ways. The past creates an unstable—even threatening—foundation for caring. In situations like these, the caring practice requires careful balancing between giving care and treatment that can be close to mistreatment or abuse (cf. Twigg 2000).

To sum up, even though the affective practice of caring becomes more settled in certain ways over time, the constant dynamics of balancing power in the care relationship remains in other ways.

Conclusions [tentative]

In this chapter, I have analysed the activities and tensions in the process of a couple relationship becoming a care relationship. Focusing on caring as affective practice

in the early phase of care, I have found that a central tension arises from the shifting power dynamics in the partners' intimate relationship. To respond to the partner's care need requires exercising power in ways that differ from the ideals and realities of a couple relationship. In a couple relationship, the partners are usually relatively autonomous when it comes to such basic tasks as taking care of personal hygiene and eating – at least if they have been relatively healthy and not chronically ill or disabled throughout their life together (see Parker 1993; Torgé 2014). Dementia challenges the power dynamics of a couple relationship because it directly affects the ability to function mentally and socially, and yet it is not clear from the start that the partner is in fact in need of care. This paper sheds light on caring as a practice in this particular context. In many ways, the care-givers' narratives of the early phase of care reflect how the affective practice of caring is initiated and managing with the challenges arising from the changing power dynamics in the relationship.

This paper makes two contributions that I now sum up. The first conclusion concerns *care research*, and the second one concerns *care policies*.

Firstly, the paper argues that there is urgent need in care research to analyse what happens in the front lines of care (Twigg 2000) bearing in mind that care is *human* activity in every sense of the word. Christine Kelly (2017: 109) has recently argued for the importance of recognizing and incorporating the more difficult aspects of care into the research. In order to do this, there has to be concepts with which to approach and analyse care. Based on my analysis, I suggest that affective practice is one such concept.

Through the analysis of care-givers' narratives, I have offered an account of caring as activity that involves acting in a power relationship. Managing the unequal power is an example of the complexity of care. This chapter highlights that the entry of care needs into an intimate relationship disrupts the power dynamics. Providing long-term care involves working in and through the power relationship. The concept of affective practice, therefore, is especially useful for capturing the ambivalences (of power) inherent in the caring practice and in the everyday lives of elderly couples.

The paper suggests that the concept of affective practice is useful because it captures the different aspects and ambivalences inherent in the caring practice and everyday lives of informal care. When caring is conceived as affective practice, it is possible to grasp how the circumstances, events and even care need itself continue unsettling the care-giving partners. By the time of the interview, caregiving partners were already familiar with the fact that their partner had a serious illness that required almost 24-hour monitoring, attention and specific kind of responsiveness. The situation kept moving them in ways that required careful balancing between knowledge arising from the encounters with the partner to be combined with other kind of knowledge concerning normative ideas about how a person with dementia should be treated and confronted. As an affective practice, caring requires careful balancing between different forms of knowledge (such as sentient, discursive and habitual).

The second conclusion concerns elder care policies that often dismiss the complexity of intimate relationships (Ahosola & Henriksson 2012; Henderson & Forbat 2002). In the care policies, family relationships are often depicted as unproblematic sites for care. Families are self-evidently seen as ideal for long-term care. Yet, the neediness and vulnerability affects intimate relationships in ways that can sometimes be erratic, inflicting unavoidable tensions that cannot be completely avoided, not even in the most harmonic relationships. If/when families are depicted as unproblematic sites of care, the complex power dynamics of intimate relationships are ignored. As European care policies are relying more heavily on informal care (Kröger & Leinonen 2012), there is an urgent need to address and respond to the tensions of care in the intimate relationships in the level of care policies.

Currently care is being shifted into close relationships in both ways that can be described as *informalisation* of care (Szebehely 2005) and *semiformalization* of care (cf. Geissler & Pfau-Effinger 2005). On the one hand, informalisation is taking place when family members take on tasks that used to belong to formal care service.¹ Semiformalisation, on the other hand, is taking place when family

¹ Reasons for informalisation of care: the lack of available, affordable and attractive (Vabø & Szebehely 2012) care services, due to the retrenchment of the public care services.

members receive public support (monetary allowance and/or services) for performing tasks that were previously carried out without any public support. The Finnish *Support for Informal Care* is such a benefit.² Through granting this benefit, a “welfare state constructed care relationship” is created (Geissler & Pfau-Effinger 2005, 9). → future research: how the affective practice of informal care is intertwined with the welfare state, normative expectations of being a ‘good carer’ (Sadler & McKevitt 2013; Winch 2006).

As western welfare states are reframing their elder care policies, they are increasingly shifting the responsibility of care to close relationships. The focus of this paper has been on couples’ relationships, but other family relationships – such as those between parents and adult children (Kröger & Yeandle 2013), are equally, although not identically, affected by care needs.

² Although it also covers care that used to be provided by public services.

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