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# **Biomedicine, patients and care-full critique: Modes of attending to gynaecological cancer advocacy practices**

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During the last two years I have been doing ethnographic fieldwork with a patient advocacy group from Sweden I call the Gynae Cancer Group (GCG). The group, consisting of cancer patients and their relatives, mobilises to increase public knowledge about gynaecological cancers, intervenes in healthcare and medical research practices, and provides support to fellow patients. As for many other patient advocacy groups, an important part of their advocacy aims to increase and speed up concerned patients' access to new treatments. For example, after several years of advocacy work, in 2018 the GCG succeeded in making the Swedish Cancer Society, which is the largest funder of cancer research in Sweden, to undertake a specific investment in ovarian cancer research. For another example, during 2019 the group pushed for a faster governmental approval of the subsidisation of poly polymerase (PARP) inhibitors – a group of new targeted cancer drugs – to all ovarian cancer patients in Sweden. PARP inhibitors are not a cancer cure, but they might prolong life, and possibly, increase chances of survival.

In the context of care studies in Science and Technology Studies (STS), Jeanette Pols has raised a concern that patient advocacy groups' extensive attention to potential or new biomedical treatments, risks marginalising a continued need to improve care practices concerning ways of living with chronic illness.<sup>1</sup> As some cancers – like ovarian cancer – increasingly are seen as chronic diseases, this is important in this context. Against this backdrop, this paper explores possibilities for

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<sup>1</sup> Pols, Jeannette. "Knowing Patients: Turning Patient Knowledge into Science." *Science, Technology, & Human Values* 39, no. 1 (2014).

doing “care-full” critique<sup>2</sup> in a context of cancer patient advocacy. My concern is the question of how to tell ethnographic stories “that are *generative* for the people and practices that the stories are about, as well as for the authors and their academic collectives”.<sup>3</sup> For me, this has to do with an ethico-political commitment<sup>4</sup> towards the *politics of* cancer patient advocacy, while at the same time “staying true to” the specificities and generativity of the worlds the representatives of the GCG live in, embody and engage with.<sup>5</sup>

I believe that one possible way of doing care-full critique is to keep asking “how to care?”.<sup>6</sup> This means to not only describe how care is enacted in a specific practice “out-there”, but also, as STS researcher Sonja Jerak-Zuiderent suggests, engage with the question of how we as ethnographers and researchers might care for our scholarly accounts.<sup>7</sup> I engage with this question in this paper. I do so through a theoretical approach that aligns with a Feminist Technoscience Studies “critical care” approach that understands care as a relational doing and an affectively charged and selective mode of attention.<sup>8</sup> In the process of cherishing some things, care also marginalises or excludes other things. In line with this approach, in this paper, I work with a multi-layered

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<sup>2</sup> In my desire to engage “care-fully”, I am inspired by for example Coopmans’ encouragement of a “care-ful engagement” in how we as STS researchers relate to our own research and fieldwork. See Coopmans, Catelijne. “Caring for Past Research: Singapore, Eye Health Care, STS, and Me.” *East Asian Science, Technology and Society*, 14, no. 1 (2020), 151.

<sup>3</sup> Winthereik, Brit Ross, and Helen Verran. “Ethnographic Stories as Generalizations that Intervene.” *Science Studies* 25, no. 1 (2012), 37.

<sup>4</sup> Puig de La Bellacasa, María. *Matters of Care: Speculative Ethics in More than Human Worlds*. Minnesota: University of Minnesota Press, 2017.

<sup>5</sup> Verran, Helen. “Staying True to the Laughter in Nigerian Classrooms.” *The Sociological Review* 47, no. S1 (1999).

<sup>6</sup> Schrader, Astrid. “Abyssal Intimacies and Temporalities of Care: How (Not) to Care about Deformed Leaf Bugs in the Aftermath of Chernobyl.” *Social Studies of Science* 45, no. 5 (2015), 667.

<sup>7</sup> Jerak-Zuiderent, Sonja. “How to Care for our Accounts?” In Blok, Anders, Ignacio Farias, and Celia Roberts, eds. *The Routledge Companion to Actor-Network Theory*. London: Routledge, 2019.

<sup>8</sup> Lindén, Lisa. *Communicating Care: The Contradictions of HPV Vaccination Campaigns*. Lund: Arkiv Academic Press; Martin, Aryn, Natasha Myers, and Ana Viseu. “The Politics of Care in Technoscience.” *Social Studies of Science* 45, no. 5 (2015): 625-641; Singleton, Vicky, and Steve Mee. “Critical Compassion: Affect, Discretion and Policy.” *The Sociological Review* 65, no. 2\_suppl (2017).

understanding of care that understands it as “an affective state, a material vital doing, and an ethico-political obligation”<sup>9</sup>. I focus both on the care that “we, as STS scholars, teachers, and feminists enact in *our relations with* the worlds we study, and that *which circulates among the actors* in the technoscientific worlds we encounter through our studies”.<sup>10</sup> I will attend to several layers of care: how I care, how my participants care, and the care practices my participants enact and intervene in through their advocacy.

I explore the question of “how to care for my accounts?” by thinking with the metaphors of “scaling up” and “scaling down”, metaphors I borrow from feminist scholars Lochlann Jain and Jackie Stacey.<sup>11</sup> In incorporating their own cancer narratives in their academic analyses, they shift their mode of attention between a focus on first-person accounts and critical analysis, aiming to “offer readers both critical purchase and affective connection”.<sup>12</sup> Inspired by this, my aim is to explore the question of “how to care for my accounts?” by analytically moving between scales of cancer, scales that together make up some of the current gynaecological cancer worlds. Therefore, in my analysis below, I move between attending to particular, often affective, stories told by the participants in the GCG about their political engagement in the organisation and their relation to gynaecological cancer, whilst attending to larger questions about biomedicine and cancer care. In doing so, I aim to care-fully choreograph my analytical attention, this to tell stories that hold together critical analysis with an affective and embodied engagement, and that aim to speak to the concern for how to care for the accounts we as ethnographers and researchers do of the empirical practices we emerge ourselves in.

### **The patient advocate Caroline**

One of the most active members of the GCG is the patient advocate Caroline. When I met Caroline for an interview in the fall of 2018, she told me that she got involved in the group due to her mother having

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<sup>9</sup> Puig de la Bellacasa, *Matters of Care*, 42.

<sup>10</sup> Martin, Myers and Viseu, “The Politics of Care in Technoscience”, 626.

<sup>11</sup> Jain, S. Lochlann, and Jackie Stacey. “On Writing about Illness: A Dialogue with S. Lochlann Jain and Jackie Stacey on Cancer, STS, and Cultural Studies.” *Catalyst: Feminism, Theory, Technoscience* 1, no. 1 (2015).

<sup>12</sup> Jain and Stacey, “On Writing about Illness”, 10.

chronic, advanced, ovarian cancer.<sup>13</sup> Caroline also soon found out that she herself is a BRCA mutation carrier with high risk of breast and ovarian cancers, something that further intensified her engagement. She emphasised that she wanted to be involved in the group as “so few people knew about ovarian cancer and I guess I was irritated about that”. “People have not heard about ovarian cancer and I was super angry that my mother’s cancer was detected so late”, she said. As many of the other GCG representatives also frequently have done in interviews, Caroline highlighted that gynaecological cancers are often marginalised in the public and medical spheres; that these cancers are less attended to than, for example, breast and prostate cancers. Therefore, she decided to get involved in the GCG to increase people’s knowledge about ovarian cancer – as well as the other gynaecological cancers – and to push for better care and support, and more research.

During the interview, Caroline said that she sometimes thought about whether she would have the energy to keep being so involved in the group and, as she called it, in “the cancer world”, when her mother has passed away. But, she continued, “I cannot put this world off”. In referring to the breast cancer risk reducing surgery she conducted a couple of years ago, she said, with laughter: “If I take a shower, wait a second, you know, where are my breasts? You are never, you know, free from it”. She continued: “The cancer is always there, nibbling in the background”. Therefore, for her, the commitment to engage in the group is not something she feels she can just “switch off”; it is in a very literal sense an embodied engagement. Her body, her life, is intimately entangled with cancer, and with biomedicine. Her engagement in the GCG, and her commitment to make gynaecological cancers less marginalised, is, in this sense, an “intimate entanglement”<sup>14</sup> that links her own experience and embodiment to biomedicine and to larger questions of the politics of marginalisation and cancer visibility.

During my fieldwork I have gotten to know Caroline. I have learnt that she and her mother are very close, best friends even. I have met her mother, a gynaecological cancer patient advocate herself, several

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<sup>13</sup> I wrote this article in early 2020 and since then Caroline’s mother has passed away. My thoughts are with Caroline and her family.

<sup>14</sup> Latimer, Joanna, and Daniel López Gómez. “Intimate Entanglements: Affects, More-than-Human Intimacies and the Politics of Relations in Science and Technology.” *The Sociological Review* (2019).

times, and many times I have listened to Caroline talking to her mother on the phone. I have also followed the progression of the mother's cancer. The first time I was supposed to meet Caroline for an interview, she had to cancel the same morning, because her mother was hospitalised and she needed to be there with her. Since then, I realised that when Caroline was not answering emails, then it was likely her mother was ill. I heard several times one of the other board members or volunteers say at meetings that now Caroline's mother is dying, and how imminent it was.

Care is a suitable word to use to describe Caroline's commitment to the gynaecological cancer cause. It is a care for the marginalised, not far from what Feminist Technoscience Studies scholar María Puig de la Bellacasa<sup>15</sup> has called a care for the neglected. Caroline, as do the others in the GCG, care intensely and passionately for a world where gynaecological cancers are publicly visible and easily talked about, where concerned women are provided the best possible care and where no one has to die from these cancers.

In her discussion of advocacy and care, feminist philosopher Lorraine Code<sup>16</sup> highlights that "it makes sense to assume that advocates, singly or as members of an advocacy group, will care about the claims and positions for which they advocate". As Code discusses, the figure of the advocate troubles a vision of a disinterested and dispassionate knower; this vision has to be re-thought when it starts "from situated, vulnerable lives".<sup>17</sup> Learning from this, it makes sense to think about practices of knowing and care as entangled in the context of patient advocacy, and to understand Caroline's engagement in the GCG as such an entanglement. Indeed, care is "a mode of engagement".<sup>18</sup> This engagement, this care, affectively and materially attunes Caroline to medical gynaecological cancer practices in specific ways.

The story of Caroline and her engagement in the GCG exemplifies how the GCG's embodied and intimate care about the gynaecological cancer cause is entangled with politics of cancer.

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<sup>15</sup> Puig de la Bellacasa, *Matters of Care*.

<sup>16</sup> Code, Lorraine. "Care, Concern, and Advocacy: Is There a Place for Epistemic Responsibility?" *Feminist Philosophy Quarterly* 1, no. 1 (2015), 8.

<sup>17</sup> Code, "Care, Concern, and Advocacy", 18.

<sup>18</sup> Schrader, "Abyssal Intimacies and Temporalities of Care.", 667.

However, as care is a selective mode of attention that allows us to see some things, and not others, the important question is not *if* patient advocates such as Caroline care, but how, what and for whom they care through their engagement and the practices they immerse themselves in. As the GCG enacts and intervenes in practices where it certainly “matters to know and act responsibly and well”<sup>19</sup>, this is important. In the following I will explore advocacy practices in two examples, one focused on new biomedical treatments and one focused on palliative care.<sup>20</sup> These two examples do not only enact strikingly different forms of advocacy practices, but, as I will show, they also require different answers to the question “how to care for my accounts?”.

### **PARP inhibitors**

Social studies of biomedicine and genomics have attended to how high expectations and optimism often are invested in new cancer drugs, and that this risks reducing scientific uncertainties and raise unrealistic expectations.<sup>21</sup> Against this backdrop, in this section I will focus in on the GCG’s practices around “speeding up” the approval of PARP inhibitors as one example of their relation to biomedicine. I do so to relate some of the concerns raised through this form of patient advocacy.<sup>22</sup>

During the autumn of 2019, PARP inhibitors were brought up several times during GCG meetings where I participated as an observer, and I came to learn that PARP inhibitors were strongly cared about, both by the GCG representatives and the group’s ovarian cancer patient members. PARP inhibitors became an issue that the GCG

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<sup>19</sup> Code, “Care, Concern, and Advocacy”, 5.

<sup>20</sup> My attention to palliative care is thanks to conversations I have had with my former postdoctoral mentor, Professor Vicky Singleton, about forms of end of life care, her work on Hospice care, and our collaboration around these issues. This collaboration has made me look differently at my fieldwork with the GCG, and have encouraged me to attend to how palliative care can “generatively unsettle” some of the more predominant practices of the GCG, focused on biomedical treatments.

<sup>21</sup> See for example, Kerr, Anne, Julia Swallow, Choon Key Chekar, and Sarah Cunningham-Burley. “Genomic Research and the Cancer Clinic: Uncertainty and Expectations in Professional Accounts.” *New Genetics and Society* 38, no. 2 (2019).

<sup>22</sup> Pols, “Knowing Patients.”

invested intense attention, hope and engagement into. For example, at a board meeting in August 2019, Karin told the rest of the group that she and one of the other board members, Alzena, have had a telephone meeting with the responsible governmental agency, The Dental and Pharmaceutical Benefits Agency. In an agitated tone, she told us that she had said to them “you know that we’re talking about women between life and death, why does not [an approval] arrive?”. She also said that Caroline had been to the agency, bringing photos of her mother with her. The aim was, Karin said, to show the agency that “it’s real people” affected by the slow approval of the subsidisation to non-BRCA mutation carriers (as many new cancer drugs PARP inhibitors are way too expensive for patients to pay for without subsidization). Karin also emphasised that PARP inhibitors are “the best thing that has happened for a long time for ovarian cancer patients”. Similarly, during a meeting in October 2019, Karin called PARP inhibitors “the new revolution for ovarian cancer patients”. “PARP inhibitors will, you know, revolutionise the treatment of ovarian cancer now when they are not only provided to BRCA carriers”, she said.

At the meeting, it was also agreed to include PARP inhibitors as a theme at the group’s yearly evening seminar in the Spring of 2020 (a seminar targeting patients, scientists and healthcare professionals). Karin emphasised that since PARP inhibitors are important for many patients, she thinks that these pharmaceuticals should be included at the seminar. As the group often does, she related to the GCG’s Facebook support group when saying this. She said that PARP inhibitors are talked extensively about in the support group, and that the ovarian patients in the group have a lot of questions about what approval would mean for them. She highlighted that many patients wonder about how PARP inhibitors might change possibilities for survival and what the side-effects are. Therefore, that it is important that the GCG helps patients by, through the seminar, providing knowledge about what an approval of PARP inhibitors would mean for them. At the meeting, through the focus on the Facebook support group, the topic of PARP inhibitors was not discussed as “in general” important for ovarian cancer patients; the discussion was situated to what the group had learned from their Facebook group, and from ovarian cancer patients. In this sense, the inclusion of PARP inhibitors at the evening seminar can be understood as an advocacy practice that



starts from the fact that patients live with cancer, and from patients' embodied realities.

In the face of life-threatening disease (“women between life and death” as Karin said at the above meeting), it is fully understandable that high expectations are invested in new treatments such as PARP inhibitors, and that such drugs are intensely cared about by advocates. Given that ovarian cancer is most often detected in advanced stages, it is even more so. But at the same time, since care is a selective mode of attention, this care for PARP inhibitors might also marginalise or exclude other potentially important matters. During my fieldwork, I noticed that the attention to PARP inhibitors as “the new revolution” have tended to marginalise existing scientific uncertainties.<sup>23</sup> While PARP inhibitors, according to the current evidence-base, may prolong an ovarian cancer patient's life with approximately up to 18 months, clinical trials have not been able to provide clear evidence for increased survival.<sup>24</sup> During the meetings in the fall of 2019 that I attended, such scientific uncertainties and specificities were not attended to.

However, saying that scientific uncertainties and specificities get marginalised or excluded is not the same as saying that it is problematic that PARP inhibitors are focused on, or that patient advocates should not try to speed up patients' access to them. The GCG representatives' attention to the support group is important in this regard, as it makes present a practice that is attuned to patients' embodied realities. The decision to focus on PARP inhibitors was not made simply because of a vision of these pharmaceuticals as the new ovarian cancer revolution, but because the GCG representatives had learned from patients that *they* care about PARP inhibitors. This, I argue, makes visible the problematics of reducing PARP inhibitors to only concerns about how advocacy practices focused on biomedicine risk, marginalising other things. As Karin said at the meeting, PARP inhibitors *do* concern “women between life and death”. Therefore, attuning patient advocacy

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<sup>23</sup> Coleman, Shawnta, Prema P. Peethambaram, and Aminah Jatoui. “Consumer Beware: A Systematic Assessment of Potential Bias in the Lay Electronic Media to Examine the Portrayal of ‘PARP’ Inhibitors for Cancer Treatment.” *Journal of Cancer Education* 26, no. 3 (2011).

<sup>24</sup> National Ovarian Cancer Guidelines, last modified May 20, 2020, <https://www.cancercentrum.se/syd/cancerdiagnoser/gynekologi/aggstock/vardprogram/>.

to embodied realities of ovarian cancer might also mean to attune to new cancer drugs such as PARP inhibitors, while at the same keeping in mind the risks of reducing uncertainties and enacting unrealistic expectations. Holding together the high-scale politics of biomedicine and the embodied realities of women such as Caroline, her mother and the ovarian cancer patients in the support group, I argue it is important to understand the GCG's practices around PARP inhibitors, and to perform a care-full critique of cancer advocacy practices such as these.

### **Living and dying well**

In the last section I focused in on the GCG's advocacy concerning new biomedical treatments through the case of PARP inhibitors, to show how the GCG's practices entangle biomedicine and embodied realities of cancer. In doing so, I followed a common route in STS research where biomedicine is given priority in analyses of patient activism<sup>25</sup>, and I have, myself, excluded other important parts of the GCG's advocacy practices. STS scholar Ingunn Moser argues that there is a "science centrism" in STS, and that this "contributes to the dominance of science and biomedicine by granting these analytical privileges".<sup>26</sup> As a result, she continues, "alternative modes of acting, for instance in care, are disarticulated and made absent".<sup>27</sup>

While I have excluded this so far from my analysis, Moser's critique is not foreign to the GCG. Indeed, the GCG representatives have discussed similar matters among each other. During the last couple of years, they have also started to focus more on practices of living well with gynaecological cancer, both by influencing policy-actors to improve, for example, rehabilitation and palliative care practices, and by communicating knowledge about such matters to patients and their relatives.

As an example, during the GCG's evening seminar in April 2019, the group included a presentation on palliative care, this with the aim to provide patients knowledge about what palliative care is, and what

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<sup>25</sup> For example, Callon, Michel, and Vololona Rabeharisoa. "Research 'in the Wild' and the Shaping of New Social Identities." *Technology in Society* 25, no. 2 (2003); Panofsky, Aaron. "Generating Sociability to Drive Science: Patient Advocacy Organizations and Genetics Research." *Social Studies of Science* 41, no. 1 (2011).

<sup>26</sup> Moser, "Dementia and the Limits to Life", 704.

<sup>27</sup> Moser, "Dementia and the Limits to Life", 704.

they as patients can expect from it. As was discussed during planning meetings prior to the seminar, the GCG had learned from, for example, their Facebook support group that many patients do not know that much about what palliative care means, and that many are afraid that they will be in much pain during the terminal phase of their disease. For example, at a planning meeting in October 2018, the board member Gunilla, a chronic ovarian cancer patient herself, emphasised that it is crucial that the GCG provides patients a space to learn about palliative care, this as it can help them in their struggle with coming to terms with their own imminent death. She stressed that she knows this from her own disease but also from the Facebook support group, in which she is an active member. Before the presentation at the seminar in April 2019, Gunilla, who was the moderator for the evening, said that “I can be sure that I will die from this cancer”, and that she therefore wants to know about palliative care and how it can help her. During the presentation a palliative care nurse explained that it is important to be “responsive” and “take in” what every patient needs. It is about creating relations to the patients and about learning from those relations; as patients are different, palliative care needs to be attuned to such differences. “What we want is to create quality of life”, she said. After the seminar, Gunilla emphasised that the GCG thinks it is important to raise these more sensitive issues, which palliative care serves as an example of.

The GCG’s practices around palliative care make visible another form of patient advocacy than the one focused on the speeding up of new biomedical treatments. It is a form of practice attuned to creating liveable lives in the presence of imminent death as an embodied reality for many cancer patients. Moreover, which I here have exemplified through the evening seminar presentation, it is a practice that enacts care as a matter of being responsive to, and holds on to, differences and relationality. This fleshes out a form of care that “remains open-ended and responsive: one does not know in advance where this attention will lead”.<sup>28</sup>

Moser argues that by primarily attending to “cutting-edge science and technology” there is a risk that STS analyses “run the risk of colluding and contributing to making present and more real very

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<sup>28</sup> Martin, Myers and Viseu, “The Politics of Care in Technoscience”, 630.

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”.<sup>29</sup> As a consequence, other worlds, risk becoming weaker and less real. In this section, I have responded to this critique by highlighting the GCG’s focus on palliative care. This has made present an advocacy practice that is not centred on biomedical solutions, but on providing knowledge to patients with chronic cancer, knowledge that allows them to think about care as an open-ended practice attuned to the specificity of each care relation, and that hopefully can help them in their struggles with their imminent death. Through this focus on palliative care I have also attended to how Gunilla, as a chronic ovarian cancer patient herself, cares about questions of palliative care, and how she is committed to allowing cancer patients space and time to come to terms with their own death. Learning from Moser<sup>30</sup>, if we as STS researchers take for granted that biomedicine is what cancer patient advocates really care about, then other cancer worlds, indeed, risk being marginalised and devalued.

### **Concluding thoughts**

In this paper I have explored different modes of attending to gynaecological cancer patient advocacy practice as a way of responding to the question of “how to care for our accounts?”.<sup>31</sup> I started with advocate, Caroline, to explore how her advocacy can be understood as an entanglement of care and knowing, and of embodied cancer experience and politics of biomedicine and cancer (in)visibility. I then adopted another mode of attention, more in line with an STS frequently used approach of “following the object”<sup>32</sup> (here, PARP inhibitors), to exemplify how also the GCG’s practices around biomedicine are entangled with embodied realities of cancer. Finally, I attended to the example of the GCG’s advocacy around palliative care to trouble my own, and in STS, frequent tendency to prioritise biomedicine.

Through these modes of attention, I have highlighted what could be called some of the “affective tensions” between the personal and the

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<sup>29</sup> Moser, “Dementia and the Limits to Life”, 707.

<sup>30</sup> Moser, “Dementia and the Limits to Life”.

<sup>31</sup> Jerak-Zuiderent, “How to Care for our Accounts?”.

<sup>32</sup> For example, Latour, Bruno. *Science in Action: How to Follow Scientists and Engineers through Society*. Boston: Harvard University Press, 1987.

abstract (between life and death) involved in cancer activism. In focusing on such affective attentions, I have been thinking with the metaphor of scaling – scaling up and scaling down – as a sensitising lens to zoom in and out between the personal, embodied, affective, and the high-scale cancer politics this is entangled with. I have done so to highlight the politics the GCG’s practices, and to discuss how I as the researcher might re-tell the stories and practices I have learnt through my fieldwork in a way that “stays true” to the GCG representatives while at the same time making links to larger political relations and concerns. This way of doing care-full critique is perhaps for me, most importantly, to try to think through what it might mean to be in ethical relation with others – with my participants and with what Caroline called “the cancer world” – and how to care for “care” in a way that holds on to the tensions of entangled cancer relations.