

# Becoming a cancer survivor: An experiment in dialogical health research

Health

2023, Vol. 27(1) 78–93

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DOI: 10.1177/13634593211005178

[journals.sagepub.com/home/hea](https://journals.sagepub.com/home/hea)



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## Abstract

The article makes cancer survivorship the topic of an experiment in a form of writing we call *dialogical response*. First, in the style of autoethnography, each author presents an account of her or his long-term survivorship of cancer and the issues that involves. Less conventionally, we then respond each to the other's story. The article seeks to contribute to an in-depth understanding of long-term cancer survivorship. More important, we offer it as an example of a form of writing rarely practiced in health research: speaking *to* those who participate in research, rather than speaking *about* those people. Among the multiple theoretical implications that could be explored, we consider Foucault's concept of subjectification. Our argument is that recognising the discursive formulation of the subject can and should be complemented by recognition of the local, immediate dialogical formulation of subjects. Rather than presenting research findings about cancer survivors, we offer a performative enactment of survivorship as an ongoing process of dialogical exchange. We show ourselves, responding to each other, in the process of becoming the cancer survivors we are as a result of those responses.

## Keywords

autoethnography, dialogue, Foucault, long term cancer survivorship, memory, subjectification

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## Survivorship as subjectification and dialogue

In both clinical and everyday settings, people speak of themselves and others as cancer survivors, using this descriptive phrase as if it were a naturally occurring identification: someone has cancer and medical treatments, then lives with different consequences of illness, and that person is ipso facto a survivor. Our project inquires into the *making* of cancer survivors as an identity, and the instability of *survivor* as a category.

We understand *cancer survivor* to be what the social gerontologist Kaufman (2017: 560), writing about dementia, calls ‘a modern form of life’. Kaufman (2017) writes:

Consider, for example, the stem cell, the embryo, the fetus, the persistent vegetative state, the cadaveric organ donor, and the brain dead. All of these forms have been brought into existence through biomedical techniques and definitions, and through the responses of politics and societal institutions to those definitions, The emergence of dementia, along with these other modern forms, into the world of science, health care, and public debate creates new kinds of relationships and obligations and new kinds of normalizing practices in addition to new knowledge. (p. 560)

The *cancer survivor* is one of these forms brought into existence through practices beginning with biomedical definitions but extending to multiple institutional interventions and what Kaufman calls normalising practices.

Kaufman summarizes one aspect of what the philosopher Michel Foucault called subjectification (Foucault, 2003; Rabinow and Rose, 2003: xix–xxii).<sup>1</sup> The *subject* is the product of – what is produced by – work done on the self by the self. Those works are variously instigated and shaped by external agencies, ranging from loosely bounded entities such as families to formal institutions. Institutions most relevant to cancer survivorship include hospitals, clinical care programs, professional psycho-social knowledges and the publicity and marketing of illness charities. These external agencies make a form of subjectivity seem natural and *right* to persons who think of themselves as so designated. These institutions have agendas for the form of subjects they produce: they more or less self-consciously seek to produce subjects whose self-understanding articulates with institutional procedures and purposes. Thus subjects are significantly *positioned*: to be any kind of subject is to understand oneself and to be understood within a matrix of institutional knowledges that convey expectations for the subject’s behaviour.

Subjectification opens useful lines of inquiry, but it has limits. A frequent critique is that Foucault imagines the subject to be shaped more than actively shaping. Cancer survivors have been notably active organising themselves in multiple ways to shape their own position (Klawiter, 2008); these subject-created organisations then shape future subjects. But accounts of grass roots organisation still imagine subjects as dependent on cultural resources that shape and express agency, even when their considerable ability to create new resources is recognized.

For us, people are the subjects that the stories they tell about themselves depict them to be. Those stories are formed within the discursive matrix of subjectification, but they are also formed by subjects’ anticipation of responses from those with whom they interact in immediate, local settings. The subject, as we imagine her, exists in an ongoing process of telling in anticipation of a response, receiving a response and responding to

the response. Perhaps the metaphor is too crude, but for us terms like *self*, *identity*, and *the subject* signify a juggling act. What is signified by these terms is always mobile, as much in the air as in the hand. That is what we mean by *process*. Selves, identities and subjects are always in process.

We seek a form of writing that shows at least part of that process in its unfolding. Part – a slice in time – is probably all that can be fixed on the page.

## An experiment in dialogical response

This article develops an ongoing experiment in dialogical autoethnography (Synnes and Frank, 2020; Thille et al., forthcoming). We understand autoethnography (Bochner and Ellis, 2016; Ellis et al., 2011; Richards, 2019) as a hybrid genre, with any particular work positioned somewhere between memoir and social scientific report. As observer to her own life, the social scientist writes in the first person, but concepts and theories of social science figure in how she reconceptualizes her experience. We expand autoethnography by making the individual voice responsive to at least one other voice.<sup>2</sup> Rather than writing about dialogue (Frank, 2004), our writing seeks to model engagement in dialogical practice.

Our interest goes against usual health research practice.<sup>3</sup> Instead of ‘findings’ about survivorship as an already objectified subject position, we offer a *performance* of how that subject position comes to be in its mixture of durability and fluidity. Our form of research is not about finding what is already there, awaiting the researcher’s discovery. Our research seeks to show how we – all of us as subjects – participate in the elaboration of what is always coming to be; again, the subject is both formulated by institutional and discursive conditions, and also continually formulating in her dialogical responses to responses. We present ourselves as participants in the ongoing elaboration of the survivorship that is our topic.

We follow no particular method, but we do have a writing process that we understand as analogical to everyday processes of dialogue. We each present a brief autoethnography emphasising what we feel shaped our subjectification as survivors. We wrote these stories by giving ourselves a simple prompt: *Tell me the story of how you became the sort of cancer survivor you are, including whether you do understand yourself as a cancer survivor*. We attempted to write our stories in a single take, as if we were responding to an interviewer, and we revised only for clarity. We treat the stories as if they were transcribed interview material. Gaps, incompleteness, inconsistencies and repetitions are part of these stories, as they are part of any stories.

We then make *autoethnography* dialogical by commenting on each other’s stories. These comments mix personal and academic responses; they blur that line, because as we engaged each other’s story, our own sense of being a survivor changed. Showing those changes is the point of our experiment. We each found it increasingly difficult, in later drafts of this article, not to rewrite our initial stories. A third section of responses to commentaries would extend the dialogue, and our choice not to proceed to a next layer reflects limits on the length of this article, not methodological principle. In our lives, we have each gone on thinking of ourselves differently as a result of our dialogue.

Our commentaries adapt an ethos of response-as-witnessing that we find best exemplified in narrative therapy (Frank, 2018a). Narrative therapy’s model is not diagnostic

but dialogical: the therapist does not classify a patient by understanding her as the embodiment of her problems, as in 'having depression' or some other diagnostic condition. Instead, both parties in the therapeutic dialogue achieve an understanding: a problem is an external actor that has entered the life of the person in therapy and is diminishing that life – although the problem may also bring some benefits, which is part of what makes it difficult to confront. Time is also spent recognising the considerable strengths that the person in therapy has already shown by living with the problem as well as she has. Based on these strengths, plans are made to respond to problems the problem and these plans can be very creative, such as writing a letter 'firing' the problem.

Narrative therapy often brings in other actors; for example, a 'reflecting team' who observe sessions and offer comments on what impresses them about how the person has and is confronting the problem. A person's experience of hearing these external witnesses speak about her struggles and strengths may be the core of what is therapeutic in the process. Therapy offers people a profound experience of being respected, listened to and responded to; in summary, it makes people feel valued. We seek a form of health research that has that effect on its participants.

Crucially, narrative therapy understands people who are doing therapy – who are emphatically not 'patients' or even clients – as *experts* on the troubles that have brought them to therapy. The therapist *consults* the person in therapy on how to respond to a problem that is not theirs alone but finds its way into many people's lives. Throughout, people's membership in communities is foregrounded, not individual personalities or psyches. What can seem like individual problems are ultimately community problems. Narrative therapy's necessarily complementary aims are to dismantle the power relations inherent in therapeutic practice and to make the diffuse and subtle power relations in people's lives available for those people to reflect upon and respond to differently.

That is the model we experiment with, selectively exporting it to health research. We imagine a form of research that responds to – it enters into dialogue with – people who are experts on problems of their health. Such health research addresses itself directly to its participants, as we address each other in our commentaries. Such research respects people's expertise by foregrounding their words, giving them more space in research reports. In researchers' responses, asking questions about lives is more important than drawing conclusions, and questions may be best left open for people to continue to think about. Forms of closure are not a goal: dialogues always continue. The ethical and political rationales for this considerable shift are important but lie beyond the scope of this article.

Following narrative therapy, our commentaries treat each other's claims generously. If we were working like a narrative therapy reflecting team, we would say more about each other's strengths – our commentaries may be too restrained, but we are not doing therapy. Mikhail Bakhtin (1984: 49) provides a fine statement of our slightly different intent: 'We see not who he is, but *how* he is conscious of himself'. Not who *cancer survivors* are as a collective identity, but rather how individuals are conscious of themselves, as they live in the aftermath of having cancer.

In our own idiom, we look especially for how people seek to *hold their own*; that is, how we humans sustain claims to a valued identity as we confront circumstances that threaten those claims.<sup>4</sup> Our responses to each other's stories seek to *respect how the other*

*person has held her own* as she continues to face what threatens not only her body but her sense of self.

## **Kari's story**

*Tell me the story of how you became the sort of cancer survivor you are, including whether you do understand yourself as a cancer survivor.*

To tell my story it feels relevant go back many years. I was born and raised in a sparsely populated area of Norway. The atmosphere in my family as I remember it was characterized by tight bonds to extended family members and rough climate conditions that fostered a survivor-spirit among us. I lost my father in a working-place accident when I was eight. I believe that made me and my siblings attentive, at a very early age, to life's precariousness and vulnerability. When my father died in the 1970s, scarce attention was paid to children's mourning. Through our extended family members and neighbours, we as children did understand that for our mother, being a widow and suddenly becoming sole breadwinner for three children was hard. Due to my mother's stamina and a welfare state that backed our family with universal services, we gradually learned to survive the crisis, but we learned less about how to articulate human losses and sufferings.

The world of books and a public library became my main personal pleasure as a child. Later I studied sociology and in graduate school was drawn to feminist theory and gender studies. I was still a student when my first child, a boy, was born. I wrote my masters thesis on pregnancy and female identity, combining constructivist understandings of gender with celebration of the embodied transitory period and corporeality that pregnancy were for me. I was thrilled to develop my scholarly work in conjunction with my embodied alteration. After my second child was born, a daughter, I began a PhD, investigating gender and power relations in the network-oriented economy. In this work, the link between personal life experiences and research were not very apparent, but in some sense, this split felt like a relief. Having a clearer line between my bodily being and my academic thinking made the research easier to both communicate and legitimize. Yet, my supervisors pushed me relentlessly to keep reflecting critically on how my social background and embodied being framed my research questions and analyses.

During my doctoral studies, my mother was diagnosed with intestinal cancer and treated by surgery and heavy chemotherapy, ending up with a life-long stoma. My mother continuously praised and still praises the public health system for the treatment she received, notably never identifying herself as a cancer survivor or expressing any criticism of the health care system.

By the time I joined the University's Faculty of Medicine, teaching and doing research on gender, health and power, I was divorced from my children's father, who was living abroad, and was co-responsible for two teenagers. While planning for research grants on gender and health, I was notified by my GP that the results from my every third year cervical screening showed severe cell changes, what my physician called 'cancer level zero'. In order to prevent cervical cancer, the medical advice was total hysterectomy. Very quickly, I entered the operating theatre to have my uterus removed by laparoscope. Six weeks after the surgery, I was brought back to the hospital by ambulance. My body

was thoroughly infected by urine and at risk of sepsis; acute repair surgery was needed at once. My bladder was seriously disrupted and had to be patched together. During my original surgery, the surgeon who removed my uterus had failed to notice that he cut into the bladder with the laparoscope. After the repair surgery came hospitalisation and recovery work for months. Days went by with staff checking whether I could gradually do without a catheter.

I was then 46 years old and for the first time in my life, I felt seriously ill. Yet, until recently I have considered the whole ‘episode’ to have been acute and thus transitory. Digging deeper in my memory, I recall speaking very quietly, if at all, about the illness and the treatment I went through. For instance, the menopause I suddenly went into due to my ovaries being damaged during the surgery was a completely new embodied dimension, changing how I characterized my being. Nonetheless, except mentioning this to my GP and a couple of close friends, I hardly talked to my mother, my siblings, friends or colleagues about the specific transformations of my body. As the years have passed, it has come to me that what I once thought of as an acute episode striking my body has gradually turned into the experience of a distinctly altered bodily being. Most distinct may be the transformation of my urinary system, which is currently extremely vulnerable. More than ten years after the repair surgery, I experience repeated infections and pyelitis as well as recurrent abdominal pain due to scar tissue from the surgery interfering with my intestines. What is this type of embodiment, I keep wondering. Is there a name for it?

That said, I am not eager to attach an illness identity to the transformation I have been through and the altered body I live by. This hesitance may be related to my trust in the expertise and availability of the public healthcare system in Norway – my right as a Norwegian citizen. I maintain this trust in spite of the surgical errors I was subjected to. Yet a new suspicion also emerges: Is what I feel to be my obligation to trust a highly appreciated welfare state with a universal right for medical treatment also why my embodied illness experience is so hard to articulate? Or are there other and more obvious reasons why I do not demand recognition of the side effects that the medical treatment has caused me?

Perhaps as a compensation for the muteness on my personal embodiment, my research interest and activity into illness stories in general, and cancer survivorship specifically, has developed in parallel with my illness experiences (Solbrække and Lorem, 2016; Solbrække et al., 2017; Williams and Solbrække, 2018). The first distinct step in this direction was a small study I conducted on young Norwegian women’s experiences of being hysterectomized (Solbrække and Bondevik, 2015). Today it is hard not to consider this study as propelled by my own illness trajectory. In my close readings of illness narratives, the repeated message in this literature is medical institutions’ discomfort responding to how lay people themselves tell their illness experiences.

I have started to wonder what this profound need to *tell* one’s cancer story in public is about. When and why did this ‘need’ originate? And why do I, as well as my mother, not participate in this phenomenon called cancer survivorship? Why do we *not* write a book, or a blog, or hang in a Facebook-groups, or take part in other venues of the cancer survivorship movement going on globally?

Developing an academic interest in cancer survivorship has not been that smooth either. During my writing of a study protocol on investigating hysterectomy, I initiated a collaboration with a professor in medicine, a gynaecologist. When I mentioned that I had been subjected to hysterectomy myself, this person responded with great scepticism and seriously questioned my motives for doing the study: Wasn't I 'too biased to do a study on hysterectomy properly'? The collaboration between us broke down, and yet the interview study on hysterectomy continued: stories dwelling distinctly on loss of self as well as altered bodies came out of it. Listening to those interviews, the aspects of muteness and even the taboo they demonstrated was gripping. My own personal illness experience has been very much muted.

### *Art's commentary*

Kari's story shows us that people can survive cancer without thinking of themselves as cancer survivors; that subjectification requires a surrounding culture. I wish I knew more about Kari's mother's situation when she had cancer. Was there an ostomy association that could have offered support? Or, in that time and place, was cancer just another disease, and living with a stoma just another infirmity, not welcome but also not unexpected at a certain stage of life? Kari does not remember attempts being made to enlist her mother into the subjectification of cancer survivor; she simply survived. The more interesting questions are what it might have cost Kari's mother to survive without being designated a survivor, and conversely, what the benefits of not having that subjectification might have been for her.

I wonder especially what counted as *support* in Kari's mother's family and community, and how she might have distinguished between material and emotional support. It's too easy to assume that one cost of her not having the *cancer survivor* subjectification available was lack of support. Instead, subjectification affects what any person counts as support.

Kari's own story begins with an initial complexity: in what sense does Kari 'have' cancer? Her diagnosis of cervical cell changes exemplifies what Kaufman describes at the beginning of this article as forms of life that are modern insofar as they are 'brought into existence through biomedical techniques and definitions'. Kari experiences cancer as a biomedical finding that occurs in a periodic screening examination. Later, her embodied experiences of illness are the result of surgery and its effects, not of cancer itself. I have talked to other cancer survivors who told me they never felt cancer; its reality depended on a physician telling them so. They, like Kari, did not immediately think of themselves as cancer survivors.

What might have developed as Kari's sense of having cancer, even 'cancer level zero', was quickly overtaken by the problems caused by surgical error. As I hear Kari's story, she never had time to be a cancer survivor; that subjectification would have to wait until the right conditions coalesced later in her life. In Kari's response to the damage done to her by surgical error, the story is, if not distinctly Norwegian, at least distinct to countries that have both an effective social welfare and universal health system *and* what could be called a culture of rural self-sufficiency, neither of which necessarily implies the other. After the death of Kari's father, she grows up watching her mother take responsibility as a single

parent, and she realizes how much state support makes their lives possible. The local library is a specific example of that support, becoming Kari's portal to a public university system in which she acquires credentials and commitments, eventually becoming a professor.

But Kari's early life has costs. She writes that she learned less about 'how to articulate human losses and sufferings'. Even if Kari had had a different experience of cancer, she might have been reluctant to accept thinking of herself as a cancer survivor, at least in places where expressive sharing of losses and sufferings are core expectations of being that form of subject.

As Kari writes her story, being a cancer survivor still does not fit her sense of herself. At a crucial moment in the story, she asks whether there is a name for her embodiment, realising there is not. Her embodiment makes her a hybrid, and only the cancer-survivor part of this hybridity has a name. Kari's continuing health problems are too particular for subjectification, and that may lead her, as a researcher, to want and even need to think beyond conventional categories of persons. Her academic work foregrounds those residual subjects who do not fit the usual subjectifications (Spencer, 2021).

I have known people in her hybrid situation who went the opposite way, embracing being a cancer survivor even though having cancer was not the biggest part of their story. Some people find what they believe they need in a readily recognizable subjectification. Others, like Kari, ask whether there is a name for what they embody. Subjectification means being able to name yourself, placing yourself among other who share that designation. The complementary cost is feeling you must think of yourself in ways that type of subject is expected to accept.

Kari questions the cost of feeling the 'obligation to trust'. One literal cost is foregoing whatever legal or financial settlement she might have gained if she had sued for the injury done to her. But more significant is the absence of what she calls *recognition*, the recognition of how severely and extensively she was injured. Without a conventional subjectification, her situation is left unrecognized, unacknowledged. Her story expresses the loneliness of being outside subjectification.

Kari concludes by writing about herself as a health researcher, studying people with whom she shares some affinity, if not a fully embraced identity. She offers a telling anecdote about the physician who rejects collaboration with her because she would be 'too biased'. That is one attitude. The alternative attitude is that unless and until a researcher shares, to some degree, the subjectification of those being studied, the research will remain superficial, always missing the sense of why what matters to such people matters as much as it does. Researchers need to be both insiders and outsiders, sharing subject positions but conscious of how they don't fit these positions. Kari's story explores these limits of subjectification.

### *Art's story*

When I was diagnosed with cancer, I had learned from prior illness experiences, both my own non-cancer illnesses and family members' lives with cancer. When I was a small boy, a recurring feature of our lives was visits from my mother's elderly aunts – they seemed to me to be ancient. One aunt in particular, a widow for many years, was often



described as ‘having had cancer’, maybe a couple of cancers. *Cancer* was thus used as an explanatory term, and since what I saw in this aunt was a pathetic figure, ravaged by time (at least in the eyes of a child), I came to associate ‘having had cancer’ with decrepitude, neediness and, blunt as a child’s thinking can be, a boring life. I would not have used the word *survivor* to describe my great aunt, though she unquestionably had survived.

My impression of having cancer changed, a few weeks after I graduated from secondary school at age 18, when my mother underwent the old-style radical mastectomy that involved incisions from her throat to her elbow. I helped her doing simple exercises to recover movement in her arm. My mother did not choose to talk about cancer. I remember one conversation in particular, when she mentioned a friend who was now volunteering in a peer support organisation. Volunteer work was an important part of my mother’s life, but about this she simply said, ‘I can’t’. Her silence became my own. I had no models, no guides for how to talk about cancer. Cancer was a great silence. These childhood memories had diffuse effects years later when I realized that I might have cancer myself.

During the year previous to my cancer diagnosis, I was in cardiac treatment for a heart attack caused by a viral infection. I had learned that individual healthcare providers, especially doctors, really could care about me, but their expressions of concern extended only to the limits allowable within institutional routines. I learned that institutional medicine accepts risks to individual patients if these are considered necessary to sustain a work flow, and interruptions in that flow are not open to negotiation. I learned that my trust in healthcare workers needed to be qualified. They would like to be on my side, but they often couldn’t be.

Mostly, in this first phase of what I did not yet think of as being a survivor, I learned from my body. Between when I first went to my physician with symptoms of what would eventually be diagnosed as testicular cancer and that diagnosis 3 months later, I lived with the most extreme pain I have ever known. And I lived with repeated experiences of physicians minimising or dismissing that pain. As I increasingly sought doctors’ help, I learned that living with cancer means being unable to communicate to others just how bad it is. I learned to take my body more seriously than I took others’ opinions about it. Later, I would learn that my body could be deceptive, mistaking old fears for present symptoms. Balancing how I understand my body against what experts say is one of the constant works of survivorship.

Eventually I was hospitalized and after further delay I was finally seen by a urologist who immediately diagnosed me. After that my treatment moved to the cancer centre, which I experienced as a constant stream of messages about how my life must now proceed in relation to their institutional demands. I learned the distance between the cancer centre’s understanding of my needs and what I felt I needed. The silence that pervaded my mother’s cancer in the middle 1960s was just ending in the mid-80s. During treatment I began reading, although accounts of illness experience – what it was like to be ill – were scarce. Breaking the silence was still a radical act.

During treatment, my senses of reality and identity depended most on constant dialogue with my wife, Cathie. Our talk replayed what had happened to us; we kept our own chart, parallel to the medical chart. We characterized the responses of medical workers, family members and friends. We learned that survivorship is a back-and-forth between

needing to trust and needing to protect ourselves from those whose needs were not our needs. Survivorship began as a state of suspicion, a we/they relation.

I completed chemotherapy in January 1987. During the next years, the couple of weeks around periodic follow-up examinations were periods of an anxiety that is difficult to convey. Waiting for my scans to be read was always literally dreadful, full of dread and it got worse every time I had a false positive and required retesting. I think of it now as follow-up induced hypochondria. It shifted – I wouldn't say it ever ended – when I went to see my family physician about some symptoms that I feared might be a recurrence, and at least what I remember her saying was: 'I refuse to give in to this'. It was a breakthrough for me, as I internalized her words and made them my own. Living as a survivor became a matter of choosing which fears it was sensible to have checked, and which I must refuse to give in to. That was one sort of threshold.

The greater threshold was writing the memoir that became *At the Will of the Body* (Frank, 1991/2003). I began writing in early 1989, 2 years after my treatment had ended. Today the phrase *controlling the narrative* is almost a cliché in political journalism. In the late 1980s, the only people who talked about taking control of the narrative of their lives were black-power advocates, feminists, and activists in gay liberation. These people became my models for what I still would not have called being a survivor.

Public witness required turning experience into text and performance. I was constantly aware of what I was leaving out, even distorting. When editing was completed on the manuscript of *At the Will*, I felt the story was mine but also no longer mine. Yet the more I did readings from the book and talked about it in interviews and public lectures, the more the text *became my memories*. That shifting of memory continues. When I now go back to sections of *At the Will*, it doesn't read the way I remember writing it. I believe without reservation the research finding that is repeated by scholars of memory, that what we remember is the last version of the story we told, not what originally happened (Frank, 2018b). Remembering is iterative storytelling. Memory is a constant process of reshaping the story each time we tell it. Survivorship is lived in acts of memory.

I continued learning to be a cancer survivor by participating in what turned out to be the last days of face-to-face support groups, before the Internet changed where and how ill people tell their stories. I was fascinated and eventually repelled by how support groups exerted not so subtle pressures on participants to tell only preferred stories. One rainy night I called another group member and asked if she'd like a ride to the group. She thanked me but said she didn't want to go, possibly ever again. She couldn't take what she called the 'enforced hilarity' of the group. The only allowable stories were of overcoming, being 'just fine', a phrase that participants were expected to repeat after they introduced themselves at the beginning of each meeting. In one of the first meetings I attended, the woman who was the main organizer informed us that a long-time participant was hospitalized with a reoccurrence. She then said it was fine to visit her, because she was 'the same old' person she had always been. The group leader specifically told us this woman was still telling jokes. I heard that as a form of assurance that visiting was safe, and also an implicit message about acceptable talk in the group. I thought, this woman is most likely dying, why *should* she be the same as she has always been? And why is her being the same the test of whether she is safe to visit? The groups were tutorials in a form of survivorship that, after a while, I could no longer participate in.

My most recent and in some ways best teacher in survivorship has been aging. When I had cancer at age 40, being a survivor meant staying alive long enough to live the life I was acutely aware of not yet having lived. Today, I have lived that life, never fully enough, but gratefully. Cancer now takes its place as one of the experiences that made me the person I am still becoming. Cancer is an important part of the narrative of my life, but for me, a life writing about cancer is more important than having had the disease. I think back to two people who went through cancer while I did; one was my mother-in-law and the other was the wife of a university colleague. They both died before I wrote *At the Will*. Survivorship is asking myself, not every day but often, what they would have wanted for me, as the one who lived. I have tried to remain a witness to what the three of us went through, but I know they would not want that to have been all of my life.

### **Kari's commentary**

Reflecting on Art's childhood encounters with cancer, especially the cancer that struck the flesh and skin of his beloved mother in such a tangible way, I realized how different the resources for imagining and communicating cancer experiences were during my own upbringing. Until I was ten years old, I hardly heard the word 'cancer' spoken. What I do remember from my childhood was sitting on the sofa in 1974 and watching US First Lady Betty Ford speaking on Norwegian television about her own breast cancer. That moment was when a new subjectification of cancer – the survivor as an identity – became available to me. Later, I saw Betty Ford and celebrities like her in women's magazines talking about their experiences. Interestingly, these stories were all about breast cancer. Mass media notice of other cancer types, like my mother's cancer, came decades later.

Although our stories took place in different decades – Art's mother's breast cancer happening pre-Betty Ford and my mother's cancer occurring 30 years later – and as different as the two women's situations were, Art's mother and mine shared a position from which experiential speech about their cancer was not expected. Neither of them shared her experience in a wider circle; even if either had the capacity to speak, no one was prepared to listen.

Both stories open up issues of silence, authorized speech and unauthorized speech. The silence that dominated the pre-Betty Ford era is exemplified by Art's mother saying, 'I can't'. Beyond her personal disposition, she could not volunteer because speaking requires a position – recognized by self and others – from which to speak, and that position was not available to Art's mother. The resonance of 'I can't' is what cannot yet be spoken.

My mother fell ill in 2002. Today, the contours of cancer survivorship as an available subject position in Norwegian public life are distinct. Still, my mother – and later I – did not fit a social position from which to speak about our experiences of having colorectal and cervical cancer. Reading Art's story about his mother's cancer and even more about his own illness trajectory, I clearly recognize that neither my mother nor I have dealt with cancer as a form of subjectification. I still do not fully understand this family hesitance to speak about the topic. Perhaps it is because colorectal and cervical cancer are still not authorized by speech. Perhaps our social background, regardless of the issue, makes

public speech inaccessible. And perhaps cancer survivorship as a type of identity does not fit our gender and the Norwegian gender role we serve.

During the decades since the Betty Ford moment in 1974, the formation of public experiential speech on cancer has gradually turned into a routinisation of speech. One aspect of this transformation is vividly described by Art via his encounters with support groups. As we hear throughout that story, the dominant script of members within these groups is, in his memory, limited to ‘being just fine’, the spirit of this phrase even extending to members who were dying. Consequently, Art’s companion could not bear the group anymore; the price of membership was too high. Routinisation of talk about cancer experience now includes creation of institutionally approved and prescribed ‘pathways’ instigated by public health programs like ‘Cancer Patient Pathways (CPPs)’ implemented in the Nordic countries and UK (Delilovic et al., 2019). That’s subjectification: the path you are expected to follow is set out for you, and patients are taught to expect that for themselves.

Listening to Art’s overall story, lack of trust seems to have defined the kind of survivor he became. From Art’s protracted misdiagnosis through his follow-up examinations at the cancer centre, the gap between the institutional demands and Art’s personal needs was deep. His story of unrecognized extreme pain exemplifies how lack of recognition for his suffering was what moved him beyond the silence in which he was raised. Art’s initial embracement of cancer survivorship was shaped by his overwhelming experience of the health care system not being on his side – despite the effectiveness of treatment he eventually received. Within this mistrusting relationship, Art was left to mainly trust his body, which at a later stage led to hypochondria. I can identify with this feeling of something potentially wrong with my body: my experience of mistreatment without a proper follow up has made me hyper sensitive to signs of reoccurring troubles in my intestine, kidney and especially my urinary tract.

The first stage of Art’s cancer survivorship seems to have taken shape as a form of protest against what the medical gaze refused to see, or in his terms, to witness. Although cancer treatment and cancer care have been for decades top priorities in many countries (Timmermann & Toon, 2012), becoming a cancer survivor out of protest to the health care system presents a distinct contrast to the current ideal in European health care, namely the active and self-reflective ‘expert-patient’. But is this what Art once longed for: being seen and treated by the health care system as the expert of his own illness. Has the promotion of openness and patient-centredness spun cancer survivorship into a subjectivity still inscribed and governed by medical institutions and health care programs themselves?

Relating Art’s story to my own experiences has, to some extent, transformed my memories and given me a different sense of what I might have longed for, namely, a more distinct form of recognition for my illness sufferings. I now have clearer, more nuanced memories of when and how cancer survivorship has been made socially and culturally available to me. The kind of recognition I desire is more complex and difficult to articulate. Brought up in a family that strongly cared for each other’s social and material needs and supported by a universal health care system that cured both me and my mother with no bills for us to have to find ways to pay – beyond our taxes – has certainly made me

feel safe and cared for. Even when the surgical error splintered my basic trust of the health care system, I mainly accepted the experience with some form of silent stoicism. I have managed my own recognition of existential suffering that runs out of illness or other losses in a subtle, even tacit way, hardly acknowledging something that calls for answering 'who are you?'

I now realize it might have been comforting for both my mother and me to have joined a support group. Without idealising these groups, exchanging stories with people who see themselves as similar and trustworthy attracts me. I can also now imagine that writing a blog, a book or a poem that potentially assembles fragmented and unarticulated experiences into a story could possibly also play such a transformative role. On the other hand, the type of support group Cathie and Art constituted for themselves, as a dyad with a critical edge, seems even more compelling than the routinized support groups or digital writing in which positivity is a premise for companionship. When writing this, I suddenly realize that maybe my current partner and I, who both have had and therefore share intricate illness experiences that are poorly acknowledged by the health care system, might constitute a companionship like the one Art and Cathie had.

Perhaps most important, these reflections bring me to wonder whether the tension between our 'splintered' trust towards the formal health care system and the continuing desire to be able to trust the other, is a fundamental contradiction that all survivors live with and an important issue to explore in future research.

This dialogue with Art continues to affect my memories and interpretations of what happened in my own life relating to cancer and how I see myself today. What telling my own story in a dialogue with Art has most specifically anchored in me is that memories are not linear or fixed; rather, rupture, forgetting and rediscovering characterize them.

Beyond that is the increased awareness of how our research project Rethinking Cancer Survivorship participates in subjectification processes.<sup>5</sup> Participation in research presupposes some identity as a cancer survivor, and interview questions suggest what ought to matter to participants in their self-understanding as cancer survivors. Just as my memories became more nuanced during our writing process, so interviews are not simply recalling memories that are already there; interviews shape memories, altering the foreground/background arrangement of memories. This effect of research is neither bad nor unethical, but rather it's how interaction inevitably affects and effects subjectification.

## Research as responsive relationships

Cancer survivorship is not a problem requiring some form of solution either by clinicians and other social care professionals or by researchers. We understand cancer survivorship as the fluid self-understanding of different people in multiple social contexts, each context offering particular resources and having both explicit and implicit expectations. Rereading our own stories and commentaries, we see them both orienting to and also destabilising the subjectification of the cancer survivor as an identity.

For us, the question for researchers is *how are you participating in the process of people living with the long-term effects of cancer?* Following narrative therapy, we believe research participates best when it makes questionable the ways that people think

of themselves. Too much health research, in our view, participates by stabilising forms of subjectification. This stabilisation is especially evident in research that presents themes common to a collection of interviews. The ‘found’ commonalities have the effect of verifying the reality of the subjectification that initially provided for sampling who would participate. Such professional knowledges can be useful, but they also serve professional administrative interests that trade upon bounded subjectifications. Stabilisation produces the particularly modern forms of life identified by Sharon Kaufman, as quoted at the beginning of this article; it makes these identities seem natural and inevitable. Recognising these forms of life to be as much epistemological achievements as ontological entities, we ask, what institutional arrangements require them, and who needs them, either to live their life or to do their work? The answer is nuanced, because the boundaries are porous between administrative categories, both clinical and scholarly professional identities, and personal self-identifications.

Our stories display our own ambivalences towards the subjectification of being a cancer survivor: we each weigh costs of that subjectification against benefits, recognising both. Subjectifications are certainly real in how they affect people’s understanding of themselves. But both our stories also show how a subjectification never fits any specific subject. Some subjects resist subjectification; others are simply indifferent, and still others never imagine the possibility. Identity, the sense of who I am, always blends conventional subjectifications and those aspects of self and personal history that people feel does not fit the subjectification.

We understand the value of detailed personal narratives to be in making possible what the literary scholar Davis (2020) calls ‘thinking in subtler fractions’ (p. 252). Themes, types and stages are large fractions. The value of subtler fractional understandings is to remind all who trade in categories – whether those categories demographic, diagnostic, therapeutic, ethical or whatever – that a cost of such thinking is to miss what individuals believe gives value to their lives, which not always but often is what falls outside the category. Thus again, our goal is to destabilize the category of cancer survivor, not to stabilize it.

To readers who respond to Kari’s and Art’s stories by finding either or both of these to be atypical of cancer survivors, we suggest that all stories are atypical, if listeners allow themselves to hear in sufficient detail and to acknowledge each story’s claim to being different. A story’s uniqueness begins in its telling, but uniqueness also depends on how others respond to the telling. Unrecognized, the story’s uniqueness evaporates.

We believe clinical practice would benefit not from more generalisations about categories of persons. What clinical practice needs is an increased capacity to respond to individual persons (Charon et al., 2017). We want to imagine at least some research, some of the time, providing clinicians with models of how to respond: speaking not about persons, as a display of expertise, but rather to them, as a way of helping. Maybe what is most important about our commentaries as a model of research practice is that we initially offered them to each other, as a form of recognition in a social scientific idiom that we share. Any form of recognition has to find its own idiom.

We give the last word to Bahktin (1984: 251): ‘Thus there can be no firm image of the hero answering the question, “Who is he?” The only questions here are “Who am I?” and “Who are you?”’

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This article is part of the interdisciplinary project “Rethinking Cancer Survivorship”, funded by the Norwegian Research Council, project number 283517.

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## Notes

1. Foucault is also translated as using the term *mode of subjectivation* (Foucault 1997: 264–265). The original is *mode d'assujettissement* which seems to convey a stronger sense of process than the English. What is involved are modes of becoming a subject: possibilities that are finite in their availability. These modes are sufficiently durable to be named, but they are always in flux.
2. An exemplary single-voiced autoethnography that illustrates the potential of the method is Anderson (2017), but that is still only one way of working in a broad genre.
3. With respect to both different research methodologies and also to cancer survivorship as a mode of subjectification, we follow Foucault's (1997) aphorism: ‘My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do’ (p. 256). We understand both cancer survivors and researchers as people who have something to do.
4. On people holding their own, see Frank (2010: 77). Our assertion here owes much to Goffman (1961: 320): ‘Our sense of being a person can come from being drawn into a wider social unit; our sense of selfhood can arise from the little ways in which we resist the pull’. Goffman explores variations of this tension throughout his writings.
5. This project is funded by The Norwegian Research Council. Although this article does not draw upon the interview component of that project, we note that it was approved by the Regional Committee for Medical and Health Research Ethics of Eastern Norway and the Norwegian Social Science Data Services.

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