

The Impact of Patients' Disease-Labels on Disease Experience For Patients Living Longer with Incurable Cancer: A Qualitative Study

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1. Abstract

1.1. Importance: Advances in oncology have resulted in prolonged disease trajectories, also for patients with incurable cancer. This has induced discussions about the 'right' medical terminology. The impact of choosing a specific disease-label on well-being can be high.

1.2. Objective: To examine the impact of disease labels on disease experience in patients living longer with incurable cancer.

1.3. Design: Qualitative study based on short conversations in the outpatient clinic in a Dutch comprehensive cancer hospital (2015-2018) supplemented with in-depth interviews from hospitals (2021).

1.4. Setting: Hospital and home setting (via Zoom)

1.5. Participants: We included 29 short conversations and 4 in-depth interviews with patients with incurable breast and lung cancer, all in stable (but incurable) condition.
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1.6. Main outcome measures: We specifically focused on disease labelling and patient's mood (positive/negative mindset) during the disease course.

1.7. Results: A substantial group of patients (n=21) used (or explicitly not used) disease-labels in their short conversations about their disease. They varied in their preference regarding disease-labels (e.g. 'chronic', 'palliative', 'human' etc.). Patients with a more positive stance seemed more comfortable with the label 'chronic', whereas patients with a less positive stance seemed to perceive disease-labels such as 'chronic' as a lifelong burden. Some patients preferred not to label their disease at all. Healthcare professionals' use of disease-labels could sometimes distress patients, especially when patients heard different disease-labels from different healthcare professionals. Patients not using any disease-label in their communication (n=12), seemed to be less engaged with their disease.

1.8. Conclusions: Patients labeling their disease is part of their coping strategy. More research is warranted to explore which disease-labels suit different patients confronted with incurable cancer, best.

2. Background

Giving a diagnosis and choosing appropriate medical terminology is pivotal in the ways medicine exerts its role in society. Today, advances in medicine have resulted in protracted disease trajectories, also in patients with incurable cancer [1]. While these prolonged trajectories were already observed in, for instance, incurable breast cancer with favorable characteristics, they are more recently reported in (subtypes of) ‘incurable’ lung cancer as well [2]. Previous studies in different settings have shown that the impact of disease-labels on patients’ disease experience, can be high [3]. This may elicit new medical terminology, such as ‘chronic’, perhaps in part anticipating further improvements like immunotherapy.

Interestingly, many studies investigated the impact of communication on prognosis [4] and treatment aims but medical terminology was never the starting-point. Few classification tools however have an impact as profound as the classification of a medical diagnosis. It first and foremost organizes an epistemological structure by ascribing labels to entities we consider ‘disease’— it thereby assigns

individuals to the population of ‘patients’. Following from these disease-labels, often specific treatment options are sought for.

Recently, these prolonged disease trajectories have induced discussions about the ‘right’ medical terminology to be used, and the impact of medical terminologies on patients’ well-being, including terminology about palliative care. In this disease trajectory, the term ‘incurable’ might have undergone a shift of meaning. Some patients diagnosed with ‘incurable’ cancer may live for more than five years and prognostication tools therefore need to be used with caution [5]. Anecdotal information shows that patients with incurable cancer often do not perceive themselves as ‘palliative’, a connotation they frequently interrelate with their approaching death.

At the same time, patients with prolonged incurable cancer may express hope about the possibility of being cured, or about possible life prolongation [6]. This suggests that medical terminology use is as important as communicating about treatment options or prognosis [4, 7]. Labelling cancer as ‘chronic’ instead of ‘palliative’ or ‘incurable’ may have profound impact on patients’ perception of their disease and consequently influence their well-being.

In this study, we aimed to explore the impact of patients’ disease-labels on disease experience for patients living longer with incurable cancer (Table 1).

Table 1:

Box. Definitional framework	
DEFINITIONS IN THE CONTEXT OF CHRONICITY IN ONCOLOGY	
Usually, cancer patients with unfavourable diagnosis (metastasised disease (stage IV)) can be described as described below, depending on the severity of the disease.	
A Chronic cancer patient	<p>According to the Royal Dutch Institute of Public Health (In Dutch: RIVM), a chronic disease is a disease with irreversible prospects and with a relatively long disease course. Furthermore, a chronic disease is different from other diseases in that these patients are care-dependent for a very long time. Cancer is categorized as a chronic disease also.</p> <p>In medical oncology, it is heavenly debated as to whether cancer should be viewed as a chronic disease or not while healthcare professionals do not want to provide unrealistic prognoses.</p>
A patient living longer with incurable cancer	<p>We define ‘incurable’ cancer as a disease phase where patients receive anti-cancer treatment such as immune-therapy, hormonal treatment, or chemotherapy for metastasised cancer and cannot be cured and in which this disease phase can be considered stable / in remission.</p> <p>Due to this long time-period, the patient’s physical condition may sometimes go up-and-down, due to treatment side-effects.⁵</p>
A patient receiving Palliative care	Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO).

3. Methods

3.1. Design and Setting

This ethnographic study consists of two parts. The first part was performed in a comprehensive cancer hospital in the Netherlands (2015-2017). The second part consisted of in-depth interviews that had been performed by Zoom (2020) and in which the patients originated from various hospitals in the Netherlands.

We purposefully chose this design to ensure that the results will eventually be practice driven and closely connect with medical practice [8]. A specific strength of ethnography lies in its ability to communicate details plotted in experiences of illness and care. Since we discovered that patients' disease label impacted how they experienced their disease, we later on included questions regarding disease label during these conversations. The fact that we - in the beginning - did not use a specific definition, may therefore result in (medical) terminology on different levels. In part 2 of this ethnographic study, we immediately included questions about disease labeling. All necessary items to ensure adequate qualitative research were checked with the COREQ-checklist.

In this study we decided to not use a specific definition for coping: When patients explicitly stated how they coped/dealt with their disease, this was interpreted as their coping strategy. For every patient, we reported the coping strategy as explained to us during the conversation. With respect to incurable cancer, we used the following definitions during analysis after having performed the interviews to put them into context (Table 2).

3.2. Recruitment and Sampling

For this specific study 1) short conversations, 2) in-depth interviews and 3) an analysis of the patients' mood (using a self-developed checklist to establish this mood) were included.

3.2.1. Short conversations (part 1): All conversations took place at the outpatient clinic of a specialized cancer hospital in the Netherlands. Such conversations were considered least disturbing for the patient (as they were already there), and they would be less likely to be affected by any specific event, such as receiving good/bad news after having had a consultation with their treating physician. During the time periods July-October 2015 and July-September 2016, 29 patients were approached at the day-care unit by HMB, a female researcher, with plenty interview experience. They

were approached as HMB was at the hospital and had time to talk to them: patient-selection was therefore purposive. In 2017, three patients were approached for a second time.

Before approaching a patient, HMB checked with the nurses at the day-care unit whether it would be appropriate to do so. If nurses considered patients to be upset or not capable of having a conversation for some other reason, HMB did not approach these patients, which was the case in three situations. After a short introduction patients were invited to participate in the conversation (they also received an information sheet). We included two patient groups: breast cancer patients, being familiar with patients living longer with incurable cancer for quite some years; and lung cancer patients for whom these prolonged disease trajectories recently came up. Only lung cancer patients who had been diagnosed with stage IV disease at least six months ago, and breast cancer patients who had been diagnosed with stage IV disease at least one year ago had been selected.

During these short conversations (10-15 minutes) (Table 2). Conversations ended due to specific circumstances (such as the end of chemotherapy provision); because patients simply wanted to stop talking; or because they had nothing more to say. None of the patients rejected to participate. In eight cases, a close relative (often the partner) of the patient was present as well.

Short conversations were openly framed. We purposefully chose to not use a large topic list and straightforwardly asked patients how they felt living longer with incurable cancer. Often, the conversation started shortly with their disease history and unmet needs. When the study progressed, we specifically asked about patients' quality of life and disease-labelling as follows: 'How would you label your disease?'. Accordingly, we collected data in which patients indirectly spoke about disease labeling, and in which they directly spoke about disease labeling. We purposefully did not develop a theoretical framework beforehand, which enabled us to openly explore how patients spoke about the disease without any pre-defined definition and thoughts beforehand.

During the conversations, observations (11 days, ~5 hour/day) were described in observational fieldnotes. HMB focused on the following topics during these observations: the atmosphere, emotions, mood (patient/personal reflections), language use, interaction between patients and healthcare professionals.

Table 2: Conversation characteristics

	<i>n</i> Interviews	Mean time (minutes)
Short conversations ¹	33	13
In-depth interviews	4	55

1. Short conversations were held at the day-care unit, while patients received anti-cancer treatment. Those short conversations were combined with observations at the day-care unit during the same time period interviews were held with healthcare professionals.

3.2.2. In-depth interviews (part 2): Patients who indicated to be willing to be approached (and signed informed consent) were interviewed. We included these patients in another hospital where we decided to perform some follow-up interviews among patients with (prolonged) incurable cancer, including disease labeling. Those interviews were held by ZOOM (due to COVID-restrictions) and in every interview they were asked how they would label their disease. These interviews lasted ~ 55 minutes. During these interviews we specifically asked patients how they would label their disease. Since interviews were held at home, more time was available to discuss things further. In total 4 patients were included.

We received oral (short conversations) or written (in-depth interviews) consent. There were no patients not willing to have a short conversation. The same held for patients who participated in in-depth interviews. We did not return transcripts to participants. Conversations/interviews were audio-taped and transcribed verbatim.

4.3. Data Analysis

4.3.1. Conversations and in-depth interviews (Qualitative analysis of patients): All conversations and interviews were coded and analyzed using Atlas-ti 8.0/.2, using a thematic content approach [9]. VB initially developed a schematic coding list, including short conversations. In this coding list we focused on: communication, disease experience and disease labeling. We (VB and HMB) initially read apart through eight conversations and checked whether this resulted in similar themes and categories. Next, we read apart through three and three conversations at different time intervals. By analyzing the themes, new ideas emerged which were checked against conversations that were already analyzed. This led us to add questions about disease-labelling more explicitly. We discussed preliminary results for interpreter consensus, and checked this again against the data.

We so characterized themes, and subsequently categories within the themes. For instance, for the category that included patients' positive feelings, categories such as 'having faith', 'being optimistic', and 'staying powerful' were examples of in-between categories. Our analysis was ongoing, implying that new themes emerging from the first conversations could be used into subsequent conversations until data saturation was reached. HMB subsequently used a similar coding list to analyse the 4 in-depth interviews in which disease labelling was explicitly discussed (part 2 of the study).

The data were discussed in multidisciplinary meetings with people having expertise in health sciences, sociology, ethics, palliative medicine and oncology. In those meetings or e-mail sessions we worked towards consensus about the interpretation of key-themes. All authors (HMB, VH, VB, AR, ES, DT, GSS) evaluated whether the final quotes were used in the right (medical) context.

4.3.2. Assessing the patient's mood: For every quote (and related transcript), we tried to establish whether patients' disease-labels were indirectly mentioned by the patients themselves, or directly answered by a question about disease-labeling. Moreover, we distilled the patient's mood out of the text fragments by observing specific words in the text and by evaluating the conversations' atmosphere (VB, HMB). Distinguishing between different types of mood was done with a checklist and discussed later on (VB, HMB). We sent a lay version to the participants who were still alive; the participants could contact the researcher to comment on/ask for clarification.

4.3.3. Ethical considerations: According to Dutch legislation, the study is not considered invasive because of the limited impact on the patient. The ethical committee provided us with a declaration of no objection (In Dutch: Verklaring van geen bezwaar, with the number P15CHR). A professional translator translated the quotes that we chose to illustrate our results. Interview quotes are described in the text.

4.3.4. Patient and Public Involvement: While starting up the data gathering, patients of this specific study were for the first time involved in this study. However, our ideas were to a certain extent developed by conversations during previous studies/consultations with patients, and accordingly informed by their priorities also. They however had no role in the design and conduct of the study, choice of outcome measures and recruitment to the study. Patients will be consulted in how we can best disseminate the results.

5. Results

5.1. Patient Characteristics

In total five men (17%) and 24 women (83%) participated in short conversations (Table 3). Ten patients were diagnosed with lung cancer (34%) and 19 with breast cancer (66%). On the basis of what patients explained to us during the interviews, 15 patients (54%) seemed to express a neutral stance, e.g., they were not overly optimistic but did not use any negative words, also during the consultations, seven (25%) patients seemed to express a positive stance, and six (21%) patients seemed to express a negative/pessimistic stance during the consultations.

During the interviews, we sometimes explicitly asked about the disease-label that patients would ascribe to themselves (Table 3 – direct). In other conversations, we distilled patient's use of disease-labels in an indirect way. In total 11 patients (38%) did not speak about disease-labeling during the conversation (e.g. 'neutral'). They did not mention any label themselves or explicitly mentioned to avoid disease labels. Six patients (21%) preferred the label 'chronic'; three patients (10%) indirectly preferred the label 'chronic'. In five patients (17%), the label 'palliative' was indirectly used by the patient. In a few cases other labels, such as 'stable', 'human' and 'patient' had been used.

Table 3: Patient characteristics

Patient	Tumor type	M/F ¹	Mood ²	Presence of partner ³	Label given by patient	Direct or indirect ⁴
Patient 1	Lung cancer	M	2	Y	Neutral ¹	Indirect
Patient 2	Lung cancer	F	3	Y	Chronic ²	Direct
Patient 3	Breast cancer	F	2	Y	Chronic	Direct
Patient 4	Lung cancer	F	2	N	Chronic	Direct
Patient 5	Lung cancer	M	1	Y	Neutral	Indirect
Patient 6	Breast cancer	F	3	Y	Chronic ²	Direct
Patient 7	Breast cancer	F	1	N	No label ³	Indirect
Patient 8	Lung cancer	M	2	Y	Neutral	Indirect
Patient 9	Breast cancer	F	2	N	Neutral	Indirect
Patient 10	Breast cancer	F	1	N	Chronic ^{2*}	Indirect
Patient 11	Breast cancer	F	NA	NA	Neutral	Indirect
Patient 12	Breast cancer	F	1	Y	Stabile ⁴	Indirect
Patient 13	Breast cancer	F	2	N	Human ⁵	Indirect
Patient 14	Lung cancer	F	3	Y	Palliative ⁶	Indirect
Patient 15	Breast cancer	F	3	Y	Patient ⁷	Indirect
Patient 16	Breast cancer	F	2	Y	No label ³	Indirect
Patient 17	Lung cancer	F	2	N	Stabile ⁴	Indirect
Patient 18	Lung cancer	M	1	Y	Palliative ⁶	Indirect
Patient 19	Breast cancer	F	3	N	Chronic ^{2*}	Indirect
Patient 20	Breast cancer	F	2	Y	Neutral ¹	Indirect
Patient 21	Lung cancer	M	2	Y	Neutral ¹	Indirect
Patient 22	Breast cancer	F	2	N	Palliative ⁶	Indirect
Patient 23	Breast cancer	F	2	N	Neutral ¹	Indirect
Patient 24	Breast cancer	F	2	N	Neutral ¹	Indirect
Patient 25	Breast cancer	F	2	N	Neutral ¹	Indirect
Patient 26	Breast cancer	F	3	Y	Chronic ^{2*}	Indirect
Patient 27	Breast cancer	F	3	Y	Palliative ⁶	Indirect
Patient 28	Lung cancer	F	1	Y	Palliative ⁶	Indirect
Patient 29	Breast cancer	F	2	N	Neutral ¹	Indirect

- Gender (male (M)/ female (F))
- Stance. We distinguished three different stances on the basis of the full conversation with every patient: 1: Negative, the patient often used negative words during the conversations.
2: Neutral/acceptance, the patient is not overly optimistic but accepts the disease and speaks about the disease in neutral terms.
3: Positive, the patient is talking about the disease in optimistic terms.
NA: This conversation was too short to be able to determine the patient's stance during the interview.
- In some interviews, close relatives explicitly participated in the interview; in other interviews the presence of relatives was indirectly assessed in how patients spoke about their close relatives.
NA: Presence of partner unknown.
- Label given by patient; direct/indirect refers to an explicit question about disease-labeling or not.
1: Neutral, no question but indirectly derived from the text.
2: Chronic, explicit question was posed; 2*, no question but indirectly derived from the text.
3: None, patient explicitly states to not use any disease-label.
4: Stable; no question but indirectly derived from text.
5: 'Human'; no question but indirectly derived from text.
6: 'Palliative'; no question but indirectly derived from text.
7: 'Patient'; no question but indirectly derived from text.

5.2. Qualitative Findings from the Conversations and In-depth Interviews

A majority of the patients ascribed different disease-labels to their (medical) condition, either on purpose or not. We identified three domains related to disease-labeling that seemed to surround the patient in multiple layers: a) Disease-labeling as a coping strategy, b) The hospital context, c) Disease-labeling by the social support structure.

5.2.1. Disease-labeling as a coping strategy: Many patients reported to use disease-labels. Patients with a more positive mood (see Table 3 for operationalization of the patient's mood) in general tended to label their disease more often as 'chronic', or at least hoped the disease would become 'chronic' in future. The disease-label 'chronic' was thus often associated with something positive.

Other patients, often with a less positive mood, felt more uneasy regarding the label 'chronic', having a feeling to be linked with the disease forever. For some, the label 'chronic' was interpreted as worse than 'palliative', implying a future perspective that was fully defined by their disease.

Chronic is almost even worse because you're going around with it for longer. Sure, you're still alive... but that's really... [...] So I've no idea. No, I don't find those terms useful at all, and I don't have a preference for one or the other either.

Patient 7; Type of cancer: Breast Cancer

Methodology: Short conversation - Disease label, None.

In contrast, speaking about death and taking the necessary preparations, appeared more present in patients that labeled themselves as 'palliative'. This could be answered explicitly or implicitly. Some patients did not want to ascribe any disease-label at all to themselves, as this would make their condition final and unchangeable. These patients appeared to gain energy from spirituality and living consciously. They reported that by not giving themselves any label, they felt more autonomous and able to maintain their identity.

Yes, that's why; I'm also very positive about that [Having a chronic form of cancer]. And the people around me too, from surprised to pleased to 'Hey, you're doing really well, that's great!' And because, um, because you do hear different stories, you see different things around you, and then I am a bit, well a bit of an exception. And I do really like... like that.

Patient 15; Type of cancer: Breast cancer

Methodology: Short conversation - Disease label, Patient.

Patients who (indirectly) used the disease-label 'chronic' sometimes reported they felt they had to be grateful because they could continue living, which contrasted with patients being labelled as 'palliative' and who wanted to continue living, but knew they had little time left. Being labelled as a 'chronic' patient then could be accompanied with pressure.

Yes... and if we can manage to make it chronic, yes, please of course. The alternative is that you die, so that's a yes. And I already said to my husband, "Let's say I now have to come here every two weeks: if coming here every two weeks lets me make eighty then that's what I'm going to do."

Patient 2; Type of cancer: Lung cancer

Methodology: Short conversation - Disease label, Chronic.

5.2.2. The hospital context: Apart from disease-labels that patients ascribed to themselves, patients were given disease-labels by health care professionals as well. These labels sometimes differed across healthcare professionals. Some patients reported to be labeled from a 'palliative' patient towards a 'chronic' patient. One patient reported that regional and academic /specialized cancer hospitals differed in their communication about their disease. Even in the same hospital, different disease-labels could be used by different healthcare professionals. This duality about the disease-label, and thereby, the impact on patients' perceptions about their disease could cause uncertainty among patients. Moreover, such differences across healthcare professionals sometimes raised questions about healthcare professionals' expertise.

Well, what I personally... what I think would be a good idea is if they, the doctors and the nurses, all the different disciplines had a meeting together and perhaps also talked to the patient together. Because now I had a totally different talk with the surgeon than with the oncologist for example, and a different talk again with the anaesthetist, although it was all in the same week and about the same subject.

Patient 7; Type of Cancer: Breast cancer

Methodology: Short conversation - Disease label, None.

Notwithstanding the disease-labels used by healthcare professionals, most patients seemed to decide to stick to their own (positive) disease-label, especially patients with an assertive attitude. Patients acknowledged that rejecting terminology as was used by healthcare professionals, was some form of denial. Such rejection was mostly observed when healthcare professionals used the label 'incurable' or 'palliative'. In contrast, chronic often appeared to result in relaxation, a smile seemed to appear while speaking about chronicity.

You do spend a very long time with this feeling that one day we'll win this battle, whether that's justified or not. The doctor says it's incurable but of course you don't want to just accept that.

Patient 3; Type of cancer: Breast cancer

Methodology: Short conversation - Disease label, Chronic.

Patient's disease-labels to a certain extent seemed to determine how they approached healthcare professionals, e.g. the hospital context. When patients labeled themselves as 'palliative', they reported to desire a safe haven when their condition would get worse. This safe haven was mostly the general practitioner. It gave a feeling of assurance, to speak with their general practitioner in an early stage of their disease about the possibility of euthanasia. This is particularly relevant for the Dutch context where euthanasia is legalized and terminology such as 'incurable' may trigger a discussion about euthanasia.

Yes, it's basically really nice to have that contact. Because... so when, um, when I knew it had spread... so I do want euthanasia and so on to be something I can discuss if necessary, at any rate with the GP... I do want a GP who's particularly open to that.

Patient 22; Type of cancer: Breast cancer

Methodology: Short conversation- Disease label, Palliative.

5.2.3. Disease-labeling by the social support structure: The interpretation of the disease-label given by friends and relatives (e.g., the social support structure), significantly influenced patient's emotional well-being. The disease-label as given by the social support structure (according to the patients) influenced how they cared for the patient and communicated about the disease; On the other hand, the disease-label patients ascribed to themselves influenced how this social support structure responded to them. Patients who labeled themselves more explicitly as a 'patient' indirectly seemed to ask for more support.

In some situations, patients decided not to tell their surroundings that they were experiencing symptoms, or were having cancer. They strove for normal energy-levels, so that they could for instance join dinner parties. Most patients wanted to be treated as 'normal'.

You know. I am a working woman with metastasis. Well, for many people, that's something, they preferably ignore this.

Patient 1; Type of cancer: Breast cancer

Methodology: In-depth interview - Disease label, Neutral.

Some external symptoms, such as hair loss, more easily resulted in being regarded as a 'patient' by close surroundings. When a patient did not show any visible symptoms, it appeared to be more difficult (and less logical) to offer support as a close relative, which was in fact often the case in patients with prolonged incurable cancer. If, however, friends and relatives became closer towards the patient, empathy became easier and their disease-label seemed most corre-

sponding with patient's own disease-label.

You're... of course you have a disease, you're ill. An awful lot of people who know you really well know about your situation. But a lot of other people around you who don't know you so well, then, then ... Initially I didn't tell people I was sick, not at all.

Patient 15; Type of cancer: Breast cancer

Methodology: Short conversation - Disease-label, Patient.

Patients reported that they understood that it must be very difficult for their close surroundings to speak about their disease. Speaking about someone's disease process required caution and empathy, in particular when patients labeled themselves as 'palliative'. These patients were more often in need of support, warmth and a feeling of being understood. Some patients reported that during their disease process some relationships had changed. They reported to have learned with whom they liked to talk about their disease. For example one patient, who labelled herself as palliative, reported the following:

Well, some people are very disappointing and others surprisingly nice and you actually get a lot from it. Which you might not have expected at all and you get far more from that. So it works both ways.

Patient 22; Type of cancer: Breast cancer

Methodology: Short conversation - Disease-label, Palliative.

6. Discussion

A majority of the patients ascribed disease-labels to themselves, either on purpose or not. Patients' (purposeful) intention to (not) use any disease-label could be part of their coping strategy. For some, however, disease-labels did not make any sense. The impact on disease experience seemed low as patients often stuck to their own (positive) disease-label, despite what they sometimes heard from healthcare professionals and others in their close environment. A disease-label such as 'palliative' nevertheless could trigger patients to visit a general practitioner, and, for instance, start discussions about care with respect to later stages of their life. In situations where disease-labels were used by healthcare professionals, it seemed that this sometimes could distress patients [10].

6.1. Labels are Important

Our results show that patients' disease-labels could be used as a coping strategy as well as a way to trigger consultations with other healthcare professionals (such as the GP, when patients are labeled 'palliative'). This labeling however probably substantially differs across patients which may blur a transition towards chronic cancer (if desired). Moreover, doctors may interfere in the labeling process of patients by for instance preferring to not label patients as 'chronic' since this could conceal their limited life-expectancy. Although we specifically focused on patients with prolonged incurable cancer (see Table), where life-expectancy in itself is more

difficult to estimate, some doctors may prefer to not use the wording 'chronic' from an ethical point of view.

A recent literature review [11] showed that when a more medical (e.g. biomedical) term is used to diagnose, people tend to have stronger preferences for invasive treatment options while they consider themselves to be more severely ill, e.g. they label themselves 'palliative' [12]. So, although we looked at patients' disease labeling, it seems that physicians' and patients' disease labeling, probably often go hand in hand.

Although we focused on patients' disease labeling, and it seems that such labeling is to a great extent correlated to patients' coping strategy, it is accordingly worthwhile to reflect on disease labeling among healthcare professionals as well. We also evaluated how patients regard certain disease labels and found that specific disease labels such as 'chronic' were evaluated as rather positive. Moreover, our study shows that apart from 'incurable' and 'chronic' there are many other disease-labels as described by patients that impact patients' disease experience. Some patients for instance spoke about their disease in neutral terms, which suggests that those patients do not give much emphasis on words at all, and primarily focus on the physical consequences. Our finding that some patients did not want to relate their disease with medical terms such as 'palliative' or 'incurable' is an interesting finding also. It suggests that they sometimes do want to label it, but in their own words, possibly to make it a little more personal and lighter (e.g., 'human' or 'light').

Our finding that patients tend to guide friends and relatives in choosing the 'right' label to guarantee optimal support, suggests that most patients will be able to accept subtle nuances in terminology use.

6.2. Ethical Implications

The observation that patients' use of disease labels is connected to their coping strategy can have great ethical implications. Apart from patients' personality that defines certain disease labels, it also suggests that labels used by healthcare professionals or social support structure might influence the patient's coping strategy, and thereby, their wellbeing. Both positive and negative consequences should be taken into account: Some could 'accidentally' use the 'wrong' label, or deliberately use labels that have a more positive disease experience for patients than the disease label that is currently used.

In more concrete terms: Doctors may choose to use disease labels that aim to preserve patients' happiness as much as possible, but what if these may at the same time jeopardize their patients' active participation in their care? And to what extent do doctors limit the informative value of their terminology for patients to make adequate (treatment) decisions for the sake of patients' well-being? And if so, would such instances reintroduce the more paternalistic spectrum in doctor-patient relationships?

6.2.1. Promotion of well-being: Relief of suffering is a traditional goal of medicine. The means of medical classification, including the use of disease labels by doctors, may likewise contribute to this goal. Aside from the main question which labels promote patients' well-being and happiness more than others, it is important to ascertain under which circumstances such labels may do so, and affect quality of life especially in incurable patients. Subsequently, how are these labels adopted, by patients, patients' relatives, society at large, and how is their content transferred from one context to another?

6.2.2. Prevention of harm: Disease labels may be conceptualised as part of the doctor's instruments. As such, like other medical instruments, they may benefit patients as outlined above, but they also entail risks and possible side-effects. Indeed, when applied inappropriately, disease labels may potentially harm patients in that their well-being is hampered, or perhaps lead them to make ill-informed decisions. It could be hypothesised, for instance, that the use of 'over-optimistic' disease labels contributes to incurable patients' determination to undergo yet another line of chemotherapy even when treatment actually may contribute to severe side-effects. At the same time, another line of treatment could also contribute to well-being and to their prolongation of life.

So, many aspects need to be taken into account while reflecting about the impact of using specific disease labels. It thus always remains unsure whether a patient's coping strategy influences their preference for certain labels, or whether certain labels influence a patient's coping strategy. Nevertheless, it is in the patient's best interest to avoid confusion, which stresses the importance to follow at least the following aspects: First, as a healthcare professional, it appears important to be consistent in the use of labels: Labels, communicated to the patient should not differ between or within health care professionals. Second, to be able to communicate with the patient in the most understandable way, it appears important to adjust to their terminology or to ask what is their label of preference. In such a way, unnecessary additional struggles in the patient's disease trajectory can be avoided. However, if it is the intention of the healthcare professional to deliberately intervene in the patient's coping strategy, different labels could be communicated with the patient as well.

Influencing disease labels used by either the patient and especially the healthcare professional requires a long-term approach. Simply mentioning a different label once or twice (towards the patient, in health care settings) will probably not suffice. To be of real benefit to the patient, labels should be discussed amongst health care professionals and patients in high frequency and via different media. In such a way, the preferred labels can be communicated to patients in a consistent and thoughtful way.

6.3. Strengths and Limitations

With our findings we aim to anticipate on appropriate medical terminology use in the context of continuous developments in cancer

treatment as well as in patients' disease experience. In doing so, we would like to raise awareness about the impact of medical terminology on patients' well-being, and explore whether and how this can be accomplished (in either positive or negative ways). By including breast and lung cancer patients, we included patient-groups where experiences with prolonged incurable cancer are going on for quite some time, and patient-groups where living with prolonged incurable cancer is a relatively new experience. Our study has limitations too.

First, our patients were rather assertive, which might have influenced the way in how they talked about their disease. This goes hand in hand with the setting of the short conversations: We spoke with patients in relatively short time-frames, and we therefore did not exchange a lot of information about the patient's disease history although we spoke about the incurable nature of their disease. By checking with the nurses beforehand as to whether our conversations were appropriate for these patients, we prevented burdensome conversations. Second, we assessed disease-labeling in a direct and indirect way. Although this approach was done on purpose, and we evaluated the use of disease-labels together (VB, HMB), possible bias cannot be excluded. This also holds for the classification of the patient's mood. Although VB and HMB hardly ever disagreed about the outcome, a more valid procedure, such as an interrater reliability score, would have been worthwhile. Finally, this study only reflects the patient's perspective, we did not explore any perspectives of healthcare professionals.

6.4. Future Research and Discussion

Our study provides interesting entry-points for further research and/or discussion.

First, apart from influencing patients' well-being/treatment decision-making, labelling a condition may also affect society. A diagnosis can be interpreted as a cultural expression of what society is prepared to accept as normal and what it feels should be treated [13]. By labelling a disease with 'heavy' terminology (like 'palliative'), this could be interpreted as a communication strategy to lessen the effect of possible overtreatment. In the context of euthanasia, disease-labelling has been shown to impact medical decision-making as well as societal control [14]. A similar pattern might occur among doctors in the context of anti-cancer treatment. By labelling the disease as 'chronic', physicians might more easily substantiate their decision to continue anti-cancer treatment [15].

Second, our results show that similar disease-labels are differently interpreted by patients. Accordingly, to be able to guarantee optimal well-being, it is warranted to explore which underlying personality and patient characteristics define the best possible outcome for patients. This requires large-scale research, possibly in an international setting also, to explore the impact of cultural differences as well as personality characteristics.

In conclusion, disease-labelling in the prolonged phase of incurable cancer, impacts the disease experience of a substantial amount, of patients included in our study. Using (or explicitly not using) disease-labels can be considered part of the patient's coping-strategy. The 'right' label seems dependent on either patient characteristics, the situation as defined in this specific disease phase, as well as the patient's mental condition.

References

1. Bishop AJ, Ensor J, Moulder SL, Shaitelman SF, Edson MA, Whitman GJ, et al. Prognosis for patients with metastatic breast cancer who achieve a no-evidence-of-disease status after systemic or local therapy. *Cancer*. 2015; 121(24): 4324-32.
2. Zago G, Muller M, van den Heuvel M, Baas P. New targeted treatments for non-small-cell lung cancer - role of nivolumab. *Biologics*. 2016; 10: 103-17.
3. Copp T, McCaffery K, Azizi L, Doust J, Mol BWJ, Jansen J. Influence of the disease label 'polycystic ovary syndrome' on intention to have an ultrasound and psychosocial outcomes: a randomised online study in young women. *Hum Reprod*. 2017; 32(4): 876-884.
4. Mack JW, Joffe S. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics*. 2014; 133 Suppl 1: S24-30.
5. Boyd K, Moine S, Murray SA, Bowman D, Brun N. Should palliative care be rebranded? *Bmj*. 2019; 364: 1881.
6. Weeks JC, Catalano PJ, Cronin A, Finkelman MD, Mack JW, Keating NL, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012; 367(17): 1616-25.
7. Clayton JM, Butow PN, Tattersall MH. When and how to initiate discussion about prognosis and end-of-life issues with terminally ill patients. *J Pain Symptom Manage*. 2005; 30(2): 132-44.
8. Murray SA, Kendall M, Mitchell G, Moine S, Amblàs-Novellas J, Boyd K. Palliative care from diagnosis to death. *Bmj*. 2017; 356: j878.
9. Green J. *Qualitative Methods for Health Research*. Sage. 2004.
10. Fenton JJ, Duberstein PR, Kravitz RL, Xing G, Tancredi DJ, Fiscella K, et al. Impact of Prognostic Discussions on the Patient-Physician Relationship: Prospective Cohort Study. *J Clin Oncol*. 2018; 36(3): 225-230.
11. Nickel B, Barratt A, Copp T, Moynihan R, McCaffery K. Words do matter: a systematic review on how different terminology for the same condition influences management preferences. *BMJ Open*. 2017; 7(7): e014129.
12. Cassell EJ, Leon AC, Kaufman SG. Preliminary evidence of impaired thinking in sick patients. *Ann Intern Med*. 2001; 134(12): 1120-3.
13. Jutel A. Sociology of diagnosis: a preliminary review. *Sociol Health Illn*. 2009; 31(2): 278-99.
14. Buiting HM, van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Rietjens JAC, Borsboom G, et al. Physicians' labelling of end-of-life practices: a hypothetical case study. *J Med Ethics*. 2010; 36(1): 24-9.

15. Dixon PR, Tomlinson G, Pasternak JD, Mete O, Bell CM, Sawka AM, et al. The Role of Disease Label in Patient Perceptions and Treatment Decisions in the Setting of Low-Risk Malignant Neoplasms. *JAMA Oncol.* 2019; 5(6): 817-823.