Psycho-Oncology: A Patient's View

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Abstract

Culturally the most important, valued, and less stigmatized part of cancer care is the medical part: The surgeon cutting the tumors out and the oncologist leading the strategic decision-making of the medical treatments available. The least valued and stigmatized part of cancer remains the psychosocial care. This chapter describes—through the eyes of an academic, psychologist, stage IV melanoma patient, and patient advocate—how one patient navigated changing psycho-oncological needs from early stage to stage IV through a whole range of psychological interventions available. Her voice joins that of all cancer patients around the world whom are urgently calling for psycho-oncological care to be fully recognized as a central part of cancer treatment.

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1 A Disclaimer

I need to start with a disclaimer. This chapter represents one patient's view on psycho-oncology. I am a stage IV metastatic melanoma patient, president and founder of the Melanoma Independent Community Advisory Board, a pilot project of the European Cancer Patient Coalition (ECPC, Brussels). I am also a psychologist and an academic living in Brussels. I started writing this chapter 1 week after my latest PET-CT scan showed again continued progressive disease. My objective here is to illustrate how my psycho-oncological needs have greatly varied throughout the different stages—Ib to IVc—and describe how I responded to those needs as a function of the psychosocial care that was available to me in my path.

2 Psycho-Oncology?

Psycho-oncology was suggested to me when the first tears welled up during one of my early diagnosis consults in 2008. After an early stage Ib "caught in time" melanoma I had progressed to a stage IIIc by March 2009. I sat in that small stuffy room while my husband told me it would be fine, and the dermatologists and an intern were telling me they would help me take care of it, while the nurse was changing the dressing on it. Like in a bad B movie time stood still and we all did our best to play according to the scripted roles. The hope we all had was that a psycho-oncologist referral would take care of the emotional distress part, which clearly seemed a separate section of cancer care. It was also the one part of my care that we were all the most uncomfortable with. In retrospect, psycho-oncology was presented as a different chapter—if not a different volume—of my cancer story. I did not know at the time that psycho-oncology was in fact a subspecialty of oncology with its own body of knowledge contributing to cancer care. I now know research in this area addresses both (a) patients' psychological reactions to cancer and (b) the psychosocial and behavioral factors that may lead to cancer (Holland 2001). As a patient I have high expectations about (a); and as a researcher I remain skeptical but curious about (b).

3 Cancer as My New Psychology Lab

I was trained as an experimental social psychologist at the University of Queensland in Australia, and I did a Ph.D. in the area of cognitive appraisal theories of emotion at the University of Geneva in Switzerland. When I became "the patient experiencing emotional distress" because of cancer I must confess I initially amused myself by applying well-known stress theories to myself (especially the model of Lazarus and Folkman 1984). I noted the different appraisals that would drive my new cancer emotional landscape including emotions such as numbing fear, anxiety, sadness and despair, and anger and hostility. In fact my Ph.D. thesis was about how our social identities (group memberships) can affect our appraisals and emotions (Garcia-Prieto 2004). I have often used social identity theory strategies (Tajfel and Turner 1986) to counter social identity-threats. For example by creatively redefining my cancer social identity in counter stereotypical ways, or by bringing attention to my professor dimension and away from the patient dimension during an interaction with a doctor, or by engaging in cancer patient advocacy and activism, just to see what would change in me and others. I just have fun with this. After all, even today the cancer social identity remains highly stigmatized by our society and the discrimination one may experience because of the cancer membership can actually lead to increased levels of stress and damage health even more. In a way, with cancer it feels like you have to pay your bill twice as you have to deal with the cancer and you have to deal with the stigma of cancer! So many of my multiple group identities (being an academic, a psychology professor, trained as an experimentalist, working in an economics and business school, codirector of a research center, etc.) represent a great psychosocial resource on which I draw when I am confronted with any hint of discriminatory behavior due to cancer. Of course, the stereotyping of cancer patients is not just done by others (she is a young mother fighting cancer for her children, she is a terminal patient, she is a difficult patient) but also by ourselves (I am an activist battling tooth and nail to join a trial, or I am a resilient cancer patient, I am cancer patient who believes in euthanasia, etc.). There is enough research on how social identities and all the stereotyping and intergroup-related processes can positively and negatively affect health (Hardwood and Sparks 2003). For me it has become an art form to strategically negotiate my way through the many available cancer social identities.

In response to stressful cancer-related situations I have used both problem-focused coping (navigated my care across the best specialties in five hospitals, researching the potential clinical trials I could access before going for my appointments, enquiring about my health rights as a EU citizen, etc.) and emotion-focused coping (binging on dark Belgian chocolate when I would have thoughts of recurrence, purchasing a very expensive leather jacket right after a "bad" PET-CT scan). Truth be told, in that first year after the diagnosis I naïvely thought I knew enough about the psychological aspects of distress to go at it alone. Until the day came that I physically collapsed on the floor in front of my two young kids, exhausted from the interferon injections, and trying to keep up being an academic, mother, wife, and “know it all of the psychology of cancer” patient. I accepted that I was strong enough to search for my first psycho-oncological consultation.

4 Psycho-Oncology as a Side Dish

Luzia Travado (current treasurer of International Psycho-Oncology Society (IPOS)) has reported that there is a great variation in access to psychological services in oncological centers in Europe: if you look at national cancer plans only 19 countries have psycho-oncological services (Beishom 2011). I live in Brussels and thanks to the work of Prof. Darius Razavi the “tracks” of psycho-oncology in Belgium are well defined. I found a great psycho-oncologist and felt comforted by familiar methodologies set clinical goals and experienced results quickly. I wanted a cognitive-behavioral perspective. I did not want a group therapy, I did not want a psychiatrist. I wanted to feel in control, to know the independent variables, mediators, and dependent variables of “my experiment of one”. Part of me believed that the psycho-oncological intervention in combination with a good anticancer diet and attitude (Servan-Schreiber 2007) could actually reduce my chances of relapse. At the very least I hoped it would prevent some sort of posttraumatic stress or depression. I did well for a beginner I guess. I knew the cognitive-behavioral approach was sound and evidence-based, proven to be just as good as antidepressants and I felt it worked at least for a while. I then started finding the relief of “relapse-anxiety” would only last the time between consults, and I did not like the feeling of being dependent on the psychologist and on the occasional low-dose Xanax my oncologist could prescribe. Interestingly, like the rest of my medical team (surgeon, dermatologist, oncologist, and nurses) I too perceived my psychological needs as a separate issue, the side dish or dessert, but clearly not as the sauce of the main course! Now I can look back and say without a doubt: psychosocial issues in cancer are grossly underestimated.

I have never heard of the “distress thermometer” or sixth vital sign around me, and I suspect given the amount of distress I have seen in hospital staff, it is clearly not yet measured among oncologists and nurses, surgeons, etc. It has taken me a long time to integrate that the psycho-oncological needs are not “a separate” part, it was the same “me” that was living with the cancer and responding with distress. How could part of me have surgery, radiotherapy, and injections of low-dose interferon and another part of me sit down and cry in the shower hiding from my kids? But that is exactly how we all proceed with psychosocial needs on an implicit and sometimes explicit level. Culturally, the most important and valued and less stigmatized part of cancer care is the medical part: The surgeon cutting the tumors out, the dermatologist doing skin follow-up, and the oncologist leading the strategic decision-making of medical treatments. The least valued and stigmatized part of cancer remains the psychosocial care, an option only to be activated “if need be”, maybe even for those who are not strong enough. Though it seems that in the US the science of psychosocial care in oncology and of caring for the whole patient is evolving (Jacobsen et al. 2012) I have not experienced this myself.

5 Embodying Cancer: Mindfulness-Based Stress Reduction (MBSR)

As per text book I have gone through denial, despair, and anger, graduated to bargaining, depression, and have experienced many different levels of acceptance (Kubler-Ross and Kessler 2005). And though I know the theory, nothing prepared me for what the phases of grief would "feel" like in the body. And that was the turning point for me. I was initially caught up in "thinking" about the thoughts and feelings about living with cancer, and despite autohypnosis and relaxation body techniques I was clearly not embodying my cancer experience. This felt like a bit of a paradox: in the case of metastatic melanoma your body gets "intervened" with a lot through surgery. Being an academic did not help. I thought of that well-known movie "Wit" where Emma Thompson plays a professor with stage IV ovarian cancer and how she succeeds in doing a full dose of an innovative chemotherapy cocktail in a trial. She masters that like any other academic project and gains the admiration of her doctors, and then she dies after a trial well done. I have approached cancer and the thoughts and experiences of the life of a patient with advanced melanoma much like I would have approached an experiment too. But in those early years I was not paying attention to the subject's body.

My first attempts to understand the psychological aspects of embodying the cancer experience lead me again to theories and research I knew. Toward the end of my Ph.D., I had seen research on long-term meditators coming out of the prestigious lab of Richard Davidson at the University of Wisconsin-Madison. Two of my best friends had in fact moved from Geneva to Davidson's lab and were there when the study took place and we had talked about it at the time, so I read anything I could find on mindfulness-based stress reduction (MBSR; Kabat-Zinn 1993) and especially as it is related to cancer (Kabat-Zinn et al. 1998) for a good summary see Carlson and Speca (2010) or Shennan et al. (2010) and the immune system more specifically (Davidson et al. 2003; Carlson et al. 2003). I was impressed.

In September 2009, I was still struggling with being an over-anxious IIIc melanoma patient in fear of relapse. I signed up for an 8 week MBSR course at my local hospital. I practiced and asked no questions. I started to become aware of how I felt in my body while I was doing the cancer follow-up routines (medical visits, blood test, follow-up scans, adjuvant treatment, etc.). I noticed the breathing changes, the tensions, the thoughts that would come and go, and the emotions that would visit me quite often. MBSR gave me a new perspective that allowed me to distinguish the thoughts about the cancer situation from the actual experience in the body of those situations. I was able to see that my awareness of my distress was not distressed; that my awareness about fear was not afraid. Work, family life, my couple, and medical experiences all became a perfect lab to test the utility of this new approach. I amazed others and myself at how good I could be at surfing the waves of cancer and at managing to go deep down when the waves became too rough. But had I yet embodied my experience of cancer? Not really.

While I was out surfing a follow-up scan I experienced my own Hokusai great wave. On December 18, 2009, a few days before I drove down to Switzerland with my little family for Christmas I found out I was stage IV and progressing fast. No treatment existed for stage IV melanoma in Belgium. Subcutaneous tumors were popping up like popcorn over the next weeks while my family was worried about the foie gras and the champagne. For the first time I started looking myself for a clinical trial and when I found out that there was one across the border from Brussels (in Paris) but that my health insurance was denying me the right of cross-border health agreements I experienced the most incredible rage I have ever felt in my life. The appraisals of injustice and of high control driving my rage were the fuel of my first steps in patient advocacy mobilizing local media, lawyers, EU politicians. I won that battle with the support of ECPC and others but the trial I fought for could not include me because my tumor burden was too low. I came back to Brussels with a new sense of despair. All throughout this ordeal I held on to MBSR.

The MBSR methodology was easy to follow and I did not need to adhere to any belief system. It was simple and I embraced the new feeling of autonomy and mastery that MBSR practice gave me compared to classic psycho-oncological sessions where I was much more passive and in demand of guidance. With MBSR the guidance was there "online" as things developed, all that I did was show up for what was already there and through each moment of attention given to breath, bodily sensation, thought, or emotion I experienced a strong sense of mastery. Paradoxically, the more I surrendered to what was already happening (tumors coming out, surgery, change of treatment, side effects) the more I felt this sense of mastery. Saki Santorelli describes this beautifully:

> Inwardly speaking, via meditation practice, mastery is cultivated through attending to thoughts, emotions and physical sensations and events in the field of awareness - by allowing these events to arise, be seen, honoured the way they are, and eventually dissipate or dissolve rather than dominate the mind (Santorelli 2011, p. 209).

I did not necessarily like what I experienced and felt, as I was terrified and angry and anxious, or in pain from the surgeries, but the difference was that this time I turned toward those experiences, which were already there anyways, and did not try to change them. Practicing presence or simply "showing up" for whatever the day threw at me radically changed my quality of life, not just life with cancer, but all of my life. I changed my attitude as a teacher, for better or for worse I changed as a wife, mother, daughter, and colleague. But during this period I recognize now that there was also a lot of bargaining with the cancer. I gave myself authority to engage in large projects and accepted increasing responsibility and accepted academic leadership challenges I would have never taken. I know now that it was a way for me to set future goals that I still needed to achieve before

I was "done". And as if by magic, things got done, and I am still setting future goals. My relationship with psycho-oncology changed. I was still heavily relying on help from a psychiatrist for my couple, which was suffering, and sometimes more than my body, but I relied less and less on psycho-oncological consults.

It was also in early 2010 that I started working with a group of like-minded people in Brussels that includes cancer patients like myself, reliable cancer therapies, Association pour le Development du Mindfulness (ADM); The Université Libre de Bruxelles; Institut Jules Bordet; UZ Brussels; UZ Gent; Institute for Attention and Mindfulness, Sint Elisabeth Ziekenhuis (ZNA), and The Chirec cancer institute and a few private sponsors on a long-term project that aims at better integrating mindfulness into oncology centers in Belgium. This work is ongoing and holds great promise on seeing one-day mindfulness-based interventions become standard part of care in oncology centers, and we hope this also becomes reality for the medical/nursing staff.

6 Meaning and Posttraumatic Growth

As the illness has progressed into a stage IV life-limiting illness, and I continue to navigate through clinical trials to extend survival I must confess classic problem—and emotion-focused coping are not enough. MBSR practice without any meaning or spiritual context is also not enough. I am not religious, nor have I been one to search for the "meaning" of life. Thus, as I reach the end I feel I am starting my spiritual awakening from scratch.

I have started more and more to experience what Susan Folkman (1997) has described as meaning-based coping. She has suggested that positive emotions play an important function in stress, and are related to coping mechanisms that are different from those that regulate distress (Folkman 2008). What is interesting in this perspective is that it seems that the coping mechanisms that decrease the negative emotions might be different than those that increase the positive emotions. She talks about the importance of creating the situations that allow for positive emotion. Indeed I am happier now than I have ever been before, and what is interesting is that I feel a quality and intensity of positive emotions that is totally different from pre-cancer positive emotions. I have indeed experienced that it is possible to experience stress from the stage IV situation yet feel both positive and negative emotions during the stress.

Another concept that describes well what I am experiencing now is posttraumatic growth or PTG (Tedeschi and Calhoun 1995). The main idea is that the experience of a highly stressful or traumatic event such as stage IV diagnosis violates one's basic beliefs about the self and the world and that some type of meaning-making or cognitive processing is activated to rebuild these beliefs and goals, resulting in perceptions that one has grown through the process (Tedeschi and Calhoun 2004). A recent meta-analysis of PTG following cancer or HIV/AIDS patients has shown that PTG is related to better positive mental health and self-reported physical health, and less negative mental health (Sawyer et al. 2010).

I have also recently engaged in a process of rediscovering my whole mind–body-spirit dimension. I can imagine this is not the sort of approach that may be readily available in most oncology centers. Yet for me, living with advanced disease, it is the most groundbreaking. I confess that I do not have all the psychological concepts to describe it in much detail here. But the process involves interacting with a therapist that enables me to embody thoughts and emotions, and to perceive what I will call—for lack of a better term—"my sensitive body". I suspect many people discover this dimension and their sensitive body through yoga, reiki, qi gong, tai chi, music or art therapy, or faith. For me this exploration started with meeting and experiencing a session with Jean Paul Resseguier, a French kinésitherapist who developed this method almost 30 years ago. He was influenced by the phenomenology movement (through authors like Edmund Husserl, Maurice Merleau-Ponty and more recently Francisco Varela) and its understanding of the body not as a machine but as a dynamic "living" body that is constantly in a state of "creative" homeostasis interacting within and outside of the body. The Resseguier method has been applied to many medical conditions in Europe and Brasil—including cancer—and patients systematically report better quality of life and enhanced pain management and reduction of side effects during treatment. Unfortunately there is no published research for cancer patients. The major feature of this method is the creation of an empathic relationship ("nouage empathique" in French) between the therapist and the patient through hand-touch in the moment to moment. Basically, you both "show" up for what is there as it unfolds. Concretely for me as an advanced cancer patient it enables me to silently witness the dynamic and sensitive nature of mind–body–spirit. During a session I may experience online physical readjustments that seems to me to occur outside of my conscious "cognitive pilot". These readjustments may be not only physically felt and observed to the naked eye, but also confirmed via medical imagery (in my case the physical readjustments have been recorded via ultrasound and in one case via PET/CT scans). This work, which I continue with a person trained by him Brigitte Maskens in Brussels, has brought me clearly out of my academic comfort zone and for now I am just purely enjoying the ride.

Personally, I must conclude that the awareness of my own death as inevitable leads me to see the absence of all lived possibilities and to hold on to the present as the only place to be. In the words of Merleau-Ponty "present without a future, or an eternal present, is precisely the definition of death" (1945, p. 388).

7 Conclusion

For us, the patients, psycho-oncology should not be presented as a side dish or separate chapter of cancer treatment to be activated only "if need be". Psycho-oncology IS cancer treatment. If empirical evidence of the impact of psychological intervention on overall survival is hard to demonstrate but it is there (see Andersen et al. 2006), there is ample evidence of its positive effect on quality of life, pain reduction and cancer treatment side-effect management. For patients it is clearly not about just extending overall survival, but about living well the time that we live with cancer. Psycho-oncology holds a central place in each step of the path from diagnosis to recovery, and for those who like me live with advanced disease, all the way to the terminal phases of cancer. This central place needs to be recognized and integrated into existing cancer centers, hospitals and national health systems, and cancer plans. Recent reviews leave us with hope that access to psycho-oncological care being facilitated not only in the US but also around the world, and in great part this is due to better-organized patient advocacy and greater inclusion of the patient view in decision-making and debates (Beishom 2011). This chapter is a clear testimony to this.

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