Unsettling descriptions: attending to the potential of things that threaten to undermine care

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Abstract
This article explores the potential of describing things at the periphery of our attention. It discusses how our practices of ‘describing collaboratively’ shifted what we attended to in observations of participants in a Swedish gynaecological cancer patient organisation. We show how the care the organisation aims to promote is troubled and seemingly undermined by attending to palliative care. Our aim is to explore the ethico-political potential of describing things that ‘unsettle’ care practices. Building on Feminist Technoscience Studies, arguing that researchers should attend to ‘neglected things’ in order to care for them, we focus on affects, atmospheres and fleeting moments that are overlooked, or threaten to undermine, participants’ practices of care. We show how our descriptions that zoom in on things at the periphery and attend to the elusive, restage what gets to count as care and could support care practices that are more liveable for those concerned.

Keywords
Affects, atmospheres, collaboration, care, gynaecological cancer, patient organisations, feminist technoscience

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Introduction

As researchers we decide what to include in our descriptions and how we describe things. The doing of description is a non-innocent, world-making practice (Gill, 2017) and it matters what and how we describe (Haraway, 2016; Law and Singleton, 2013; Moser, 2011). In this article we start from here to explore care for dying and death in practices of patient representatives who are attempting to ensure the best possible care for cancer patients. Our article does things with description in order to intervene in what gets to count as care.

The argument we develop emerged through our discussions about research in two sites: a gynaecological cancer patient organisation in Sweden called the Gynae Cancer Group (GCG) and a Hospice in the United Kingdom administering care for people with life-limiting conditions. In the two settings carers and patient representatives are trying hard ‘to put something good in practice’ (Pols, 2015: 83). In doing so, their practices attend to some things while producing other things which threaten care. Our descriptions seek to explore the potential of some of these threatening things as they rub-up against participants’ practices of care. In doing so we attend to barely perceptible affects, relationalities and fleeting moments. We draw upon a body of research in Science and Technology Studies (STS): Feminist Technoscience Studies (FTS) inspired by Puig de la Bellacasa’s (2017) call for research as ‘matters of care’. This work approaches care as ‘an affective state, a material vital doing, and an ethico-political obligation’ (Puig de la Bellacasa, 2017: 42). It attends to the relational, affective and material webs that are vital for collective flourishing. The work informs our research practices in two key ways. Firstly, it restages knowledge to include affective, embodied and material layers and promotes research practices that hold on to the potential of affective and material relationalities (Puig de la Bellacasa, 2017: 65). Secondly, it builds on our feminist commitment to attend to ‘silences, secrets, omissions and erasures that take place during fieldwork and writing up’ (Flood and Gill, 2010: 3). This article attends to things that are often devalued and neglected, in order to generate better ways of caring.

Puig de la Bellacasa’s (2011, 2017) call for restaging research as matters of care can be understood as a political intervention into the practices of description. She developed the notion in conversation with Latour’s (2004) theorising on ‘matters of concern’. Latour argues that matters of fact are also matters of concern: facts have built in (and they build) normativities. Latour (2004: 232) introduced ‘matters of concern’ as ‘another powerful descriptive tool’, referring to the long-standing commitment in Actor-Network Theory (ANT) to describing the practices of assembling networks of heterogeneous actors as constitutive of realities. Love (2010: 377), discussing the usefulness of Latour’s approach, argues that for Latour good descriptions are ‘close but not deep’, they do not add any ‘extra’ layers to the description but aim to ‘account for the real variety that is already there’. Love (2010: 377) suggests that, instead of calling upon ‘imponderables like human experience or human nature’, Latour’s descriptions trace and assemble relations and networks. She emphasises that this enables descriptions that are ‘faithful, detailed, and complex’ (Love, 2010: 378). Indeed, Latour encourages researchers to take ‘the risk of writing a true and complete report about the topic at hand’ (2005: 127).
However, Puig de la Bellacasa (2011) argues that Latour’s notion of matters of concern lacks a critical edge that care brings. She argues that care can assemble neglected things and make some previously imperceptible politics perceptible. Puig de la Bellacasa’s (2017: 35) reading of Latour foregrounds the knowledge politics of his descriptions, and that it matters what reports we write. She emphasises that ‘[c]onstructivist approaches to science and nature, no matter how descriptive, are actively involved in redoing the world’ (Puig de la Bellacasa, 2017: 30). Grounded in a feminist commitment to situated knowledges, she emphasises the need for critical perspectives that take responsibility for the becoming of the things we engage with in our research (that we are implicated in their becoming). We read this as a call for more accountable descriptions that take seriously that our ‘descriptive tools’ matter for how and what we describe (Marcus et al., 2016: 12), and that our descriptions come with ‘ethico-political’ commitments (Puig de la Bellacasa, 2017). Puig de la Bellacasa (2017) promotes an approach to description that takes seriously that how we do descriptions is deeply entangled with worldly politics, and that therefore we tend to devalue and dismiss some things and attend to other things. Our ‘complete reports’ (Latour, 2005: 127) might, then, not be as complete as we think. In writing this article we have become increasingly attentive to how affects and fleeting moments have been neglected within our own descriptions. However, our practice is not one of adding extra layers (Love, 2010) to our descriptions, but it rather pays careful attention to layers easily overlooked (Puig de la Bellacasa, 2017).

We pay particular attention to things that threaten to undermine the stories that our participants want to tell about care. In doing so, we explore the potential of attending to things that are easily sensitised out from our descriptions (López-Gómez, 2019). These are things that are easily overlooked yet hold the potential to generatively rub up against and ‘unsettle’ (Murphy, 2015) care practices. Murphy (2015: 722) argues that ‘unsettling’ can be understood as ‘the purposeful undoing and troubling of particular arrangements so that they might be acknowledged and remade in better, less violent, more liveable ways’. Inspired by this, we think of our unsettling descriptions as troubling and redoing the patient organisation’s care arrangements in ways that might hold the potential of better, more liveable care for women living with gynaecological cancer. In particular, we explore what an ethico-political commitment to things that are deemed potentially undermining of care might mean for the politics and practices of describing care practices. We understand this as an analytical and descriptive practice that aims to ‘generatively unsettle’ (López-Gómez, 2019: 10) practices of care.

We draw upon empirical material from the GCG study to do descriptions that work closely with participants’ care practices but simultaneously aim to unsettle them. As suggested above, just as practices of description foreground some matters and not others, so do care practices. Care is a selective mode of attention and it has a dark side: in the process of cherishing some things, care inevitably marginalises or excludes other things (Lindén, 2016; Martin et al., 2015; Singleton and Mee, 2017). In their care practices, the GCG pay attention to some things and not others and they tell specific stories about what they do and how they make a difference. Of particular importance for this article, the GCG put a lot of effort into providing ‘hope’. Their motto is ‘knowledge saves lives’ and they associate this with telling hopeful stories about people surviving cancer. The GCG
is not unique in this regard. A focus on hope dominates the work of many patient organisations, for example as attention to new or potential therapies (Novas, 2006), and hope is a focus in many cancer contexts (Brown, 2012). Many patient stories circulating in the public sphere describe how cancer sufferers have survived thanks to new treatments (Jain, 2012). These stories link hope with cancer survivorship and care with saving lives, as does the GCG. Hence, in the GCG care practices, hope rubs up against care for dying and death, which tends to enact ‘temporal tensions’ (Brown et al., 2015: 207), and palliative care becomes something unsettling for the GCG representatives and their care.

Our descriptions of the GCG care practices are informed by discussions between the authors about approaches to care for dying and death within their respective research locations. In contrast to the GCG, in the hospice where Vicky has conducted research, end of life care is the daily work of the staff. They are troubled by care that prioritises treatment and cure at the expense of attending to death, dying and bereavement. In the accounts from the hospice staff hope is not linked with survivorship but rather with achieving ‘a good death’ for each patient and their family. The hospice provides care that supports ‘living well with’ life-limiting illness and with dying: respite care, management of symptoms, control of side effects and care at the end of life. Staging care as supportive of living well implies ‘active intervention and therefore leaves space for hope’ (Gysels et al., 2013). Hence, in the hospice, hope is linked with living with illness, dying and death rather than with saving lives, as it is by the GCG.

Our motivation to attend to the GCG’s care practices related to dying is to explore how attending to this topic can generatively unsettle the stories that the participants, and we as STS analysts, tend to tell about care and the descriptions we provide. The collaboration on this article has pushed Lisa and Vicky to look differently at their respective fieldwork and to attend to things at the periphery. Lisa, in her ethnographic research with the GCG, has paid little attention to end of life care, and has tended to prioritise the organisation’s focus on new treatments. Vicky, in the interviews with hospice staff, has tended to pay little attention to care for saving lives and has prioritised the staff focus on ‘a good death’. We had both focused on the more striking aspects of our participants’ practices, and things that they had prioritised when asked about their activities and goals. In this article, we focus only on the GCG’s practices in order to do detailed and nuanced descriptions that hold on to the affective and elusive aspects of care. However, we also want to hold onto the layers that informed our writing. This is to show how thinking across research sites, doing a form of descriptive collaboration, can open up unexpected and generative ways of doing description of one’s research. In particular it can promote attention to that which is easily overlooked or threatens to unsettle dominant stories.

Our descriptions of the GCG’s practices attend to fleeting moments of affective tension and seek to ‘restage’ (Puig de la Bellacasa, 2017) their struggles to attend to care for dying. We make present, and also complicate, the uneasiness of the relation between GCG care for living well and care for dying well. Our examples attend to things brushed aside or unsettling as we hold on to the potential of things that seemingly undermine care. This is in order to explore how the practices of doing descriptions can hold the potential of care practices that are more liveable for all those concerned.
A politics of description: care for dying in the context of patient organisations

Patient organisations no longer ‘confine their activities to the provision of help to their members and/or to advocacy for their rights and interests, but actively intervene in the “war on diseases” with an aim at finding a cure’ (Rabeharisoa et al., 2014: 112). Patient organisations for conditions such as cancers (Klawiter, 2008) and HIV/AIDS (Epstein, 1996) have intervened in biomedical activities with the aim to accelerate the arrival of new treatments. This change in focus has increased the amount of STS attention to the practices of patient organisations, with an abundance of studies focused on how patient organisations mobilise hope in order to shorten the ‘horizons of biomedicine’s potentialities to develop cures or therapies’ (Novas, 2006: 295). Hence, in many STS analyses, the attention to biomedicine within patient organisations has taken centre stage. The provision of care services to members, such as the GCG’s practices around end of life care, have received less attention. There is a small number of STS studies focused on end of life and palliative care, which describe the doing of care in locations of practice. Pasveer (2019) analyses how time is done in multiple ways in Dutch hospices, and Pols, Pasveer and Willems (2017: 89) show how dignity is done through professional carer’s ‘relational engagement in concrete care situations’. This work articulates care as located practices of relational engagement, rather than, for example, implementation of a general principle of dignity or following clock time. The descriptions provided by these authors do not, as we do, explore the generative potential of unsettling care. Rather, they articulate how care is done.

We are pointing here to a politics of description. In her analysis of dementia care practices, Moser argues there is a science centrism in STS, and that this ‘contributes to the dominance of science and biomedicine by granting these analytical privileges’ (Moser, 2011: 704). As a result, she suggests, ‘alternative modes of acting, for instance in care, are disarticulated and made absent’ (Moser, 2011: 704). The problem with this, she asserts, is that STS analyses run the risk of contributing to ‘making present and more real very particular versions of reality; of assuming that these are more powerful and make their way into, impose themselves upon, and order other locations and practices’ (Moser, 2011: 707). Moser is explicitly concerned with how STS analysts do descriptions and what they do descriptions about. She argues that what we describe and how we describe things has to do with ‘politics and normativity in STS’ (2011: 708). Moser’s work, and that of Pasveer (2019) and Pols, Pasveer and Willems (2017), articulates end of life care in locations of practice, and restages care as being done in relational terms. This work has provided rich and detailed ethnographic descriptions of care-in-practice (Mol et al., 2010), but it has emerged largely in parallel with the FTS on critical care we introduced earlier (Martin et al., 2015; Puig de la Bellacasa, 2017).

Both bodies of work are doing a politics of description of care, but in different ways. The former seeks to describe good care because it ‘is silently incorporated in practices and does not speak for itself’ (Mol, 2008: 2). In doing so it draws attention to mundane, unarticulated and taken for granted constituents and practices. So, for example, Moser asserts that whereas some aspects of, in her case, dementia practices are gaining attention in our descriptions (predominantly biomedical aspects), others are not and this produces
norms of dementia care. With a different focus, feminist critical care studies are concerned about ‘the tacit moral economies that contour our research questions and practices and that define some things or phenomena as the proper objects of care while others are cast aside’ (Martin et al., 2015: 636). Martin et al. (2015) call us to examine the ‘dark side of care’: on the one hand, this refers to the ways in which care is ‘feminised, devalued, overlooked, or rendered invisible by materially and morally privileging mind over body, public over private, reason over emotion, and waged labor over unpaid care work’ (Martin et al., 2015: 628). On the other hand, as discussed above, this understands care as a selective mode of attention that cares for some things while it neglects other things. It is this critical care approach that has led to a call for unsettling and ‘vexation’ of the seeming innocence of care (Duclos and Criado, 2019; Murphy, 2015).

Our approach draws mostly on the critical care approach. We sought not to reproduce the seeming innocence of the care described by the GCG. Our engagement with our research participants had created an appreciation that in the GCG and the Hospice they are striving to put something good into practice. Hence, it became easy to go along with the stories our participants want to tell about their care and their organisations. Yet when doing so we run the risk of overlooking, or even devaluing end of life care as an important focus for patient organisations dealing with patients with life-threatening illnesses. In the context of patient organisations we assert that to focus on care for dying foregrounds something that is neglected and unsettling and in doing so restages care. Pols (2014) is concerned that as many patient organisations focus on biomedicine, their focus on improving ways of living with chronic illness may be marginalised. To this we add that social scientists might be at risk of colluding with this by ignoring organisational practices that, while fleeting or seemingly undermining of care, are not primarily about biomedicine. Consequently, and paradoxically, attention to improving care practices may be marginalised (cf. Moser, 2011). We suggest that such practices devoted to caring might become (further) marginalised through our decisions about what to describe. Inspired by FTS on critical care, we endeavour to unsettle our descriptions because this matters for how we can intervene in care practices.

Our studies: methods and doing description collaboratively

As previously stated, the analysis in this article is informed by discussions between the two authors about common threads and differences between their individual research projects that both focus on how care for people with a life-limiting illness is constituted and described. The first is an ethnographic case study of a gynaecological cancer patient organisation in Sweden, and the second is an interview-based study on hospice care in the United Kingdom. The fieldwork for the patient organisation study was conducted between 2018 and 2020, and included ethnographic observations of events and meetings, interviews with GCG representatives and extensive textual and online data. The in-depth interviews with seven professional carers working at the hospice took place between 2016 and 2018. Both projects have been granted ethical approval and participants’ names and the organisations have been coded. The data included in this article is mostly from the patient organisation study. It includes a small section of the dataset which draws on
fieldnotes from a meeting where palliative care was discussed. However, the entire dataset has informed the concerns raised in this article.

The GCG is focused on influencing healthcare and research, increasing publics’ and professionals’ knowledge about gynaecological cancers and providing support to afflicted women and their relatives. In recent years, they have devoted extensive efforts to increasing funding for ovarian cancer research, improving the cervical cancer screening programme and increasing women’s knowledge about ovarian cancer symptoms. The organisation has no paid staff and approximately 1300 members. All interviews were transcribed and the transcriptions, fieldnotes and analysis of websites and texts were analysed through thematic coding to elicit key practices and common themes.

The practice of doing our descriptions, discussed below, effectively placed our two studies in relation with one another. The hospice focus on end of life care suggested the need to attend to care for death and dying in the GCG and how it was made peripheral or unsettled. Our descriptive collaboration allowed us to work against the grain in our descriptions, to look at them differently. Looking for un/common threads across our two studies and working with competing multiple descriptions of care enabled us to keep ourselves curious and thereby to attend to details and qualities we had previously overlooked. It also enabled us to get ‘closer to the variegated lives’ (Love, 2010: 377) of our participants because our descriptive collaboration enabled us to ‘see more and to look more attentively, more fully, and more selectively’ (Marcus et al., 2016: 14). Instead of foregrounding that which is often (already) foregrounded, we were able to see the potential of those things often overlooked, by ourselves and others. It was a collaborative practice that resisted brushing aside aspects of our fieldwork, things seemingly trivial and non-relevant. Ultimately, when coupled with Puig de la Bellacasa’s (2017) feminist commitment to the neglected, this allowed us to explore the ethico-political potential of unsettling our descriptions and of doing descriptions that unsettle. This collaborative work of unsettling descriptions could be understood as a version of what Love (2010: 375) calls an ‘alternative ethics’ grounded in description and documentation.

Descriptions attending to affective layers and fleeting moments

Below we analyse data from the GCG ethnography, paying particular attention to describing how the participants staged care for dying and how it becomes something unsettling and troubling for GCG representatives. This focus emerged through putting the care that the participants seek to promote in relation with hospice staff accounts of care. Vicky had found that, in her interviews with hospice staff, end of life care is privileged: hospice care is achieving ‘a good death’. For example, Sister R said that she measures success in her job by, ‘that the patient has a good death’ and Sister N said that, ‘When we can’t provide a good death, it makes me angry that we can’t do what we are supposed to do’. Reflecting on hospice staff accounts of what constitutes care in relation with the GCG care practices pushed us to look differently at the GCG care practices and to zoom in our descriptions on participants’ struggles with care for dying.
Describing atmospheres

It is a Tuesday evening and the GCG board and some of the organisation’s volunteers have their first meeting about their upcoming gynaecological cancer seminar. It is a seminar for, and with, patients, practitioners and researchers. One of the board members, Caroline, has sent out a document via email to the group before the meeting with her ideas. The volunteer Marlena immediately refers to this document and says: “I saw this with palliative care and I think it’s good that we raise this issue because we should not be afraid to bring it up”. Caroline’s idea is that the seminar should end with a presentation from a palliative care nurse about what palliative care is and what forms of palliative care patients can receive. Marlena says, however, that they should start with the theme of palliative care instead of ending with it. Caroline immediately shakes her head intensely. She does not agree. Malena, however, continues, and says that she thinks it is not really ideal to end the evening with palliative care, because they then end in “a depressing way”. The board member Karin looks thoughtful and says that she agrees with Caroline, “it sets a strange tone” to begin with palliative care. She emphasises that, with their focus on “knowledge saves lives”, they want to “create hope” and to start with palliative care is not really being hopeful. Caroline nods, she seems to agree. They decide to place palliative care in the middle of the program. “It doesn’t feel so sad then”, Karin says, and will still show that it is important by not leaving it to the end (fieldnote 25/08/18, GCG planning meeting).

Once a year the GCG organises an evening seminar about gynaecological cancer in several cities in Sweden. The seminar consists of short talks by practitioners and researchers about topics of relevance to gynaecological cancer, combined with short films where patients tell their stories. In recent years the seminar has been structured around the themes of prevention, research and care. The above fieldnote was written based on the first planning meeting for the 2019 seminar, focused on what to include. At the meeting not much time was devoted to palliative care, considerably more time was spent on their identified ‘key areas’, which include cervical cancer prevention and promoting research on ovarian cancer. This, however, is not to say that the GCG doesn’t care about palliative care. During the meetings before the 2019 evening seminar, Lisa had begun to appreciate it is a topic they find important yet marginal in relation to many other topics. As such, it is easy to overlook.

At the above meeting, contested issues, such as possible links between stress and cancer and the use of preimplantation genetic diagnosis (PGD) to select embryos without the genetic mutations BRCA1 or BRCA2 (high-risk genes for breast and ovarian cancer), did not give rise to disagreements. The topic of PGD, for example, was easily agreed upon as important to include. For example, Karin related its inclusion to the GCG’s motto, ‘if we say that knowledge saves lives then we really have a mission in this’. PGD was included as an obvious example of ‘knowledge saves lives’. From previous meetings and activities prior to the planning meeting Lisa had learnt that PGD had strong appeal for many in the organisation. For example, Karin had repeatedly said it would, ‘break the chain of this bad genetic heritage’. The hope for the GCG is that PGD will allow for better care because concerned families will have the option to screen for BRCA susceptibility; moreover, disease will be prevented and lives saved. But PGD is also a debated topic that, in other contexts, has raised concerns, for example about the ethics of de-selection of ‘unhealthy’ embryos (Franklin and Roberts, 2006). Despite this, the GCG members
seemed to agree that PGD is a valuable and hopeful service for their members and it was enacted as care because it was associated with saving lives.

Things were different with palliative care. Malena’s suggestion to begin the seminar programme with the presentation about palliative care was an attempt to avoid ending ‘in a depressing way’. However, Caroline and the others disagreed because they felt it would set a strange tone and would not create hope. Where to locate the topic in the programme may seem to be a trivial issue, especially as this issue was not whether it should be included and it was clear palliative care was important to them. But it caught Lisa’s attention because this seemingly trivial matter was troubling for the participants. Moreover, it wasn’t only what was said that affected Lisa, it was also changes in facial expressions, tones and bodily movements. Lisa felt the room change in response to Malena’s suggestion. The GCG representatives shook their heads and Lisa saw discomfort and wariness in their eyes. Caroline was the one who expressed this most intensely, she shook her head immediately and forcefully to show that this was not a good way to care for their members. These bodily movements, what we here define as an ‘affective atmosphere’ (Anderson, 2009), are what Lisa had quickly scribbled down in her notebook as important.

Atmospheres are not easy to describe, they are elusive and difficult to attend to (Law, 2004). As McCormack (2019) discusses in a paper on the possibilities for ANT approaches to trace spaces of affect, atmospheres can be understood as something ‘vague yet palpable’ (McCormack, 2019: 185) with an excessive quality. This suggests that they also partly escape our attempts to describe them. As McCormack continues, this quality also impacts on how to describe them. He suggests that we need to attune ourselves to ‘ways of sensing, being moved’ (McCormack, 2019: 187). That is, it is important to describe not only how things are assembled but also how they are sensed. Atmospheres, therefore, attune us to ‘affective relationalities’ (Puig de la Bellacasa, 2017). For example, they require that we try to describe ‘the tone and style of particular meetings and gatherings’ (McCormack, 2019: 186). Such detailed description of fleeting bodily movements and tones can be defined as a ‘thin description’ (Love, 2013), attending to ‘surfaces, operations, and interactions’ (Love, 2010: 375). In describing bodily tones and expressions we do not add an extra affective layer, we attend to how an atmosphere is done in practice. However, in attuning our description to ‘affective relationalities’ (Puig de la Bellacasa, 2017), we approach such bodily gestures as indicative of affective qualities.

At the meeting, a tension between creating hope and palliative care directed the GCG’s attention. Palliative care was enacted as something that could potentially undermine how they do care. If it was located in the ‘wrong’ part of the seminar, it would risk not being care. The issue was settled by placing palliative care in the middle of the programme. Through this adjustment of the programme, palliative care was made to fit ‘well enough’ as care. This description focuses on the meeting as an ordering practice where care is achieved through tinkering (Mol et al., 2010). However, it ignores the atmosphere that we previously suggested was important. Lisa’s scribbled notes, about tones and bodily movements, allowed for a ‘restaging’ (Puig de la Bellacasa, 2017) of the situation, and for a description of both the seminar programme (as a material device) and the GCG representatives as enacting a specific atmosphere. As Anderson (2009: 80) argues, atmospheres emerge from collective situations, but are often felt as ‘intensely personal’.
Lisa had sensed, as something intensely personal, the room change in response to Malena’s suggestion, and this sensing of the meeting became important to descriptions of the situation. This ‘vague yet palpable’ sense of what people felt to be the right thing to do had shaped decision making. Hence, we argue, including the atmosphere in this description ‘expands and multiplies the sense and scope of the empirical’ (McCormack, 2019: 183). While explicit affects were also part of the group’s talk (they talked about being ‘hopeful’, ‘not being afraid to’ and ‘depressing ways’), the more subtle and elusive affective relationalities, we suggest, are easier to overlook, but expand and extend possibilities for care.

Through this example we have attempted to show how trying to describe elusive atmospheres might be important in attending to the potential of things that threaten to undermine what gets to count as care. In this specific example, doing so intervenes in discussions about how patient organisations’ predominant focus on biomedicine risks marginalising care practices (Moser, 2011; Pols, 2014). The fieldnote provides an example of an organisational practice where palliative care is enacted as way of putting something good in practice, despite its enactment as potentially undermining care and as being in tension with hope and saving lives.

**Describing fleeting moments**

Later on during the Tuesday meeting the GCG representatives are talking about the content of films featuring people with experience of gynaecological cancer to be included in the seminar. Caroline suggests a film with a patient in palliative care that would complement the presentation from the nurse and combine professional expertise and patient experience. “A chronically ill patient who can tell us a little about her life”, she says. “A normal everyday life for her”. The board member Mia immediately looks doubtful and Karin responds quickly, “but isn’t that a bit sad?”. “But is it? It can remove some fear too, I think” Caroline says. Mia nods, seems to agree with Karin and says “Well, I think it adds a bit of a sad feeling”. Karin nods, she seems to agree with Mia. As a gesture to make sure Caroline is not upset Mia stresses that she understands how Caroline thinks, but that she believes “it can have the opposite effect, people may become sad and fearful instead of hopeful. “You might be right”, says Caroline. Her tone is wary and she looks hesitant, like she doesn’t quite agree. The group decides to not go with Caroline’s suggestion and instead include a film with a vulva cancer survivor (they have decided to pay attention to this particular cancer this year), and one about a family with BRCA. Karin says that they can “create some hope” with these (fieldnote 25/08/18, GCG planning meeting).

The above fieldnote describes the second time palliative care was mentioned in the planning meeting. Caroline suggested including a film with a palliative care patient to complement the presentation by a palliative nurse. This was immediately responded to with concern and the atmosphere in the room changed. The meeting had been running smoothly for about an hour but when palliative care was brought up the atmosphere changed. People looked wary and said that the film would be ‘too sad’. Some shook their heads. Unlike the presentation from the nurse, it was not possible to make the patient film fit with their care. There was consensus that a patient film with a palliative care patient would be too sad and would, thus, not enable feelings of hope. The atmosphere was part of producing this consensus as wary tones and bodily movements directed
people’s responses. A film with a palliative care patient was enacted as not providing care in practice. Here, palliative care and hope clashed and, in the end, a patient story about palliative care was not included and more ‘obviously’ hopeful stories about cancer survivors and living well with BRCA (including a focus on PGD treatment) were selected. Thereby the GCG’s attempt to ‘put something good in practice’ was unsettled by what was talked about as ‘a sad feeling’ of palliative care. Since the GCG links hope to survivorship, a patient story about palliative care easily becomes an impossibility because it cannot be (only) about survival. It will also, implicitly or explicitly, be about dying and death.

However, while Caroline said ‘you might be right’ Lisa had written in her notebook, ‘I get a feeling that Caroline “gives up” rather than actually agreeing’. She noted Caroline’s hesitant expression and wary tone. Indeed, saying that ‘you might be right’ is not the same as saying that ‘you’re right’. Caroline’s hesitation hints at a tension in the GCG’s decision that is present in many meetings: consensus doesn’t mean that everyone agrees. To be clear, Caroline’s hesitation was not a big part of this situation. It was a moment that passed by quickly and then was forgotten about. In fact, it is likely that Lisa would have forgotten about Caroline’s suggestion and hesitation if Lisa and Vicky had not had discussions for this article about Vicky’s research about hospice carer’s attention to care for dying and death.

Caroline’s hesitation is a ‘fleeting moment’ (Jerak-Zuiderent, 2015), one we hold on to that allows for re-staging the description of care, where palliative care is not deemed to threaten putting something good into practice. In the context of feminist approaches to care in STS, Schrader (2015: 684) argues that slowing down our analysis allows for ‘the generation of space-times for hesitations’. Considering this, it is possible to describe the situation above differently, in a way that does not ignore Caroline’s hesitation. While a palliative care patient film was still, in the end, excluded, an alternative world where a patient story about palliation as care is made visible through a description that holds on to the potential of Caroline’s hesitation and potentially undermines the (seeming) group consensus about what constitutes care. Caroline’s hesitation zooms in on the practice of the non-innocence of care; that it attends to some things at the expense of others. As the fieldnote shows, at the meeting Caroline hinted that a patient story about palliative care could be hopeful, if hope is enacted differently and disentangled from survivorship. Removing some fears about palliative care, as Caroline suggested, might also provide hope and perhaps more importantly, provide an important service to patients living with chronic cancer, who want to learn from other patients about their experiences of palliative care. Learning from Vicky’s Hospice study, this might be a way to foster ways of ‘living well’ while dying.

Our practices of description attend to a feminist commitment to the neglected. The fleeting moment of Caroline’s hesitation could easily pass by, go unnoticed or be brushed aside. However, in including it we foreground a small part of the meeting to tell a story that the research participants would likely not tell themselves. This is ‘a descriptive tool’ (Latour, 2004) that works with the empirics but foregrounds fleeting aspects. This complicates the relation between practices of description and feminist speculation: we work with the participants’ stories while simultaneously working against the main story to speculate about what might count as care (cf. Haraway, 2016; Puig de la Bellacasa,
In this particular case, this allows us to intervene in the practice of telling hopeful stories, so common in cancer contexts (Brown, 2015; Jain, 2012) and patient organisations (Novas, 2006). Caroline’s hesitation suggests that ‘things could be otherwise’: that telling a hopeful cancer story does not have to be a story about survivorship, and hope can be disentangled from survivorship. Thus, it might also be a story about the mundane practices of living well as a chronic cancer patient and how care practices attending to those lives might look and be attuned to patients’ experiences. The above description can ‘generatively unsettle’ (López-Gómez, 2019) care practices by responding not only to the practices of the GCG, but, importantly, to cancer care practices out there. It allows space-time (Schrader, 2015) to hesitate and speculate around what might count as good care if that which is easily overlooked or deemed to threaten care is centralised in our descriptions.

Discussion

In this article we have sought to shift our analytical attention to describe things at the periphery of our attention and hence easily neglected in our descriptions of our research. Specifically, we have attended to things that seem to unsettle or threaten to undermine the stories that we and our research participants want to tell about care. For this purpose, we have worked with fieldnotes from Lisa’s ethnography with a gynaecological cancer patient organisation in Sweden. The GCG representatives struggle with palliative care because it is related to death and dying. They tend to enact their care as saving lives, and to link this with cancer survivorship and hope. Therefore, while they consider palliative care an important issue, they are uneasy about it being too sad, and they struggle with enacting it as hopeful. In zooming in our descriptions on GCG practices around palliative care we have sought to ‘restage’ (Puig de la Bellacasa, 2017) our descriptions in a way that is more liveable for gynaecological cancer patients, because it allows space-time for issues of living with dying, and for patients’ experiences of being in palliative care.

We have focused our descriptions on tensions around caring for ‘surviving disease’ and caring for ‘living with disease’, the latter includes care for dying. These descriptions required a shift in our analytical attention, from a focus on the more striking aspects of the GCG practices to palliative care as something troubling and threatening. This was made possible through our practices of collaboration in writing this article. Discussing our respective fieldwork about how people care for others with a life-limiting illness helped us to attend to what is neglected and elusive in our respective data. In particular, this made us see the importance of trying to describe fleeting atmospheres and thereby attend to, not only how things are assembled and ordered, but also how they are sensed by us, the researchers doing the descriptions. Doing a form of ‘thin description’ (Love, 2010) of things at the surface allowed us to identify bodily tones and movements as indicative of affective qualities, and to describe those qualities as fleeting yet important. In line with Latour (2005) and Love (2010) we have not ‘added a layer’ to our descriptions but have paid detailed attention to what is already there. Yet, differently from Latour (2005), with a feminist speculative commitment to the neglected we have foregrounded easily overlooked affective moments. In doing so, we have emphasised the politics of describing care practices. Taking up Puig de la Bellacasa’s (2017) call for
thinking about research practices as ‘matters of care’, we have developed a version of Love’s (2010: 375) ‘alternative ethics’ of description that actively tries to use ‘descriptive tools’ (Latour, 2005) to intervene in worldly politics by paying fine-grained attention to the neglected and devalued.

Our descriptions have unsettled the ‘seeming innocence of care’ (Murphy, 2015) as we have attuned them to affective tensions in the GCG practices around what gets to count as care. In the context of the GCG we have shown that some forms of care are enacted as potentially undermining or easily get overlooked. Considering concerns that STS researchers and patient organisations have paid attention to biomedicine at the expense of adequate attention to practices of living (and dying) well with chronic illness, our descriptions of atmospheres and fleeting and easily overlooked moments have developed a more specified argument. Our descriptions have shown that experiences of dying, and of care while dying, are at risk of becoming/being devalued because they are in tension with a predominant focus on survivorship.

Writing this article and doing description collaboratively has helped us to attend to neglected and fleeting things and to ‘unsettle care’ (Murphy, 2015). Looking at un/common threads between our two locations of care for people living with dying, exposed things that were deemed to threaten care practices and the stories told about care. This collaboration to ‘unsettle descriptions’ took considerable time and a willingness to be, ourselves, unsettled. Our ethico-political commitment to the effects of our research practices and processes of doing description was coupled with a collaborative speculative commitment to the transformative potential of attending to things that threaten to undermine practices of care (Martin et al., 2015; Puig de Bellacasa, 2017). In particular, this was a commitment to our descriptions as generated in our affective and material engagement in collaboration, rather than as presentation of amalgamated pre-existing analysis. This was a practice of allowing analytical space-time for turning potentially threatening things, and peripheral, fleeting moments, into empirical concerns, in order to hold onto the potential for more liveable forms of care for all concerned.

Our methodological approach allows for a bridging of description and speculation. While Love (2010: 382) argues for a ‘disengagement’ from speculative thought about human nature, meaning and depth, our approach allows for another form of speculation, that is made possible by working across research sites, paying close and fine-grained attention to what is there, at the surface, but easily overlooked. It does not add an extra layer to the descriptions, rather it foregrounds fleeting aspects at the periphery of that surface. While we have focused our descriptions on care practices, our analysis highlights the ethico-political potential of engaging in a practice of unsettling descriptions that takes the STS lesson that ‘description is intervention’ (Vikkelsø, 2007) seriously, and by doing so, actively tries to speculatively describe things in ways that might allow for collective flourishing.

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**References**
Anderson B (2009) Affective atmospheres. *Emotion, Space and Society* 2(2): 77–81.
Brown N (2015) Metrics of hope: disciplining affect in oncology. *Health* 19(2): 119–136.
Brown P and de Graaf S (2013) Considering a future which may not exist: the construction of time and expectations amidst advanced-stage cancer. *Health, Risk & Society* 15(6-7): 543–560.
Duclos and Criado TS (2019) Care in trouble: ecologies of support from below and beyond. *Medical Anthropology Quarterly* 34(2): 153–173.
Epstein S (1996) *Impure Science: AIDS, Activism, and The Politics of Knowledge*. Berkeley: University of California Press.
Franklin S and Roberts C (2006) *Born and Made: An Ethnography of Preimplantation Genetic Diagnosis*. Princeton: Princeton University Press.
Gill N (2017) Caring for clean streets: policies as world-making practices. *The Sociological Review* 65(2 suppl): 71–88.
Gill R and Ryan-Flood R (eds) (2010) *Secrecy and Silence in the Research Process: Feminist Reflections*. London: Routledge.
Gysels M, Evans N, Meñaca A, et al. (2013) Diversity in defining end of life care: an obstacle or the way forward? *PloS One* 8(7): e68002.
Haraway D (2016) *Staying with the Trouble: Making Kin in the Chthulucene*. Durham: Duke University Press.
Jain L (2013) *Malignant: How Cancer Becomes Us*. Berkeley: University of California Press.
Jerak-Zuiderent S (2015) Keeping open by re-imagining laughter and fear. *The Sociological Review* 63(4): 897–921.
Kehl A K (2006) Moving toward peace: an analysis of the concept of a good death. *American Journal of Hospice and Palliative Medicine* 23(4): 277–286.
Klawiter M (2008) *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism*. Minneapolis: University of Minnesota Press.
Latour B (2004) Why has critique run out of steam? From matters of fact to matters of concern. *Critical Inquiry* 30(2): 225–248.
Latour B 2005 *Reassembling the Social: An Introduction to Actor-Network-Theory*. Oxford: Oxford University Press.
Law J (2004) *After Method: Mess in Social Science Research*. London: Routledge.
Law J and Singleton V (2013) ANT and politics: working in and on the world. *Qualitative Sociology* 36(4): 485–502.
Lindén L (2016) *Communicating Care: The Contradictions of HPV Vaccination Campaigns*. Lund: Arkiv Academic Press.
López-Gómez D (2019) What if ANT wouldn’t pursue agnosticism but care? In Blok A, Farias I and Roberts C (eds) The Routledge Companion to Actor-Network Theory. The Routledge Companion to Actor-Network Theory. London: Routledge, 4–13.

Love H (2010) Close but not deep: Literary ethics and the descriptive turn. New Literary History 41(2): 371–391.

Love H (2013) Close reading and thin description. Public Culture 25(3): 401–434.

Marcus S, Love H and Best S (2016) Building a better description. Representations 135(1): 1–21.

Martin A, Myers N and Viseu A (2015) The politics of care in technoscience. Social Studies of Science 45(5): 625–641.

McCormack DP (2019) Is ANT capable of tracing spaces of affect? In Blok A, Farias I and Roberts C (eds) The Routledge Companion to Actor-Network Theory. London: Routledge, 181–189.

Mol A (2008) The Logic of Care: Health and the Problem of Patient Choice. London: Routledge.

Mol A, Moser I and Pols J (eds) (2010) Care in Practice: On Tinkering in Clinics, Homes and Farms. Bielefeld: Transcript Verlag.

Moser I (2011) Dementia and the limits to life: anthropological sensibilities, STS interferences, and possibilities for action in care. Science, Technology, & Human Values 36(5): 704–722.

Novas C (2006) The political economy of hope: patients’ organizations, science and biovalue. BioSocieties 1(3): 289–305.

Pasveer B (2019) Deadlines: doing times in (Dutch) hospice. Mortality 24(3): 319–332.

Pols J (2014) Knowing patients: turning patient knowledge into science. Science, Technology, & Human Values 39(1): 73–97.

Pols J (2015) Towards an empirical ethics in care: relations with technologies in health care. Medicine, Health Care and Philosophy 18(1): 81–90.

Pols J, Pasveer B and Willems D (2018) The particularity of dignity: relational engagement in care at the end of life. Medicine, Health Care and Philosophy 21(1): 89–100.

Puig de la Bellacasa M (2011) Matters of care in technoscience: assembling neglected things. Social Studies of Science 41(1): 85–106.

Puig de La Bellacasa M (2017) Matters of Care: Speculative Ethics in More Than Human Worlds. Minneapolis: University of Minnesota Press.

Rabeharisoa V, Moreira T and Akrich M (2014) Evidence-based activism: patients’, users’ and activists’ groups in knowledge society. BioSocieties 9(2): 111–128.

Schrader A (2015) Abyssal intimacies and temporalities of care: how (not) to care about deformed leaf bugs in the aftermath of Chernobyl. Social Studies of Science 45(5): 665–690.

Singleton V and Mee S (2017) Critical compassion: affect, discretion and policy-care relations. The Sociological Review 65(2_suppl): 130–149.

Vikkelso S (2007) Description as intervention: engagement and resistance in actor-network analyses. Science as Culture 16(3): 297–309.

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