Meeting a cancer patient in pain: stories of difficulties

Daniela Leone¹ - Stefania Anania² - Ivan Fossati²
Claudio Cassardo² - Vittorina Zagonel³ - Elena Vegni¹,²

¹ CURA Centre, University of Milan, Italy
² San Paolo University Hospital, Milan, Italy
³ Istituto Oncologico Veneto, Italy
daniela.leone@unimi.it
doi: 10.7358/neur-2012-012-leon

Abstract

Current literature only partially explored the physician’s experience of being with a cancer patient in pain. The aim of the study was to explore the internal representation of physicians specialized in oncology and pain medicine of a challenging meeting with a cancer patient in pain. Using a written open narrative format, 46 physicians specialized in oncology and pain medicine were asked to tell “the story of a challenging meeting with a patient who was in pain”. The narrations were analysed in accordance to Interpretative Phenomenological Analysis. Three main categories were identified each with sub-themes: (1) “Non-written stories”; (2) “Written stories”; (3) “Family members”. The study showed the difficulty to be patient centered, in a context in which the pain is central, forbidding a relation between human beings. The family members, a third party, could be an interesting medium to consent a possible, and difficult, human relation.

Keywords: Interpretative phenomenological analysis; Oncologists and pain medicine specialists’ representation; Pain; Qualitative research

1. Introduction

Pain represents a challenge in the oncologic and palliative care context due not only to its clinic complexity but also to the emotional and motivational concomitants of persisting pain symptoms (Perl, 2007). Specialists
in pain medicine commonly experience psychological assaults to their self-esteem and their self-protective and defensive coping mechanisms when being with patients in pain who seem unreasonably demanding (Banja, 2008; Twycross, 2002). Those theoretical understanding of the experience of being with a patient in pain are supported by very few evidence. In a previous contribution we studied the views of physicians managing patients experiencing pain in an experiential perspective (Vegni et al., 2005). The study proposed a very general view around the concept of being in relation with a patient in pain and only 25 subjects out of 151 participants were oncologists.

Because of the peculiar significance of pain in cancer and palliative cancer care, the aim of the present study was to explore the internal representation of physicians specialized in oncology and pain medicine of a difficult encounter with a patient in pain. In particular, the study aimed to answer to the following research questions: which is the internal representation of physicians who meet oncological patients in pain? Which is the origin of their difficulty? Which kind of resources are implicitly described by these physicians?

2. Methods

2.1. Sample and data collection

At the beginning of a training program on pain management, physicians specialized in oncology and pain medicine were asked to write: “[…] the story of a challenging meeting with a patient who was in pain”. The use of written material constitutes a particular tool in qualitative research. Writing a story entails unique aspects for an in-depth understanding of a given experience: the choice of what to tell and what to omit is entirely up to the narrator, as the language chosen (Graffigna et al., 2011); moreover, the narrative engages the reader and invites interpretation, offering the experience of “living through”, and not simply “knowledge about” (Greenhalgh & Hurwitz, 1999).

Narrations were anonymous; socio-demographic data were collected. Results of a preliminary analysis were discussed as a part of the training program. Physicians signed an informed consent to use their narratives in the present study. The study was approved by the Ethical Committee of the San Paolo Hospital, Milan, Italy.
2.2. Data analysis

The narratives were analyzed in accordance to Interpretative Phenomenological Analysis (IPA) (Conroy, 2003; Richards & Morse, 2007). IPA allows the analysis of the individual’s lived experiences and of the way in which sense is attributed to the experiences. While Grounded theory (Pope et al., 2000) aims at explaining a psychosocial phenomenon during time until the construction of a theory, IPA deals with psycho-emotional phenomena aiming at a deep comprehension of the possible subjective and even unconscious meaning of being in a peculiar lived experience (Smith et al., 1999). Interpretation is critical to this process of understanding: the challenge is not to bracket our interpretations of a text but rather to work with them in the quest towards understanding (Smythe et al., 2008). The analysis of texts is an iterative, inductive process that starts from a detailed reading of the texts. At the beginning a limited number of narratives are analyzed in order to provide researchers with a deeper understanding of the same (Smith et al., 2009). At this stage, the researchers took notes about the meanings that participants attributed to their experience (Smith et al., 2009). The analysis proceeds with several re-readings, and with sharing interpretations to detect and describe the themes present and the interconnections between them. The end of this process occurs when a place of sensible meaning is reached, free of inner contradictions (Smith et al., 2009). In our research, IPA was performed by two researchers (C.C., D.L.) who independently read and coded 25 narratives, randomly chosen, identifying an extensive list of the issues that were explicitly or implicitly described in the stories. In a joint meeting the issues were discussed and grouped in categories. An independent researcher (E.V.), read the narratives and provided feedback on the veracity of the categories (Morse et al., 2002). The 21 additional narratives were read in order to ensure the completeness of the categories identified. Excerpts were chosen from all the narratives to explain the categories. The final results were extensively discussed with a palliative care physician (V.Z.), to gain a clinical perspective.

3. Results

46 narratives were collected. See Table 1 for socio-demographic data are presented in three categories were identified to describe the physicians’ experiences: (1) “Non-written stories”; (2) “Written stories”; (3) “Family members”. Description of results is followed by excerpts (in round brackets the narrative’s code from which the excerpt is taken).
Table 1. Social and demographic characteristics of the sample (n = 46)

<table>
<thead>
<tr>
<th></th>
<th>Mean age (range)</th>
<th>Mean profess age (range)</th>
<th>Professional position</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Chief (52.3%)</td>
</tr>
<tr>
<td>Tot (46) *</td>
<td>53.4 (31-66)</td>
<td>26 (2-40)</td>
<td>21 (47.7%)</td>
</tr>
<tr>
<td>M (38) 84.4%</td>
<td>54.2 (42-66)</td>
<td>26.8 (10-40)</td>
<td>17 (38.6)</td>
</tr>
<tr>
<td>F (7) 15.6%</td>
<td>49.3 (31-59)</td>
<td>21.7 (2-32)</td>
<td>4 (9.15)</td>
</tr>
</tbody>
</table>

* The gender % is calculated on a total of 45 subjects (1 is unknown); for all other values (age, professional age, and position) averages and % are calculated on a total of 44 subjects (2 are unknown).

(1) Non-written stories. The “non-written stories” describe the disease as if they were clinical charts. The “human” element is removed, the stories are free of interpretation or involvement, are not commented, nor narrated.

“40 year old patient with pulmonary K, bone metastasis, opioid resistant pain. Appearance of painful brain metastasis → opioid medication → radiation therapy vomiting caused by opioid medication → hallucinatory syndromes. Limit situation: alteration of pain threshold, tolerance to pain-killers, hypersensitivity” (27).

Sometimes suspension dots, question marks and non-technical words are used, thus suggesting the willingness of telling without saying and leaving the reader the difficult task to understand the meaning and uncover the unsaid: “22 year old female, affected by osteosarcoma of the left humerus with lung metastasis, mother of 2 children, five months pregnant, for this latter reason, adequate pain therapy is denied. VAS pain: 9 (untreated pain with memory +++). What to do? Radicular block” (26).

(2) Written stories. The “written stories” help the reader to understand why some stories were not written. The types of difficulties that emerge are related to: the physician, the pain and the relationship.

Stories of physicians. The main character is the physician in the role of “Hero-Divinity” who can save life (from death) or even save death (from pain).

“The husband asked me to visit the wife at home […] for days she had been suffering uncontrollable pain […]. I was suddenly face to face with a pale-eyed woman of faded beauty […]. I told her I would take care of her and her pain, if only she would trust in me. I caressed her face and promised I would visit her again soon. The day after, the husband told me the wife had rested well all through the night. It had not happened for months” (13).
“At the end pain has been broken through […] sedation (at least he died in peace!”) (16).

Stories of pain. Pain is the protagonist while the patient is the great absentee.

“As if in slow motion and with eyes like a wounded animal, I was suddenly face to face with a pale-eyed woman of faded beauty […]” (13).

Besides de-humanizing the patient, the pain seems to consume the doctor’s omnipotence, exposing to the limits of his/her own or of medicine.

“The patient does not complain, does not protest, does not threaten to sue or anything […] the patient does not even ‘glare’ at you. The patient just bears with the pain […]. This kind of patient is disarming, the kind of patient that forces you to face your personal limits […]” (22).

“I had to care for my hospital’s chaplain, affected by an inoperable tumor of the pancreas […] he began presenting acute pain symptoms that did not respond to medication: ‘Doctor, why do you suffer for my pain? I do not like to see you so sad just because you cannot alleviate my suffering. I have He who gives me the strength to endure’ […]’ (37).

Stories of difficult or impossible relationships. In those stories where an omnipotent Hero and a de-humanizing Pain are described, the relation is sometimes very difficult or impossible to build: it seems there is no way to have a relationship based on a mutual understanding.

“[…] the patient senses that the doctor possesses the technical skills to remove her pain […] but: ‘Doctor, I don’t want you to get rid of all my pain, but only a part of it, to be able to live better’. […] I would have needed the capacity to understand the meaning of that pain” (32).

“A 50 year old male, father of 2 children […]. Increasingly I realized that the patient’s pain goes beyond the merely biological aspect. It is an existential pain that decidedly requires a human, and most of all, spiritual approach which, perhaps, we had been lacking” (85).

Family members. Even if not mentioned in all the stories, the issue of Family members constitutes the third knot of meaning in the narratives. The family member may have two roles: he/she is a sort of amplifier of the patients; or he/she is the “other”, a third party in the relation, and a witness.

Family members as amplifier of the patient. Family members are often identified with the patient and must be cared for and protected due to the anticipatory grief for the loss of the loved one: in the doctor’s view, a personal loss and a defeat.

“Yesterday I was at the death-bed of a 23 year-old patient affected by terminal cancer […]. Suddenly, with her mother present, the patient asked me: ‘Doctor, how much longer will I have to suffer?’ […] the relative broke down
into tears uncontrollably and at the time, I too was deeply moved. I drew a long sigh, moved closer and took her hands in mine and despite my efforts one single, but interminable tear rolled down my face. I was not able to leave her before one hour, one hour of interminable silence had passed» (35).

Family members as witnesses. Family members act as the spokesperson for the relationship, thereby preserving it. They are a third party who may consent the physician to experience pain in a safe manner: not the devastating and totalizing pain of the patient, but a more human and thinkable pain.

“I thought about her pain, a mother’s pain, and the psychological and physical pain of her child […]. I remember that I prescribed oral morphine. Few days later I received a telephone call from a family member informing me of the child’s death […]. They thanked me because I had helped, with my simple prescription, to give the child one last, innocent smile” (14).

4. Discussion

Relating to seriously ill exposes physicians to complex feelings (Meier et al., 2001). The physician’s clinical work with patients in pain is especially distressing both because it is often not possible to fully alleviate the pain and because the relationship is very complex (Vegni et al., 2005). No studies have been conducted to understand how physicians experience the relationship with a cancer patient in pain. Our results seem to add some new understanding of this experience.

“Non-written stories” seem to confirm the difficulty to experience a feeling of empathy with cancer patients in pain. While the need of considering the patient’s subjective experience and patient-centered cancer care have become a priority, especially in the field of oncology (Pelzang, 2010; Haidet et al., 2009), studies described the pattern of communication with cancer patients in pain as typically disease and physician-oriented (Berry et al., 2003). Non-written stories help us to understand the physician’s subjective experience of being disease-centered (i.e., avoid emotional involvement), while the “Written stories” suggest a possible reason for the prevalence of a physician-centered approach: the pain is a wall that moves away the patient, becoming a non-human subject to care or even to cure. A process of clinician’s detachment who tend to “avoid otherness” (Favre et al., 2007) may result as a functional mode of coping within a relation with a not human subject such as pain.

Also the semantic knot of “Family members” appears very interesting. The presence of the family member reinforces the theme of a subject-patient
annulled or at very least diminished by pain: where the other is cancelled by suffering and the family member is no more than the amplification of this pain, a paternalistic (Emanuel & Emanuel, 1992) approach seems almost necessary. On the other hand, physicians also point to another role for the family as a third party who permits the physician to “remain different” that is to avoid dissolving into identification with the patient. To talk with the family shouldn’t be seen as a way to avoid talking with the patient: a clinician who speaks, confronts and shares with family members is perhaps capable of losing the role of the Hero and acknowledging his/her limits, accepting the relationship with the family member as the only possible.

The study has a series of limits, in addition to those that are naturally inherent to the qualitative methodology. The experiences refer to a complex semantic field where being with cancer patients in pain is twisted to being with dying patients. One previous study (Aase et al., 2008) conducted on physicians who had to cope with the issue of death sheds light on the key concept of vulnerability as an essential element of the medical profession: further studies may analyze the importance of the variable “patient who dies” in the case of “cancer patient with pain”.

ACKNOWLEDGMENTS

We are grateful to all the doctors who participated in the study. We thank Grünenthal, the sponsor who provided the financial support for the training program on pain management in which data had been collected.

REFERENCES


