

What symptoms tell us: a multiple case study of symptoms in oncology consultations

Short title: A multiple case study of symptoms in cancer care

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Abstract

Objectives: while patient' symptom experiences have been widely investigated, there is a lack of contextualized studies investigating how symptoms circulate in the medical consultation, how patients present them, what they convey, how physicians respond and how patients and physicians negotiate with each other to find ways to address them. To explore patients and physicians handling of symptoms throughout oncological consultations with a multiple case study approach.

Methods: five consultations, purposively selected from an existing dataset of audiotaped consultations with patients with advanced cancer, were analyzed by means of an inductive analytical approach, based on a sensitive framework from the literature.

Results: patients' symptoms showed multiple dimensions: medical, cognitive, emotional, psychological, interactional, symbolic, experiential and existential.

Significance of results: different symptom dimensions remained unnoticed and unaddressed in the consultations. The physician-centered symptom approach that was observed leads to consumed time and missed opportunities for relationship building with the patient. Physicians showed a lack of sensitivity regarding the multiple dimensions of symptoms. Based on the findings, strategies for a more comprehensive symptom approach can be conceived.

Key words: symptoms, multiple case study, qualitative research, cancer, palliative patient

Introduction

In 1976, Jewson demonstrated in a paper entitled “The Disappearance of the Sick-Man from Medical Cosmology” (Jewson, 1976) that the production of medical knowledge shifted between 1770 and 1870 from the sick towards medical investigation, and from the whole person towards a fragmented perspective. Indeed, prior to the anatomical-pathological method, physicians relied on symptoms, identified through the patient’s discourse, as illustrated by the epistolary heritage of Tissot, who treated patients throughout Europe based on correspondence (Barras & Louis-Courvoisier, 2001); patient or significant others detailed in letters the bodily experiences and Tissot provided advice. Patient’s subjectivity was thus key to orient the physician.

The anatomical-pathological turn, attributed to Bichat (Shoja, Tubbs, Loukas, Shokouhi & Ardalan, 2008), revolutionized medicine by linking lesions observed in autopsies to symptoms experienced by the diseased. The medical gaze (Foucault, 1973) thus started his successful journey, later replaced by more and more sophisticated methods to “look into the body” like analyses of fluids, biomedical imaging or molecular-biology. These techniques allowed considerable progress, but also diminished the relevance of the subjective experience of the sick-man.

The psychosomatic movement (Wittkower, 1974), raising after World War II, and the subsequent bio-psycho-social model introduced by Engel (1977) aimed to rehabilitate the patient as a whole person. However, the biomedical model still prevails, despite recent efforts to promote patient-centeredness, empowerment and shared decision-making (Epstein & Street, 2011).

Symptom descriptions remain important to diagnose diseases, but also to understand illness representations and associated behaviors, and symptoms provide cues for engaging in an empathic relationship and to strengthen therapeutic alliance (Hall, Ferreira, Maher, Latimer & Ferreira, 2010).

Besides documentation and quantification of symptoms (Bruera et al., 1991; Tranmer et al., 2003; Kirkova et al., 2006 ; Trajkovic-Vidakovic et al., 2012), researchers investigated symptom distress and experience (Akin et al. 2010; Molassiotis et al., 2010), symptom attributions, meaning and beliefs (Jones et al., 1981; Richer & Ezer, 2000; Heidrich et al., 2006; Estacio et al., 2017, 2018), situational and existential meaning of symptoms (Richer & Ezer, 2000; Armstrong, 2003), symptom burden (Doumit, 2007; Gill, 2012) and symptom familiarity (Jones et al., 1981). In addition, socio-anthropologists and phenomenologists identified cultural, educational, social and economic determinants of symptom experience (Kirmayer et al., 1994; Lobchuk & Stymeist, 1999; Bell, 2009).

Studies assessing how symptoms circulate in real-world conditions are rare and mainly conducted in patient populations representing major challenges to clinicians, like those with medically unexplained symptoms (Ring et al., 2005; Salmon et al., 2005; Stortenbeker et al., 2020). These studies demonstrate that physicians rarely respond to suffering and misinterpret what patients expect from them (e.g., medical investigations according to physicians, empathy according to observers) (Salmon et al., 2005). With regard to studies of medical consultations, Beach et al. (2005) observed in video excerpts that physicians exhibit minimal receptiveness to patients' lifeworld disclosures (e.g., they redirect attention to their medical agenda). Estacio et al. (2017) found that in palliative care consultations, the main response to patient's symptom presentation – independent of the symptom meaning – was medical. Others observed that physicians show difficulties to identify informational and emotional cues conveyed by symptoms (Zimmermann et al., 2007), and when giving patients explanations for their symptoms (van Ravenzwaaij et al., 2010).

Against this background, the present study aimed to comprehend how symptoms circulate in the medical encounter, how they emerge, disappear and sometimes re-emerge, what they convey, which functions they fulfil, and how physicians respond to them. In other words, the goal was to situate patient's symptoms by examining them inductively in real world conditions.

Methods

Material

The material is part of a dataset consisting of 134 consultations of 24 oncology physicians with 134 patients with advanced cancer, audiotaped and transcribed verbatim for a naturalistic multi-center observational study (De Vries et al., 2017); the study received approval by the ethics committee of the participating hospitals, and patients signed an informed consent form. Patients knew that they have advanced cancer and that they receive palliative treatment. The objective of the consultations was to discuss results of investigations (e.g., CT scans, tumor marker levels) documenting disease evolution.

Five consultations were purposively selected, based on a previous identification of specific symptom discussions.

Data analysis

Based on the empirical literature (Jones et al., 1981; Beach et al., 2005; Ring et al., 2005; Salmon et al., 2005; Doumit, 2007; Zimmermann et al., 2007; Akin et al. 2010; van Ravenzwaaij et al., 2010; Gill, 2012; Estacio et al., 2017, 2018; Stortenbeker et al., 2020), we developed a framework for the analysis, which provided ‘sensitising concepts’ (Bowen, 2006). These concepts suggested “directions along which to look without prescribing what to see” (Bowen 2006; Bombeke et al., 2012). The analysis consisted of iterative reading to gain a comprehensive view, coding, and group discussions to obtain a fine-grained understanding of the symptom dimensions. We adopted a multiple case study approach, which allows in-depth contextual explorations of complex issues (Crowe et al., 2011).

In the results section, the four consultations are shorten in a way to both keep the flow of interaction between the patient and the oncologist, and to account for the consultation content around and beyond symptom discussions. The speech turns to which we refer in the following are numbered in square brackets, which relate to Tables 1 to 5 (transcripts).

Results

Case 1: A dialogue of the deaf

What strikes first is that the patient calls his symptom “belt” (“I have a belt here inside of me”) [14] (see Table 1), which illustrates that patients describe symptoms based on their lay representations (Stiefel, 1993), and that symptoms are situated in the lived experience of the body (Lindqvist et al., 2006). In this experience, emotions and not only (cognitive) representations, influencing each other, play an important role (Ford et al., 1996). Here, the symptom may be associated with shame, since the patient links it to the possible existence of hemorrhoids [32-35]. The symptom seems most relevant, the patient repeatedly evokes it throughout the consultation [14, 88, 118, 206, 346]. For cancer patients, new symptoms are first of all related to cancer (Lindqvist et al., 2006), unless a less threatening explanation is found. In this case, the symptom seems not threatening, but shameful.

The other symptom, related to his knee [304-307], carries a specific significance for the patient, who seems not to understand that it is not a priority to operate his knee (given the limited life expectancy). It could also be that the symptom is introduced as a non-threatening topic, or – if an operation is proposed – a mean to gain hope for a certain life expectancy. If this latter is the case, the presentation of this symptom is a displacement, expressing psychological needs, which require clarification and an adequate response.

The physician focuses on symptoms, which are signs of cancer progression [159] or serious medical problems (coughing and trouble to breath) [49-53]. With regard to the “belt” symptom, the oncologist remains vague [35, 39, 101, 209, 213, 345], and avoids to address an issue of which he cannot make any sense. Concerning the complaints about the knee, the physician answers indirectly (“I don’t think they will operate on you”) [307]. An alternative would be to acknowledge that one does not know the origins of this symptom or to discuss the limited life expectancy.

A lack of dialogue is observable with a physician asking for symptoms the patient does not have [49-53], and a patient evoking symptoms, which remain unheard, and thus repeatedly re-emerge during the consultation. Moreover, associated shame, burden (“belt”) or limited life expectancy (knee) remain unaddressed.

Previous research demonstrated that oncologists focus on the biomedical (Ford et al., 1996). In this consultation, the physician links symptoms to clinical and para-clinical investigations [101-143]. Consequently, the “invisibility” of the “belt” symptom obscures its existence, motivating the patient to ask for an investigation (colonoscopy) [173], which may render it more visible, existent and addressable. Finally, medical rationality dominates, since the physician decides which symptoms are relevant or not and associated representations, emotions, concerns and psychological functions await to be addressed (Beach et al., 2005). Consequently, time is wasted and opportunities to strengthen therapeutic alliance – at the core of situations with limited medical power – are missed.

Case 2: Who needs reassurance?

This consultation raises the issue of how to reassure – if necessary – when a symptoms of somatic or psychic origin emerge (see Table 2). Patients are expected to report their symptoms and physicians to respond. Symptoms thus connect patients and physicians, their lay and biomedical frameworks, however, separate them (Gibbins et al., 2014; Estacio et al, 2018).

It is widely accepted that pain is subjective, may exist in the absence of tissue damage or has a psychological origin (Loeser & Treede, 2008). In this consultation, the patient reports pain in her chest, hips and pelvis [118, 227]. The oncologist insists that the pain is not tumor-related, based on its location [206-222, 230] (the scanner showed no lesions that could explain the pain, and the tumor itself is not supposed to hurt ...), and provides alternative explanations (scars or sequela of chemotherapy) [198, 222]. We do not know whether the patient believes that the tumor hurts or whether she simply reports every symptoms assuming the patient role, as has been observed in cancer patients (Beach et al., 2005; Estacio et al., 2017). The physician does not consider the symptoms as dangerous, or at least not caused by the cancer, and repeatedly states that there is nothing to worry about [206, 214, 220, 222, 280]. She appears to believe that the patient fears the symptom and links it to cancer – this is indeed often, but not always the case –, but she does not explore if this is really the case. Either the oncologist fears that the patient fears the symptoms and attempts to reassure her, or reassures herself by repeatedly stating that the symptom is not cancer-

related, or she is contaminated by the patient's anxiety. While physicians usually aim to transform the patient's situation into a clinical situation, here the circulating emotions triggered by symptom expression transform the clinical situation into a psychological situation, marked by anxiety-induced avoidance.

Sometimes patients use complementary treatments (Ben-Arye et al., 2006), as in this consultation, in which the intake of baking soda is discussed [363]. The patient hereby not only reveals her illness representations, she also demonstrates active coping (Weisman & Sobbel, 1979), which has a (self-)reassuring function. Baking soda can be considered as a third party object – complementary medicine –, which may indicate reluctance to delegate responsibility for treatment solely to the physician. By ignoring the psychological aspects of baking soda [370-428], the clinician misses an opportunity to explore and validate the patient's coping strategies or to address her potential lack of trust.

Finally, this consultation also illustrates the differences between physical and psychological symptoms. While somatic symptoms call for a medical response, psychological symptoms need expression, clarification, understanding, and if pathological, orientation towards specific treatment. At the end of the consultation, the oncologist tries again to reassure the patient, but this time with regard to feelings of guilt [463-464]. The underlying motive of guilt, however, remains unexplored. A possible explanation lies in an often-observed desire of clinicians to “solve patients' problems”, which – when this seems impossible – provokes premature and inadequate reassurance or downplaying of the patient's experiences (Stiefel, 2006). Here, the oncologist does not explore the patients' feelings of guilt, but attempts to reassure by communicating that she suffers and should not feel guilty of feeling fine, and that if she does not suffer much, it is because she is very brave [464].

One might ask what this reassuring stance, which runs like a red string throughout the consultation, signifies. Do the attempts to reassure have the intended effect or do they increase the patient's uneasiness? Indeed, since they lack exploration and understanding, they could decrease the patient's feeling of isolation (Beach et al., 2005). In other word, the oncologist's attempts to reassure may respond to her own psychological needs. Here, the clinician turns a clinical situation – from a psychological point of view – into a non-therapeutic situation.

Case 3: Symptoms as protection

In presence of a third party, such as in this consultation with a member of the family, the probability that a symptom is reported increases (see Table 3). For reasons such as forgetting to tell, not to bother the physician, shame or fear that treatment would be reduced, patients may indeed silence or minimize symptoms (Lindley et al., 1999) [4]. Here, it is the wife, who reports the symptom and specifies its intensity, which seems to be higher than the patient indicates [222]. Intensity alone does not determine symptom experience, which depends also on its frequency, associated distress, attributed meaning and disruptive effects (Armstrong, 2003; Gill et al., 2012). The wife and the patient attribute a different meaning to the symptom. The wife fears it to be cancer-related and hopes it to be mobility-related, (“I hope it’s just that”) [245], and the patient is not worried (“As it is now, even if a little bit, I’m not sick. For me, I’m normal”) [528]). The patient renounces to elaborate on the symptom, and it remains unclear if – in the constant cycle of feeling ill and feeling well (Lindqvist et al., 2006) – he is truly feeling well.

There are nowadays many ways to monitor diseases, as illustrated here by the references to the light chains [165]. Even when patients are reluctant to talk about a symptom and/or down play it, the physician can thus rely on a laboratory or imaging data. The patient’s shifting the discussion to diabetes [174, 182] may indicate that he actually links the back pain to increased disease activity, and thus displaces the attention to another, less threatening topic (see also case 1). A clue for displacement is that the patient expresses almost no concerns with regard to the myeloma.

The oncologist probably reacts (unconsciously) to the patients’ displacement and stops to focus on the disease, but introduces as a new topic the last treatment and the next chemotherapy. Paradoxically this shift provokes the remembrance of a symptom, which has a specific significance, feared by the patient: hair loss [493-522]. Hair loss materializes the disease, designates the patient as a cancer patient, and exposes him to the gaze of others. In addition, hair loss can provoke loss of self-esteem and trauma, and modifies social interactions (Rosman, 2004). Here, discussion of hair loss temporarily breaks the patient’s down playing of the disease and/or its severity [524-528]. Hair loss also illustrates the symbolic aspects of symptoms, carrying individual meaning, linked to

biography and collective meaning, as hair loss is associated with old age and disease, especially cancer, but also with stigma and punishment (Hansen, 2007).

Finally, the tendency of the patient to down play his disease might be facilitated by the fact that myeloma, unlike solid tumors, have a hidden and ubiquitous localization, and might thus create more anxiety (and denial) (Ernst et al., 2011) [528].

Case 4: Iatrogenic symptom persistence

In this consultation, the patient clearly favors complementary over biomedical treatments [110, 354, 401] (see Table 4), which can be an indicator for mistrust, anger, deception, anxiety, a desire not to put all eggs in one basket or of certain representation and belief system. Consequently, this stance should be explored from a cognitive-representational, emotional and interactional perspective, especially when treatment side effects or iatrogenic symptoms bother the patient. Depending on motivations, answers differ and are not limited to warn about possible interferences of complementary approaches with oncological treatments [111].

The consultation also illustrates that patients consider their symptoms diachronically: when treatments end, side effects are also expected to end (Harrington et al., 2010; Wu & Harden, 2015). This patient has either not been informed or has not retained the information, and the oncologist has thus to confront her with the possibility that side effects persist for some time or even become chronic [133, 135, 468].

In oncology, iatrogenic symptoms are the price to pay for treatment benefices. To put it differently: the end justifies the means. However, iatrogenic symptoms may provoke anger or deception, especially if treatment is not effective or, as here, the patient did not anticipate that they persist [134, 465-469, 473, 578, 580]. On the other hand, the oncologist may feel guilty, especially, when side effects surpass benefits of treatment. Furthermore, having to choose – to decide upon “the price to pay” – puts pressure on the patient-physician relationship [133-136, 142-143]. However, reducing the dose of chemotherapy in view of side effects can also provoke fears, and decreased side effects may

be interpreted that treatment is not effective (Bell, 2009). This illustrates, that – exceptionally – symptoms may also have positive meanings for patients (Zimmermann et al., 2007).

The physician's statement that the abdomen is very supple [309], seems not to be as relevant for the patient as it is for the physician; it might be comfortable for the physician to discuss good news, and to provide explanations [321], illustrating that things are under control. It might not be pure chance that this statement comes right after delivering the bad news that there might be persisting side effects (which surprises the patient). For some patients – as for some physicians –, explanations may be helpful, but they do not make symptoms disappear (Ream & Richardson, 1996). Addressing eventual feelings of deception or understandable anger over side effects might thus be more beneficial.

Another striking element is that the physician repeats the information about persisting side effects several times [5, 129, 133, 135, 470, 547, 553, 579], but never asks if the patient understands. A clue, that the patient might not have understood why and how side effect persist, is the analogy she makes with her sleep (“it will get better and better”) [473]. Later in the consultation, the oncologist again addresses the absence of certain symptoms [509], probably to reassure the patient or to convey that she has been spared of other symptoms. Does this kind of consolation reassure the oncologist or the patient? Again, is it pure chance that such explanations are provided, while handicapping and persisting side effects exist [553], which might be difficult to bear [465]? Are these explanations an expression of the oncologist's anxiety or guilt?

Finally, we see that when a third party – here a third party welcomed by the oncologist –, has to solve medical problems (the skin problem (makeup)), the oncologist overhears the associated difficulties expressed by the patient. The physician evacuates the problem by delegating it to the third party, even if this third party does not seem to be of much use [612-621]. As for patients, physicians' introduction of a third party (e.g., another specialist, psychologist or chaplain) has various motivations, among them are negative counter-attitudes (Tzartzas et al., 2019).

In this consultation, the clinical situation is overshadowed by the relational situation, which is under pressure by third party elements and persisting side effects.

Case 5: A total symptomatic body

Acute symptoms indicate a disorder and orient care (see Table 5). In this consultation, we observe a cacophony of symptoms; one could speak of a *total symptomatic body* in analogy with *total pain* (Clark, 1999), which hampers the orientation of care. Despite the fact that multiple symptoms are frequent and provoke other experiences than single symptoms, studies are most often limited to clustering symptoms and examine the patient perspective (Mehta & Chan, 2008). Here, symptoms are caused by the disease, and co-exist with iatrogenic and psychological symptoms [7, 102, 148-149, 479, 482, 791].

The patient seems to endure a traumatic experience, which reduces her discourse to a testimony of repetitive grievances. The medical response can thus not be limited to the evaluation of each symptom and the prescription of an antidepressant, but has to address the trauma and existential suffering.

The question is how to care for this multi-symptomatic patient? We are here beyond disease expression, beyond psychosocial consequences or determinants of symptoms, and beyond symbolic meaning. The existential dimension of the symptoms requires acknowledgement that the patient suffers and that her state is unbearable (Le Breton, 2006). Such an intervention – even if this will not reduce symptom burden – would allow the patient to feel understood and reduce her loneliness (Beach et al., 2005). A supportive response, consisting of a statement that the physician is affected by the patient's suffering, recognizing his own impotence and inability to help, would here also show the family, who has turned their own impotence into an aggressive denial of the patient's distress, an example of an alternative stance [467-473, 749-794, 803-811]. The mere mention of an antidepressant, on the other hand, may convey that the patient's suffering is due to a psychiatric condition, and may be understood by the patient that the physician, like the family, wishes to silence her [774-794].

Discussion

This case series revealed that symptoms are situated in a socio-historical context, anchored in the patient's lived experience, loaded with psychosocial elements, and possess interactional and communicative purposes.

We identified seven main and often interwoven symptom dimensions. The *cognitive dimensions* relate to representations and attributions, influenced by a variety of factors like the origins of the symptoms (disease, side effects/iatrogenic), associated emotions, medical and lay information, or experiences with one's own or others' diseases. The *emotional dimensions* play a role with regard to symptom intensity (for example, by amplified anxiety) and symptom expression – shame or guilt may deny or downplay a symptom. The *psychological dimensions* orient and distract the clinician's attention (e.g., to unthreatening symptoms in case of displacement), and influence symptom perception and expression. The *interactional dimensions*, operating in symptoms conveying distress, explore the clinician's views (e.g., with regard to survival) or express anger (e.g., over iatrogenic symptoms). The inverse may also take place, with patients, who wish "to protect" the physician by denying symptoms. The *symbolic dimensions* encompass signs with an individual or collective meaning, such as hair loss. The *experiential dimensions* refer to symptoms, which alter how the patient "relates to, moves in and is affected by the world" and restrict his/her world (Goldstein, 1995). The *existential dimension* as appearing in a total symptomatic body may cut patients from others and the world, throwing them into an unbearable state of isolation.

Physicians, on the other hand, receive the symptom not in a neutral, unaffected, rational and scientific way. Perception differs, if the symptom is related to cancer (or not), understood (or not), caused by the disease or treatment, useful (or not) to monitor disease and of somatic or psychic origin. Physicians' capacity to contain suffering and to tolerate uncertainty and impotence will determine how they deal with a symptom, as does the individual medical approach (e.g., more or less patient-centered).

Symptoms allow interaction. However, a symptom may also become the joint focus of patient and physician to avoid the bigger picture, namely the progression of disease and its consequences. Symptom are thus not only a mean to diagnose, symptoms require themselves a diagnosis. Before providing a therapeutic response, the physician has to "diagnose" and understand the significance of

the symptom, since his/her response differs depending on the aforementioned dimensions involved in the symptom production. For example, information may respond to the *cognitive dimensions*, empathy to *emotional dimensions*, understanding to *psychological dimensions*, relationship building to *interactional dimensions*, verbalization to *symbolic dimensions*, interest for the daily living to *experiential dimensions*, and capacity to contain to *existential dimensions*.

The fundamental challenge for the physician is the symptom's subjectivity, not only with regard to its impact – this has been repeatedly underlined in the medical, especially the palliative care literature – but in the sense of the other in his/her otherness. This case series illustrates that a lack of effort from the physician to explore different symptom dimensions may hamper understanding, and turn the symptom, which should unify patient and clinician, into an obstacle of their encounter, provoking misunderstandings and deceptions. On the other hand, when the different symptom dimensions are explored, symptoms become a bridge between patient and physician.

This case series illustrates that the art of medicine is to turn a situation into a clinical situation. The beauty of the clinical situation – and this is certainly one of the motivations to become a physician – is that a clinical situation is a cognitive, emotional, psychological, interactional, symbolic, experiential *and* existential situation, for both, the patient *and* the physician.

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Table 1: **Case 1 – A dialogue of the deaf**

[The patient [Pt] comes to have the results of the last scanner, the oncologist [O] asks him if there are any changes since the last consultation one month ago]

14. Pt: It seems to me that I have a belt here inside of me, did you see something there? [...]

15. O: Yeah uhm what does that mean a belt? Are you tightened?

16. Pt: Yeah sometimes, now I don't know

17. O: Bloated?

18. Pt: Yeah that and at the same time, then almost painful at times I don't know

[...]

32. Pt: Yeah sometimes I have a bit uhm, precisely I don't know if I have these internal things or I don't know something

33. O: Rather constipated?

34. Pt: Yeah no not the same but I don't know if I have these internal things or else if it has how do you call it: hemorrhoids or

35. O: Well as that, it's all the way down there, that shouldn't hurt your stomach

36. Pt: It shouldn't hurt?

37. O: No

38. Pt: So, I don't know if there is something, because you didn't see anything on the scanner?

39. O: Well I didn't know, I will look, I will look yes

40. Pt: [...] I swallowed that product they put in my blood; there was some reaction

[O does not react to the hypothesis of the contrast product]

49. O: You are not coughing at all?

50. Pt: No, I was coughing before but not anymore, but I had a bit of a hoarse throat

51. O: OK. And the breathing?

52. Pt: Breathing is normal, well I'm not running the 100 meters, but I have no trouble breathing

53. O: And this stomach pain is it more during the day or during the night?

[...]

77. O: Is it more when you're doing the dialysis or the days before?

78. Pt: No, I don't see it like that, one or two times it seemed to me that it's like, for me, gases, you see, a lot, but appetite and all that normal. It's ok

[O decides to do a clinical examination]

87. O: Can you show me with your hand where it hurts? where more? rather below, rather there huh

88. Pt: I think it is like I have a belt sometimes [...]

89. O: it burns, it pulls? no? Does that hurt you?

90. Pt: Yeah

91. O: Like that?

92. Pt: Yeah that, that really hurts me, but I feel the spot all uhm

93. O: It's a bit sensitive there

94. Pt: Here yeah yeah, if you touch me it's a bit sensitive. It's not a uhm horrible pain

95. O: Yeah

96. Pt: I think it's a bit like, I don't know how you say, I feel like that this time it's not bad right now but it got better quite a bit since I think yeah it, it, the pression got a lot better since a good month

[...]

99. O: I'll let you get dressed

[The oncologist is scrolling through the images of the scanner]

101. O: I'm just looking again and then I show you after what I think [...] Well honestly in the stomach area I see, I don't see anything that could explain these symptoms

[...]

104. Pt: Nothing?

[the patient goes back to his hypothesis that the pain is because of hemorrhoids]

118. Pt: No but I'm saying it's like I have these internal things I don't know these

119. O: these hemorrhoids?

[...]

[O moves on and talks about the results]

143. O: So, in three months we see an evolution to the less good with more nodules that grew bigger, which confirms our impression that those are metastases of the bladder cancer which, which spread to the lung

144. Pt: what is the verdict? [...] are you going to do something?

[...]

159. O: Right now, it's hard to say if it nevertheless is related or not or if there is something we don't see? Well I will wait to look at the report of the radiologist because if he thinks it could be, that there's also something that started in the stomach, right that's it?

160. Pt: yeah yeah

161. O: If there is something going on in your stomach, isn't it nevertheless necessary to start treatment pretty fast if that's where we're headed

[...]

172. Pt: [...] last time they did a colonoscopy so would it be necessary to do another one or not, I did one two three years ago?

173. O: why did you have it?

[...]

206. Pt: Well I, I feel like it is like I have these internal things like that

207. O: mm mm

208. Pt: Well I don't know if you want to check that maybe

209. O: yeah, it's a problem but I don't think it explains the stomach pain, eh

[Pt then takes up O hypothesis]

212. Pt: Well maybe it's the dialysis or I don't know maybe it's an effect of the dialysis

213. O: It's possible yeah

[due to the progression of the disease, O expresses his wish to encounter the wife of Pt, who doesn't want to. O also stresses the importance for Pt to "settle his affairs". O would like to discuss the question of death but gets interrupted by a phone call and after the call comes back to the symptoms of the patient]

297. O: Yeah, I will check with the radiologist because of the stomach, it is what is bothering you

[...]

304. Pt: yeah, another question, normally I should change a knee, but it is another surgery again

305. O: change a knee, you mean a prothesis?

306. Pt: yeah, a total one, it's not really recommended, no?

307. O: well with all that it's not really reasonable, I don't think they will operate on you

[...]

345. O: But I will tell you for the stomach if I have an idea

346. Pt: thanks, I don't know what it did to me but one or two times it really wasn't so great

347. O: No, I don't know

348. Pt: we will see if it continues or if it was just temporarily, sometimes it is that

349. O: Very well. Does it work like that?

350. Pt: well yeah, we'll try to go with that [end of the consultation]

Table 2: **Case 2 – Who needs reassurance**

[The oncologist [O] remarks that the patient [Pt] is feeling better than usual after a chemotherapy and then begins very structured questions about symptom occurrence]

111. O: ok and the pain? did it come back?

[...]

118. Pt: [...] pain in the rib cage and vomiting

[...]

121. O: because of the chemo, you would say, vomiting?

122. Pt: yeah, I think

[...]

131. O: you were nauseous a little bit all the time and then it came? or it came all of a sudden?

132. Pt: No, it didn't even come, it's a little nausea like that. I had it during the day and then at night. It's what made me feel like getting out of bed, bend over the toilet bowl and then go to get some Primperan

[...]

151. O: this time you had, you had two episodes. It wasn't really vomiting, was it reflux?

[Pt does not answer the question and talks about medications she had received]

155. O: but you've had two refluxes, does it hurt when you have that reflux? [...]

156. Pt: Yeah, it upsets the stomach, what! (laughs) it turns it upside down, you know

157. O: then the Primperan helps you?

158. Pt: well yes, right away, it's effective

[...]

174. O: the chest pain, where is it?

175. Pt: I don't know, in the chest?

176. O: Is there a specific location or is it?

177. Pt: No, it's quite diffuse like that

[O seeks to better define the location and quality of the pain]

194. O: [...], it's hard to say what hurts you, is it the scars inside of the operation you had?

195. Pt: but they react to the chemo then?

[...]

198. O: so, the chemo what it can do is provoke a little bone pain! which means sternum and ribs!

[...]

206. O: in terms of the thorax, I have a hard time imagining, when I look at your scanner, that there are thoracal lesions that hurt

[...]

210. O: Well, we're going to talk about it later, but the scanner [showed] no lesions that could hurt, you know the lesions in the middle of the lung don't hurt

[...]

214. O: so, your tumor itself is not supposed to hurt

[...]

220. O: it can make you cough; it can make you spit because it's inflamed, but a tumor that hurts, yours doesn't have the geographical characteristics to hurt

221. Pt: yeah

222. O: so, I would say it's more like scars or a little bit the chemo that provokes, it wakes up scars if you want, it wakes up bone pain, that's possible. But it's not the tumor itself

[...]

227. Pt: Yeah, I also think[...] like you [...] that it's bone pain, because you talk to me about the pelvis, I sometimes feel it in the pelvis, sometimes I have a little pain in my hips or like that

[...]

230. O: the bones that produce the marrow like that are mainly the sternum and ribs, a little bit the vertebrae, not necessarily the pelvis and femur. The femur can sometimes hurt, there are people who say they have pain in the femur

[...]

233. Pt: oh yeah? No, but the pelvis does

234. O: and the pain in front of the pelvis where the radiation was?

235. Pt: No, so now it's okay, it doesn't remind me of anything. It's like I have nothing

[O explains the results of the last scanner]

280. O: but that's really that because it's normal that it hurts more, hurts more and then slowly it will re-ossify. I think that in about six months, we'll already see that it's become, it's going to disappear, we won't see the hole so much anymore if you want to [...] But it shouldn't hurt you again

[...]

296. O: so, if it hurts, don't hesitate to say, we can do a little x-ray again, we'll see if we can see anything

[O informs the patient about the follow-up with the next chemo]

363. Pt: what do you think of baking soda in relation to cancer?

364. O: So, yeah, there are a lot of theories arguing that cancer but also pain, and arthritis is provoked by the acidity of the body

[...]

370. O: it comes from a bit alternative medicines, so we [as physicians] we don't know anything

[...]

384. O: it can do good at best; it can do nothing at all as an effect at the least

[...]

397. Pt: I read a couple of articles about it, then I thought, 'Well, maybe it could help me,' I was thinking mostly about bones

[...]

428. O: ... we hear a lot of talk, but we don't have time, we can't give advice on that

[O summarizes the consultation and asks if Pt has any questions]

463. Pt: [...] I had had a good evening and all of a sudden, I thought to myself, 'but I'm feeling guilty because I'm fine!' - I said 'boo, what's going on?' I was thinking, 'but it's not normal for you to be doing so well'

464. O: I think you don't have anything to feel guilty about, you still have to tell yourself that you have chemotherapy every month, that every month for a week you're pretty much isolated at home because of the side effects, so you still really accepted all that. Because you'd have something to complain about! [...] you could say 'it's still not easy! to come for chemo all the time, to have a week where you're not well' it's also because you're optimistic and brave. it means you're a fighter in the positive sense of the word

[O continues to reassure the patient and concludes the consultation]

Table 3: **Case 3 – Symptoms as protection**

1. Oncologist [O]: Ok, so you are feeling well? Currently? Yes, no? I see your wife is nodding
2. Patient [Pt]: yes
3. O: she is shaking her head
4. Pt: I have a little back pain, but well
- [...]
15. O: is it the same symptomatology that you had in 2006, when everything started?
16. Pt: I don't know, I don't remember (laughs)
- [...]
26. Pt: Well and at the time only this foot here is cold, before both of them were cold. [...] nowadays I'm even warm everywhere, and yes, this foot here and then it goes up! Then it goes up there
- [...]
51. O: Ok, so now you still have the ants?
52. Pt: Yeah
53. O: the, the coldness?
54. Pt: that's it!
55. O: but no pain eh
56. Pt: no, [...] I have no pain
57. O: pain in your leg?
58. Pt: it's the coldness
- [...]
62. Pt: that is not good, but it is still a let's say manageable pain
- [...]
67. O: [...] do you have to renounce from certain things because of this pain?
68. Pt: [...] to walk once a day that's enough for me
69. O: ok, so you're going, are you going out less because of that?
70. Pt: that's it
- [Pt explains his pain more precisely. Then, O and Pt speak about blood pressure and treatment, and O delivers the results]
165. O: [...] it is clearly pathological, it is not an evolution, let's say it is not natural that these light chains are produced, it's undoubtedly the myeloma which is very very slowly waking up
166. Pt: ha ok!
- [while O is talking about the cancer waking up, Pt changes the subject]
174. Pt: I was also wondering about the diabetes [...]
- [...]
182. Pt: [...] because I have a sister uh, a nephew, two sisters a nephew and well nowadays even my brother, I think he has a bit, he told me, so he wanted to see if by chance uh, I have it as well, you know
183. O: the glycemia is a bit elevated like it can be after meals, but thereupon I can say absolutely nothing
- [...]
189. O: And if there really is a suspicion of diabetes, at that point we do a glucose tolerance test, which means we take a standard dose of glucose, that's 100mg and then we do the glycaemia after, after one and a half hour, so that is something you could do at your
190. Pt: at my doctor's?
- [O reverts back to the symptoms of the myeloma]
214. O: [...] you didn't have a fracture these last three months?
215. Pt: no, no, no
- [...]
220. O: nothing but this pain?
221. Pt: that's it, nothing special otherwise
222. [O speaks to the patient's wife] ok, you seem to express that this pain is more important than he says and describes
- [...]
235. Wife [W]: I don't know if it's related, but currently we're packing boxes because we're moving by the end of the month so
- [...]
245. W: I hope it's just that

246. O: yeah, ok
[O is doing a clinical exam to evaluate the pain]

335. Pt: right now, the belly is good! but my problem is going to the toilet!

336. O: which means?

337. Pt: if I go

338. O: constipation?

[...]

361. O: is it a longstanding problem?

362. Pt: 15 or 20 years

[...]

375. O: it's neither a problem of lack of fibers nor a hydration problem

376. Pt: no, no, no

[O finishes the clinical exam and goes to talk to his supervisor to decide whether imaging is needed]

415. O: ok, so I discussed it with Dr *, at the moment we won't do another imaging, what I suggest is that if you have pain, you treat it because all the same it has an obvious impact on your daily activities, right

[...]

424. O: so I will write a prescription for Dafalgan and then we will see each other in three months, exactly like we did this time, I give you an appointment for a blood sample one week before, like that we have the time to have the results in the morning

[the oncologist wants to make the patient talk about his experience of treatment and chemotherapy]

[...]

493. O: for you, this is a very bad memory?

[...]

502. Pt: and the loss of hair

503. O: yeah

504. Pt: this I really, I really had a crisis

505. O: it really really hit you?

506. Pt: I lost my mind, so one night I left the hospital, I didn't even know where I was

[...]

522. Pt: but it was my worst memory of my, frankly, of my chemo and everything, it was then when I lost my hair

523. O: yeah

524. W: it means it is then when you really understand, I mean

525. O: yes

526. Pt: I wasn't sick!

527. W: but, yeah

528. Pt: because as it is now, even if a little bit, I'm not sick. For me, I'm normal

[O and Pt discuss the follow-up and the exams that need to be done, Pt is hasty to do the exam for the diabetes]

622. Pt: [...] I need to go do at the doctors' upstairs? I want to do the blood draw for the diabetes

623. O: no that's not at all urgent

624. Pt: I can come in the morning empty-stomached, so we take it here when I come for the other blood test?

625. O: yes, but I find it, you know I find it – how to say? I find it, yeah, ok we can do that

[They cannot find a date that fits so the patient agrees to go do the blood test for the glycaemia at his family doctor's office. The consultation ends]

Table 4: **Case 4 – Iatrogenic symptom persistence**

[In the beginning of the consultation, the oncologist [O] explains the results of the scanner which are good, the tumor is in regression]

1. O: [we can continue like that] as long as you're not too handicapped in terms of sensibility
2. Patient [Pt]: no but what it is, is that the first week [after chemotherapy] I'm quite handicapped but I put on some lotion, I massage, I do a bit of drainage. And next week it's better, yes
3. O: you find it better? You don't have weakness?
4. Pt: yes, the two first days
5. O: but you have to tell me because we shouldn't invalidate you either
- [...]
110. Pt: no but because I see a naturopath, he always gives me things to alleviate all of that
111. O: yeah? Be careful not to counteract
- [...]
129. O: but you really have to tell me, right? because [...] Well we aim to cure the cancer and, in the end, we handicap you
130. Pt: but it will get better once the chemo is over
131. O: well that's hard to say
132. Pt: yeah that's hard to say
133. O: you could recover all, you could recover partly or not, that's hard to say
134. Pt: yeah but I work with my hands
135. O: yes, that's why I'm warning you, be careful, you may recover all, or part of it or not at all
136. Pt: but then what would you want to do, when you say: 'we follow the same treatment'
- [...]
142. O: well either we reduce the number of chemo we had originally planned [...]
143. Pt: ha ok
- [O and Pt about the results of the scanner and compare them to the original scanner. O performs a clinical examination]
298. Pt: [...] I think I had a little drop in blood pressure. I don't really know
- [...]
302. Pt: I didn't know at all, if that's when I had the diarrhea attack, but then I was on a diet
303. O: you have to be careful when you get diarrhea, you can get dehydrated very quickly
- [clinical examination]
309. O: the abdomen is tender
310. Pt: but it is still painful
- [...]
321. O: but no, now it's very supple, but I think it's working, if you've had three interventions, there are likely adhesions inside
- [discussion on nutrition]
353. O: no pain? no fever?
354. Pt: no, but since I've been going to that naturopath, I have to say I have less diarrhea
355. O: ok, if that helps you, for me there is no problem, just now she shouldn't give you things
356. Pt: now it helps
- [...]
401. Pt: but now I sometimes have three four days during which I don't have diarrhea, huh? since I go to the naturopath
402. O: the constipation was well resolved, resolved after enema, so before you had the extreme and now, you're, so I just hope the
- [The discussion continues on the management of stool flow]
448. O: [...] in regard of your hands, you say the first two days it's disabling
- [...]
465. Pt: all that I hope is to regain them in the end
466. O: yeah!
467. Pt: because since I work with my hands
468. O: well yes! that's it that's what I'm telling you, it is: I can't guarantee you that it is certain that you get it all back
469. Pt: you said after that, there were going to be treatments for that
470. O: yes! there are treatments that can help but ok, but you need to regain your tactile sensitivity
471. Pt: Well, yes, because I do a lot [with my hands]

472. O: I don't want to go to an extreme and to handicap you [...]
473. Pt: It's like for my sleep, where the second week I sleep better anyway, right?
[...]
509. O: but is it the chemo that does it? There, the skin is much better, the mucous membranes, heart, lung, liver not perceived, the abdomen is very calm, no lymphoma, no edema. And we're going to watch the blood test
[O and Pt discuss on chemotherapy, and O returns to the hand issue]
541. O: [...] you really have to tell me about your hands, because I don't want that
542. Pt: ha the first few days it's horrible
[...]
547. O: ok, but if in the second week you say, 'it's not like before, I don't recover', so we'll stop (the chemotherapy)
[...]
551. O: you really have to be attentive to that
552. Pt: attentive to everything, what?
553. O: [...] if we see that we risk handicapping you, that's not the point
[O and Pt plan the different dates for chemotherapy]
577. O: neuropathy is, you really have to pay attention to that
578. Pt: Yes, because a scientist when he told me 'there are people who don't recover', it made me
579. O: That's why, but I can't guarantee you anything!
580. Pt: I said 'with my job it's horrible if I don't have any sensitivity'
[...]
603. O: but it's good that you take care of yourself
604. Pt: Well, I was already taking care before
[...]
612. Pt: [...] There is also that I can't wear makeup because I feel like I've lost a lot there, and maybe I don't have any more
613. O: but you could see * (first name) you know?
614. Pt: but I don't dare to put it on, because before I used to put on makeup, now I feel that the eyes are very sensitive
615. O: but you could see with *(first name) you know our cosmetician
616. Pt: yeah, she came because I have black fingernails
617. O: that's it
618. Pt: she said she couldn't do anything
619. O: but you could ask her for advice
620. Pt: mhm
621. O: but ask her, that's why she's here
[Pt agrees to talk to the cosmetician about makeup. End of the consultation]

Table 5: **Case 5 – The total symptomatic body**

6. Oncologist [O]: how are you?
7. Patient [Pt]: ok, so listen what irritates me the most is that things were really going really well, much better, finally I was making good progress, then I go to the scanner and I can't bear lying on a table like that anymore, without something underneath, he didn't want to put it, I have this cruralgia again but that hurts!
8. O: rooooh!
9. Pt: and I think it's the worst thing you can get in your legs is this cruralgia. He has no empathy, it's always the same nurse who is not mean but who has no empathy for the person in front of him [...]
- [Pt continues to complain]
22. Pt: well that bothers me [...]
23. Husband [H]: it was necessary to retake morphine
[O directs the discussion to the prescription and then the discussion continues around the pain and the transfusion appointment where they did not use the port-a-cath]
75. O: I think you've already suffered enough, it's your right that we use this little thing [the port-a-cath]
102. O: and how is the bleeding?
103. Pt: it's the same
104. O: it's still the same thing, okay, so we'll check again today, right?
105. Pt: for the hemoglobin?
- [O delivers the results of the last CT scan that shows metastases in the lungs, but Pt says not to have symptoms of this]
144. O: so, the problem here is the bleeding because you still bled enough, that you needed transfusions, right? because the hemoglobin was still down to 70 ehm and a few if I'm not mistaken
145. Pt: ah yes, it's still
146. O: yeah, it was still pretty low! At that time when I saw you in January
147. Pt: [...] I was desperate
148. H: yeah you had no more balance
149. Pt: I lost my balance, I had nothing left, I even burned myself on the stove
[O proposes a treatment plan after having announced that the cancer is not curable (as already discussed in the past) but that they hope to be able to control it together with the radiologist]
216. H: yeah if you wouldn't have pain
217. Pt: if I wasn't in pain, it would be nirvana
[...]
- [after discussing the CT scan, the discussion returns to other health care professionals who, in the opinion of Pt, were not kind to her. Then the family expresses their fear that O will no longer follow Pt because she reduces her percentage]
467. Pt: [...] but it's a shame because I got pain again and it's true that these cruralgias are painful!
468. O: yes
469. H: yeah that, every time when she cries, I can't stand it
470. Son [S]: her swollen foot
471. H: I can't stand it
472. O: yes
473. O: but the swelling went down a bit, no?
[...]
476. O: it's less red than it was, no?
477. Pt: yes, yes, yes, yes
478. O: ok
479. Pt: look, I don't know if you have the same opinion, but my physiotherapist who still seems to know a lot about it, she tells me, you know there's the problem with the swollen arm, "it has to be drained"
480. O: yes, the lymphatic edema, yeah
481. Pt: so she tells me that maybe with what's at the bottom of the spine it can have a side effect like for the arm in breast cancer
482. O: yeah, that's right, and then the second thing is still the leg that got the thrombosis
483. Pt: yes
484. O: so, we also know that the veins
485. S: are damaged?
486. O: are weaker, do you have the impression that the morning is a little better or not at all?
487. Pt: yes, a little bit better

488. O: so probably there are the two components? So, there's probably a little lymph
489. Pt: yes
490. O: but there's probably also a little venous insufficiency, which makes it swell up and I think that lymphatic drainage does indeed do you good if it feels good
[O explains that they have to take a blood test to see if there is not a transfusion to be done again before the radiotherapy and then Pt talks about her blood pressure]
744. Pt: when I went to do my transfusion but suddenly I became anxious, then the person who made me, who placed the port-a-cath, she saw, but she put her hand on my shoulder she said to me 'what is happening to you?' and I said, 'I'm afraid I'm going to have a reaction like I had during the second chemo'
[...]
749. Pt: yet I am strong in character but sometimes there are times
[...]
751. O: but it's normal, with everything that's happening to you Mrs.* that there are moments of anxiety and
752. Pt: of incertitude
[...]
755. O: I mean, it wouldn't be human if you didn't have moments of distress, as we say
[...]
759. S: precisely, because sometimes my mom gets anxious at night. She doesn't really want to take something
760. O: yes
761. S: but isn't there anything that could?
762. O: of course
763. Pt: it's at night fall, but it's awful!
[...]
769. S: and she's got a lot of anxiety anyway
770. O: yes?
771. S: and then we can stay with her, we can talk to her
772. O: of course
773. S: [...] Isn't there something that could help her without being too strong?
774. O: we could try Temesta, it's a pill with small dosages that can help to let go a little bit? It's an anxiolytic and then maybe it can even help you a little bit to sleep, and it can actually take away some of the anxiety
[...]
789. S: I think it would be good for you, Mom
790. H: exactly, because she also cries regularly
791. Pt: I cry all the time now
792. H: yeah that hurts
793. O: but would we then try it because the other option we have, I know it's always scary the word but, we have antidepressants that have very good effects on anxiety too eh
794. Pt: I'd rather like the Temesta
[...]
803. Pt: and and there are times when I do read, but I can't even focus anymore
804. H: even the crying, now it's not
[...]
811. H: I can't stand it (phone rings) because I don't think it's normal
[The radiologist [R] joins the consultation and O quickly explains the bleeding problem]
858. O: at the scanner they were not very nice, they didn't want to put something under her knees, since Friday she has more pain again
859. Pt: but that's only because I can't stand lying like this anymore without having something underneath, it's this cruralgia, it's something very painful
860. H: yes
861. R: but otherwise, in fact, there are no other symptoms?
862. O: elsewhere? No
[O quickly explains where there are metastases and R explains the possible side effects of radiation and would like to weigh Pt; what she refuses in front of her family, so they do it when the son and husband are out. R would also like to examine the patient what she refuses. They all organize together the dates for the next meetings. End of the consultation]

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