

# Ignoring Symptoms

## The Process of Normalising Sensory Experiences after Cancer

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**ABSTRACT:** This article explores the process of interpreting bodily sensations after completed cancer treatment. We base our analysis on repeated interviews over a period of 12 months with eight participants who had different cancer diagnoses. By using the concepts of ‘sensation schemas’ and ‘sensation scripts’, we explore how sensation schemas of cancer dominated in the first period, while schemas of late effects and reduced tolerance for daily life activities gradually became more important as time went by. Scripts, or actions taken to reduce unpleasant sensations, gradually turned from seeking medical advice and check-ups to ignoring and waiting for it to go away. Later, adapting daily life to the new health situation became prominent, such as balancing rest and activity to avoid becoming exhausted.

**KEYWORDS:** cancer, coping, everyday life, late effects, sensation, symptoms, uncertainty

At the end of 2013, more than 232,000 Norwegians were living with the experience of having had at least one cancer diagnosis, recently or several years ago (Cancer Registry of Norway 2015). After cancer treatment, a number of patients experience different late effects such as pain, fatigue, depression and anxiety, sleep disturbance, and physical and cognitive limitations (Harrington et al. 2010; Loge 2013). Also the fear of recurrence or new cancer is an important part of life after cancer treatment (Bailey et al. 2007; Horlick-Jones 2011; Lillehorn 2013; Miller 2014; Mishel 1988; Somerfield et al. 1999). This fear has been an underlying dimension of a research focus on life quality and well-being after cancer (Horlick-Jones 2011; Lillehorn 2013) and on coping strategies (e.g. Brennan 2001). Coping may refer to ‘behaviour that protects people from being psychologically harmed by problematic social experience’ (Pearlin and Schooler 1978: 2). Or, according to Lazarus and Folkman (1984: 142), managing ‘demands that are appraised as taxing or exceeding’ a persons’ resources. In empirical studies

the most prominent coping strategies identified and used have been: problem solving, seeking support, avoidance, distraction and positive cognitive restructuring (Geyer et al. 2015). The strategies used will vary over time, as there are different challenges during the disease process, depending both on the illness trajectory, the individual and the social context (Brennan 2001; Geyer et al. 2015; Somerfield et al. 1999).

Our study of the process of interpreting bodily sensations might be placed within the field of cognitive and emotional coping strategies in terms of coping as appraisal, being ‘evaluative cognitive processes that intervene between the encounter and the reaction’ of an event (Lazarus and Folkman 1984: 52). Through this process a person ‘evaluates the significance of what is happening for his or her wellbeing’ (ibid.). Still, these processes can be unconscious and the agendas that shape appraisal are not always easily accessible (Lazarus and Folkman 1984). Adding to this, we focus on the process of the participants’ realising how the way they perceive their body has



been changed by cancer illness, and how this influences the way they interpret their bodily sensations, cognitively and emotionally.

The way people sense their body is an important basis of their interpretation of the state of their body, health and illness and decisions about healthcare seeking (Hay 2008). To get an understanding of the liminal states (Blaxter 2010) of cancer and what is happening in the process of learning to interpret the body again after cancer treatment, we wish to bring in the concepts of 'sensation schemas' and 'sensation scripts' as argued for by Hinton et al. (2008: 142). Hinton et al. propose a heuristic use of these concepts and their aim is to contribute to knowledge within psychiatry about sensations as cultural and differing across cultures. We argue that the concepts are of interest to the understanding of our interpretation of sensations in general and that they link to coping strategies.

Sensation schemas are various networks of meaning (Hinton et al. 2008: 152), conceptual models (Classen 1993) or cognitive maps (Brennan 2001) that are connected to sensations and are used to understand the sensations we feel. The sensation schemas will interact with physiology, attention and imagination and will be connected to previous experiences, worldviews and metaphors. They can also include ideas of causation and models of process. Thus they are cultural as they build on common ideas and local knowledge of a group, but they are also individual as they are based on the individual's life experiences (Hinton et al. 2008).

The schemas we choose will point at certain sensation scripts that fit the schemas (Hinton et al. 2008: 153). The scripts suggest what actions to take. When we adhere to a certain sensation schema, the schema activated will place the sensation in specific social contexts that 'embed sensation in a larger web of meaning and expectations' (ibid.) and thereby point at certain actions to handle the situation. This handling can be seen as coping strategies, and are processes of meaning-making based on what we already know, but also of actively creating new meaning. When people become aware of the existence and maybe negative influences of scripts, it makes way for deliberately 'rescripting' (ibid.) a sensation, and opens up for new ways of handling the situation. Hinton et al. argue that when a script is invoked that increases 'a sense of efficacy and promotes positive engagement in life process' it can be a step in a process of healing (ibid.).

The aim of this article is to investigate the interpretation process of bodily symptoms and sensations after cancer diagnosis. We will do this drawing on

theories in sensorial anthropology, mainly the concepts of sensation schemas and sensation scripts, to explore if this can contribute to a general and added understanding of the process of interpreting and coping with bodily sensations after cancer.

## Method

We used semi-structured one-to-one interviews as our main method (Kvale and Brinkmann 2009) and this article is based on an analysis of 40 semi-structured interviews supplemented with field notes from participation in activities. Participants living in a larger city in Northern Norway were recruited through their general practitioner. A total of eight patients agreed to participate, six women and two men. Their average age was 56 and except for one aged 75, they were all between 40 and 63 years old. The participants had different cancer diagnoses: breast cancer, prostate cancer, ovarian cancer, cervical cancer, lymphoma and colon cancer. They had finished medical treatment between one and ten years before the interviews started.

We followed all participants through most of 2014 and undertook four to seven interviews with each of them, distributed over the year. We started with an open narrative (Kvale and Brinkmann 2009) where we asked the participant to tell his/her story about the illness. The following interviews were semi structured with the use of an interview guide and follow-up questions focusing on health situation, everyday life and social activities. The questions concerning health and symptoms were about their perception of general health situation at the moment, experiences of pain, discomfort or changes in the body, tiredness or worries about health since last interview. In case of discomfort or worries, we asked if these had disturbed their everyday life, and we asked what they thought could be the source of any pain or discomfort. Due to late recruitment and life events some participants got fewer interviews than they otherwise would, but the interviews were adapted so that the planned course of the topics was covered.

We also used voluntary health diaries and drawings of social and geographical maps as additional tools (Aquist 2003; Hägerstrand 1985), mainly as a help to remember and talk about activities and arenas. In addition, the first author took part in some activities with participants as well as in cancer-related organised activities such as in the Cancer Society. The interviews have, however, been the main sources of insights and can be considered as a type of participant observation (Rubow 2003) as we have been fol-

lowing the participants with repeated interviews and conversations over months.

We analysed data both by categorising and contextualising (Maxwell 2012). We sorted data into broader themes, as for instance sensations, worries and wishes, handling, social arenas and rationales. The themes referred to meaningful units in the data and were connected to our research interest in the understanding of the sensing and interpretation of bodily sensations after cancer. During analysis we consulted literature on different theoretical notions and found that an angle on interpretation by schemas and scripts might shed light on what the data conveyed.

## Sensation Schemas in Transformation

### *Feeling Safe*

The participants in this study say that they considered themselves as being in good health before cancer, some above normal health, strong and active. Most of them did not think of cancer when they started noticing the bodily sensations that turned out to be cancer. John (56), who all his life had been far above average fit and athletic and who had never smoked, did not consider cancer as a possibility. He believed cancer was caused by smoking and he stated: ‘Cancer, no, that was not in my ... , it was not here [pointing at his head]. ... I have never smoked, and in my head I was ... , well, they were the ones to get it.’

In retrospect some participants seemed a bit surprised at their own lack of awareness of cancer. ‘It has often struck me afterwards, that I was not walking around being worried. It’s because you, you just didn’t think about it’ (Hanna, 58). We may say that the active repertoire of *sensation schemas* did not contain schemas with cancer or other severe illnesses as probable explanations of unpleasant sensations. We argue that this reflects an idea about one’s own health as being good, and not being vulnerable to serious illness.

### *Feeling Unsafe – Everything Can Be Cancer*

‘You got a bit uprooted, of course, when you got such a severe illness. (...) In a way you lose your sense of safety’ (Hanna, 58). As much of our experience of physically, socially and culturally being in the world has been mediated through our body, our understanding of the world and ourselves is partly connected to bodily sensations and to processes that we do not verbalise and often are unconscious of (Block

1994; Connerton 1989; Csordas 1990). As long as we have a general experience of being in good health, the sensation schemas we draw on to interpret our sensations can be assumed to be dominated by this, since schemas interact with bodily experiences and cognitive and social processes. Thus, new experiences can change the schemas. After cancer, the participants’ feeling of safety and confidence in their own health seemed to be gone.

After treatment, the perception of cancer in itself had changed from being an irrelevant disease to becoming the biggest fear of the participants. The participants’ minds seemed to be tuned in on cancer, as they saw cancer everywhere, in media or in the crowd on the street. Also, when it came to bodily sensations most participants said that the anxiety and fear of cancer relapse was always in the back of their mind, especially when they felt pain or were unwell or ill for a period:

So the catastrophe thoughts have been living in my head now. The first days are easy, – it is the flue. But then I had a sore throat and I could not swallow. So I got tested to see if it could be an inflammation, and then they found that it was not. So what do you think then? And I said to the doctor – “Then it is throat cancer.” (John, 56)

Bodily sensations were interpreted within a cancer context by sensation schemas with cancer as a possible cause of their sensations. These schemas were partly formed by the participants’ ideas and experiences of cancer illness and their thoughts about how it might manifest in the body.

In general, the participants’ ideas about symptoms after treatment were based on uncertainty. The participants expressed uncertainty about what symptoms to look for. They were unsure about what had actually been the symptoms of cancer before diagnosis. Others got a diagnosis after a routine scan and had been searching their memories afterwards for possible symptoms that they might have been unaware of before getting the diagnosis. This made interpreting sensations after cancer difficult:

It’s hard to tell what it can be. It can be injuries from radiation ... , chemotherapy. Difficult when you don’t have anything to compare with or others who have been through the same. (...) You don’t really know. I’ve had a lot of flu and have been ill too ... It’s really hard to find an answer to it. (Anna, 45)

Recalling the illness period did not help much as the participants were uncertain about what had been side effects and what had been symptoms of cancer during treatment. Still, the memories of bodily

sensations and the feeling of being ill from cancer, side effects or the cancer disease itself, were there, and contributed to the cancer sensation schemas and to the interpretations of bodily sensations. They remembered pain, nausea, feeling exhausted or a general feeling of being unwell, and these sensations now seemed to be part of the cancer schemas as possible symptoms. Often the participants were referring to the body remembering:

Haven't felt really well lately, but I think it is a cold or something. I think the body remembers. Yesterday when I got out of bed I felt a bit unwell and a bit nauseous, and then I immediately am reminded about the time I had chemotherapy. Then I think the body is remembering, and so it becomes nastier than before. (Hanna, 58)

In general I don't hesitate seeing the doctor. I become really afraid, well, when I get ill, my body goes into a kind of ... , I think my body remembers. I become so dispirited and sad, and full of sorrow. So I think my body remembers how it is to be so miserable. It becomes like a flashback to that time. (...) Oh, and I remember that nausea! But it is a bodily sensation, so I think the body is, it leaves tracks in your body I think, and I don't have any theory about how this comes about, but it is like some memories are just stored there. I can react completely ... hmm, well almost reflexively. (Emma, 40)

Memories, especially traumatic memories, can generate and amplify sensations connected to these memories (Hinton and Hinton 2002; Hinton et al. 2008; Nichter 2008). This can be understood in terms of the 'memory-associational body' and the 'catastrophic cognition body', as the focus on memories and our worst fears influence how we sense and interpret our bodily sensations (Hinton and Hinton 2002). The embodied memories added an extra dimension to being 'ordinarily ill', and when embedded in a complex network and context of meaning, it seemed to activate a cognitive schema or an idea of illness as cancer. Evoking emotions of fear and sorrow became a flashback to being ill from cancer.

When the cancer schema and fear for cancer became too strong, it took all the focus and became an obstacle for living a good life. 'Then I feel that I completely lose grip of my everyday life. Everything is focused around this anxiety and panic' (Emma, 40). Her previous diagnosis had been lymphoma and she had finished treatment nearly 10 years ago. In order to keep the grip on the everyday routine and maintain a good life, it became necessary to find strategies to limit this fear. On one hand, the biggest fear for the participants was to get cancer relapse. If it should

happen, they wished it to be discovered as soon as possible. On the other hand, if they let the fear of new cancer dominate too much, it was difficult to live a normal life. Getting their normal life back was what they all longed for after going through a cancer episode, so they needed to find strategies to cope with the fear. We believe that these strategies can be seen as questioning the cancer schemas and as 'rescripting' the way to handle their health situation (Hinton et al. 2008).

#### *Questioning the Sensation Schemas: Taking Control*

When the sensations in our body are interpreted within the context of sensation schemas, this context also points at sensation scripts that suggest actions to handle the situation. But the relation between sensation schemas and sensation scripts is not one-directional:

Which 'script' a sensation activates will have profound effect on its meaning, and the creation and evocation of scripts pertaining to sensations is a key dimension of healing. (...) Treatment often involves development of some awareness of the existence and influence of these scripts, which is a type of metacognitive awareness that may allow the individual to replace an automatically evoked script with a deliberately chosen alternative script. Healing involves using awareness of these scripts to 'de-automatise' the unfolding of these maladaptive scripts to learn new scripts. (Hinton et al. 2008: 153)

As we have seen, when the participants after treatment interpreted their bodily sensations in the context of cancer schemas, the scripts that followed were to seek medical aid to find out if this could be cancer. So they went to see their general practitioner and maybe also a specialist. As a consequence their worries were kept alive until they eventually were assured by the doctors that this was not cancer. Sometimes the worries still persisted because no other explanation was found. As awareness of the most often maladaptive function of the dominating cancer schemas grew, some of the new strategies were to postpone seeing the doctor and not discussing unpleasant sensations with others, because once they did, their worries became more real. 'I cannot run to the doctor every time. It is a part of the strategy not to put too much into it. Because if I do, I get into a track that is hard to get out of. (...) As soon as I start talking about it, it becomes more real' (Emma, 40). Others spoke about keeping up activity or keeping their mind on other things as a strategy to get their mind off worries about unpleasant bodily sensations: 'Because I've learned these techniques, I try to focus on other things. Then the bad thoughts are just momentary.

But earlier they could last for longer, and they came more often (Hanna, 58). Trying to ignore sensations and wait for them to go away seemingly developed into new scripts that were deliberately chosen as an alternative to the cancer scripts. Not as a part of healing cancer but as a part of healing everyday life after cancer.

Awareness about the maladaptive function of cancer schemas seemed to have emerged out of a growing amount of experiences with unnecessary worries about unpleasant sensations that were not found to be cancer and the re-scripting was an alternative way to handle it. However, this also meant that sensation schemas with other explanations than cancer gradually stood out as possible and relevant to the participants. Many of the participants did not expect late effects like the ones they had experienced after finishing treatment. They could not remember having been given this information at the hospital at the end of treatment: 'You got to know that chemo would be out of your body after three months. But that is just rubbish. I have heard more people telling that chemo rested for a year. It really did. You can feel it in your body' (Hanna, 58). Their knowledge had grown gradually by searching information from the Cancer Society, the Internet, other cancer patients, and health personnel they had been in contact with during this period after treatment. At some point in their process of returning to everyday life, all participants seemed to have realised that late effects could be an explanation of some of their problems. New sensation schemas emerged and opened up for interpreting sensations in a late effect context and through 'late effect schemas'.

The late effects of cancer treatment seemed to affect many dimensions of body and mind, not only physically. One participant described it as having become more vulnerable in general. Most participants said that they did not have as much energy and could not stand stress the way they used to. Stress was now caused by normal activities making people extremely tired from everyday situations at work and in private life. The participants in general easily became tired and when they got too tired, it was difficult to live a good life and to keep away the fear of the cancer returning. 'So if you are in really poor shape, are tired, then the psyche is tired as well, and you are not in the state of thinking right, to put it that way' (Hanna, 58).

Interpreting the sensations of being tired or exhausted through a late-effect schema made the participants consider these sensations to be caused by a lower level of energy and a reduced ability to cope

with stress. Strategies or scripts to prevent stress and exhaustion were then developed to keep away the fear of cancer as well as to serve as a way of taking control over the new life situation, increasing 'a sense of efficacy' and promoting 'positive engagement in life process' (Hinton et al. 2008: 153).

In order to keep away stress and exhaustion and maintain energy it became important to balance how to spend time: 'I must all the time consider the pros and cons. How much of my energy will this cost?' (Emma, 40). Planning for plenty of time to rest, spending a lot of time on the sofa, and going to bed early were strategies used by many. Limiting social life and staying away from activities or situations that caused stress or tiredness was another strategy. When the energy level was a bit higher, physical activity, especially outdoors and in nature, was a strategy to feel relaxed and obtain mental balance. A more mentally oriented strategy was to practice mindfulness exercises and meditation as a way of mastering stress and preventing weakening the body and its resistance towards cancer relapse. Overall, the participants struggled with keeping the balance between rest and activity, referring to a goal of mastering balance in life.

## Concluding Discussion

When the participants became aware of how their fear of cancer dominated the way they interpreted bodily sensations and how their interpretations amplified their fear of cancer, it opened up for other ways of handling the situation. As their knowledge of late effects after cancer and treatment grew, this opened their minds to understand their bodily sensations in a different way. Ignoring sensations, not seeking medical aid immediately but waiting to see, was a new sensation script and a step along the way. The sensation schemas containing cancer as explanation were gradually replaced by schemas with late effects as probable explanations.

When the participants replaced the script 'see the doctor' with the script 'ignore symptoms – wait and see', it seemed to contribute to stopping the spiral of fear and it gradually made way for understanding the bodily sensations through alternative schemas. However, the dilemma of when to ignore sensations and when to get them checked will always be present, as the possibility of cancer relapse is a real threat.

Adapting everyday life to their new health situation by balancing activity and rest became a new main script and strategy. The dimension of the par-

ticipants finding balance in their new life is also connected to the fear of stress and tiredness as a cause of cancer or a factor that increases the chance of getting it by weakening the immune system. This idea about exhaustion and imbalance as causation is also expressed in popular media and it fits what Blaxter named the 'ancient idea of homeostasis – the idea that the normal state of the body is order' (2010: 7) and also today the biomedical model of health is compatible with an idea of equilibrium, or balance, she argues. As pointed out by Hinton et al. (2008: 153) the scripts people use may have multiple other effects than serving to handle the sensations. They can also serve to 'construct and position the self in terms of specific forms of (bodily) experience and identity'. We suggest that the ideas of balance are to be seen in other areas of society, such as in the focus on ecological and sustainable living and in activities like yoga and 'mindfulness' that are popular today.

This article has further shown how the ideas of sensation schemas can contribute to understanding the way former cancer patients continue to interpret sensations in a cancer context long after treatment is finished. Hinton et al. (2008) argued for a heuristic use of the concepts of sensation schemas and sensation scripts as a contribution to the medical anthropology of sensations especially in psychiatry and panic disorder. Our analysis has shown the usefulness of the idea of sensation schemas and scripts in other areas, analysing the process of learning to live with a changed body after cancer treatment. This analytic approach contributes to linking processes of interpreting bodily sensations with both a link to theories of coping (appraisal, evaluation) and to theories of sensorial processes, pointing to an attempt to join body and mind.

A practical implication points to the need for follow-up of former cancer patients after treatment finishes. In particular more information on late effects was requested, as well as information about what bodily sensations to be aware of as possible symptoms of recurrence. In addition some information about possible challenges to their new life would be welcomed, as many expressed a feeling of being the only one struggling with getting back to normal life after cancer.

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