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1 Introduction

Communication is a natural and elemental skill, yet it is also extremely complex. What we say matters, how we communicate, where, who is involved and under which circumstances. Often it is not what we say, but what we don't say that transports the message. In some situations we might send implicit requests. Therefore, misunderstandings, talking at cross purposes or similar undesirable outcomes happen frequently (Schulz von Thun, 1981). There are situations when these matter more than others. Communicating a terminal cancer prognosis to a patient is one of these.

By the time the cancer has progressed to a point where it is no longer curable, most patients will have undergone several rounds of check-ups, examinations, testing and treatments. In all likelihood, they will have been desperate and then started hoping again and met several different doctors with varying opinions about what would constitute their best care. The end of curative treatment is not, however, the end of medicine. *Palliative medicine* is aimed at relieving symptoms and raising quality of life without the aim of curing the underlying disease. It is one of the tasks of physicians to guide patients through this transition.

In Austria part of this would be an *Aufklärungsgespräch* literally meaning an enlightening conversation. Any conversation between a physician and their patient in which crucial information is exchanged might be labeled an Aufklärungsgespräch. The word is generally used in its singular form, suggesting that this transition ought to be made clear to the patient in just one conversation. Severe time constraints often make this situation even more challenging. Further the inner workings of both involved parties should be considered.

Physicians are morally and ethically duty-bound to be up-to-date on cutting-edge research, to know current treatment options, their prognoses, risks and side effect. Before talking to their patient they need to decide what is relevant in the current situation and prioritize information. Without overstraining the patient and their caregiver physicians are meant to convey this information wholly, truthfully and in lay terms. The physician might have formed a relationship with the patient or not, but in any case this conversation ought to be gentle, truthful and open.

Patients will have to fully open themselves up to the information provided by the physician so that they might then participate in making rational and responsible decisions about their care. In order to do so, they might have to suppress thoughts of hope and

despair and fade out the suffering endured so far. If a relative or caregiver is present, they too will be under a lot of strain not to react too emotionally, maybe ask questions and mainly support the patient.

The international scientific community refers to these conversations as *end-of-life discussions*. The term can also be employed to describe when important decisions about end-of-life care are being made. Many studies about end-of-life discussions are concerned with questions such as whether physicians actually shared a terminal prognosis with the patient and how they did it, what might be the best way to do so and how much information patients desire. Very few studies and none so far in Austria have asked patients to reflect on past end-of-life discussions and recorded their recollections. This Master Thesis seeks to do just that through a descriptive, explorative, qualitative and cross-sectional study design.

In the next chapter, a literature review will give an overview of the current status of information and best practice scenarios for end-of-life discussions. This will lead to the project's aims and objectives in chapter 3, followed by a detailed outline of the methodology in chapter 4. Results will be presented in chapter 5, before the Master Thesis closes on the discussion (chapter 6).

2 Theoretical Background

Cancer is the second leading cause of death in Austria, claiming over 20.000 people in the year 2017 alone (www.statistik.at). Despite the fact that cancer is a complex and varied disease able to afflict every organ in the human body and that its treatments and cure rates are vastly different depending on a number of factors, it is perceived by the general public as one disease. Media constantly report on new treatment options or human interest pieces about cancer survivors. As people grow older, they all at least know of someone who has or had cancer or died from it. Naturally, this exposure to the discourse of cancer triggers an individual emotional reaction when a person is given a cancer diagnosis.

A cancer diagnosis not only sets in motion an emotional and psychological response, but a medical one as well. Patients will have to take in a lot of medical information, usually within a short period of time, in order to give informed consent for treatment. Oftentimes the sheer volume of information is overwhelming and exceeds a patient's capabilities. They potentially will have to endure side effect of their treatment and may even have to face

their own death. In everyday life some of us keep the knowledge of our own mortality at bay through the adherence to cultural philosophies that provide a sense of worth and sustainability as the *terror management theory* suggests (Greenberg, Pyszczynski, & Solomon, 1986). Having been diagnosed with cancer, some patients must face the challenge of coping with a terminal prognosis.

A pivotal role in patients' understanding, decision making and later adjustment to their situation is the way in which the news of a terminal prognosis is received (Fallowfield & Jenkins, 2004).

2.1 Definition of key terms

Before the delivery of bad news in medicine and coping mechanisms can be discussed sensibly in section 2.2, some terms must be defined.

2.1.1 Curing cancer. The World Health Organization defines: „Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (www.who.int). The National Cancer Institute of the US Government (www.cancer.gov) lists a definition of cancer as:

> A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer (Definition of cancer).

Bringing this definition together with the definition of health by the WHO, it can be noted that in regard to cancer a patient would be cured if every malignant cell was removed from their body.

However, the National Cancer Institute of the US Government (www.cancer.gov) dedicates an entire page to „Understanding Cancer Prognosis", in which they differentiate between cure and remission:

> Cure means that there are no traces of your cancer after treatment and the cancer will never come back. Remission means that the signs and symptoms of your cancer are reduced. Remission can be partial or complete. In a complete remission, all signs and symptoms of cancer have disappeared (Understanding the difference between cure and remission).

Of particular interest is the next paragraph which states:

> If you remain in complete remission for 5 years or more, some doctors may say that you are cured. Still, some cancer cells can remain in your body for many years after treatment. These cells may cause the cancer to come back one day. For cancers that return, most do so within the first 5 years after treatment. But, there is a chance that cancer will come back later. For this reason, doctors cannot say for sure that you are cured. The most they can say is that there are no signs of cancer at this time (Understanding the difference between cure and remission).

Curative treatment is all medical intervention designed to remove all cancer cells from the body. This is considered successful even if the achievement of this goal cannot be proven, but the patient has entered remission and survived a number of years without developing new symptoms of cancer.

2.1.2 Palliative Care. The history of palliative care is closely intertwined with that of the *hospice* movement. Caring for the sick and dying has been a practice that can be dated back to the 4th century (Saunders, 2001). Hospices were places outside of the hospital where dying people would be cared for, such as the institutions founded by Jeanne Garnier (www.federationjeannegarnier.org). The St. Joseph's Hospice in London is where Dame Cicely Saunders' career as a nurse began and where she met the patient David Tasma. Through conversations with him, she realized that patients' needs were not met and decided to study medicine so as to ensure that she might be heard (Saunders, 2001). She developed the concept of *Total Pain* (Saunders, 2001) and founded the St. Christopher's Hospice where she died in 2005 (http://www.stchristophers.org.uk).

The concept of Total Pain is similar to the *bio-psycho-social model* (Engel, 1979) in that it seeks to encompass all aspects of life. It touches on physical, psychological, social and spiritual issues and thus offers a holistic approach to a patients' suffering (Saunders, 2001). The movement initiated by Dame Cicely Saunders has evolved rapidly and spread across the globe.

Today, in most western countries, a difference is being made between hospices and palliative care units. Yet, the lines along which this difference is drawn may vary from one country to another according to the specific legislation. In Austria, in 2004, a conceptual paper for a modularly tiered hospice and palliative care system was developed by the Österreichisches Bundesinstitut für Gesundheit on behalf of the Federal Ministry of Labor, Social Affairs, Health and Consumer Protection (2004). It was updated and republished in

2014 (Federal Ministry of Labor, Social Affairs, Health and Consumer Protection). This document lists in detail the specific tasks and qualitative conditions the legislator requires of palliative care units and hospices in Austria. Most notable is the difference that palliative care units are to be integrated in (or work in close co-operation with) acute hospitals while hospices may be part of a home for the elderly or an entirely separate entity.

Another important difference is that in hospices doctors are not required to be present around the clock, whereas they are in palliative care units. This is due to the fact that palliative care units are tasked with the treatment of acute symptoms so that patients may be discharged. Hospices on the other hand are the new homes of patients and are charged with raising quality of life until the moment of death and in the case of relatives even beyond that point.

Through these differences between hospices and palliative care units, it becomes clear that palliative care is not an exclusive line of treatment nor should it be. As Greer et al. (2012) pointed out, palliative care ought to begin as early as possible and support the patient throughout the progression of their disease. Advances in oncology have given physicians the power to delay or even halt the growth of cancer cells to the point where one can speak of a chronification of cancer, meaning that patients may not be curable (see 2.1.1) but may have a long life with cancer. This means that what used to be a clear line between a curable cancer and a person in need of hospice care is no longer an either/or distinction regarding the progression of this disease. Treating cancer has become more of a continuum of probabilities that is difficult to relay to patients. Despite possibly making it harder for patients to understand and accept their prognosis this development of turning cancer – potentially – into a chronic disease and starting palliative care earlier in the progression of this disease has been proven to be beneficial to the patient (Greer at al., 2012; Temel et al., 2010).

2.1.3 Shared decision making (SDM). The communication between a physician and their patient is characterized by a trade-off between trust and an imbalance of power and knowledge. It is the physician who is able to interpret the medical reports and has the task of translating them for the patient. Patients in turn will have to trust that the physician is competent and provide them with the care they desire. As such, doctor-patient communication is the center of a vast field of research (Butow, Maclean, Dunn, Tattersall, & Boyer, 2014; Elwyn et al., 2012; Uchitomi & Yamawaki, 1997). Historically doctor-patient

communication used to rely on the therapeutic privilege which allowed physicians to withhold information to spare the patient pain and suffering. This practice has been deemed unethical in recent years and has been replaced by the *shared decision making* paradigm in a landmark ethical decision (Bostick, Sade, McMahon, & Benjamin, 2006). Shared decision making places itself between the traditional paternalistic model of having to accept physicians' decisions without necessarily having received all information and the informed consent model wherein a patient is given all the information and then asked to take the decision on their own.

The concept of shared decision making consists of involving the patient in their personal therapeutic process as much as they desire. Patients' autonomy and dignity are respected by sharing with them all medical information available regarding their test results, treatment options, possible side effect and the right to deny treatment. Physicians and patients are meant to become partners in a shared process. Ultimately, however, it is the patient who decides what will happen next (Kane, Halpern, Squiers, Treiman & McCormack, 2014). This practice was already in use before the ethical decision mentioned above and has been studied extensively (Charles, Gafni & Whelan, 1997; Elwyn et al., 2012). Benefits of shared decision making include higher patient satisfaction, better therapeutic outcomes (Kane et al., 2014) and increased quality of life (Kashaf & McGill, 2015). Despite these findings, shared decision making remains a discretionary guideline in Austria and not the rule. Patients of the AKH (Allgemeines Krankenhaus der Stadt Wien) are to sign informed consent forms called Perimed- or Weissauer Bogen (Fruhmann, 2016; Landauer, & Weissauer, 1994) before treatment. This is different from SDM as patients are informed, but will ultimately have to either accept or refuse treatment, but shared decision making is gaining momentum in the clinical practice.

2.1.4 Coping with a terminal diagnosis. Coping is the mechanism with which people deal with adverse situations or events ranging from unmet expectations to grief. It has been a focus of psychological research for decades and is still being investigated today in a variety of settings (Dardas, & Ahmad, 2013; Saadatpanah, Zare, Malekzadeh, Sadeghi, & Khorashadizadeh, 2017).

When it comes to coping with a terminal prognosis, the Kübler-Ross model (Kübler-Ross, 1969) describing five stages of grief (denial, anger, bargaining, depression and acceptance) is possibly the most widely known. Contrary to popular belief, Kübler-Ross did

not intend for these stages to be understood as a linear progression but rather to be considered as possible coping strategies available to patients (Kübler-Ross, 1969).

Other coping models include the Grief to Personal Growth Model (Hogan, & Schmidt, 2002) or ATTEND (Attunement (A), Trust (T), Touch (T), Egalitarianism (E), Nuance (N), and Death (D)) (Cacciatore and Flint, 2012).

While these models help to categorize an individual's response to loss (such as a terminal prognosis), they do not serve to illustrate what physicians may experience in their interactions with terminally ill patients. To account for this the scope must be adjusted to include everyday coping mechanisms such as middle knowledge (Weisman, 1972). The prevailing aspect of this coping mechanism is the juxtaposition of expressing knowledge of the impending death and total rejection of said impending death through the verbalization of plans in the distant future. Responding to such paradoxical statements can be rather challenging for those unfamiliar with this mechanism.

Middle knowledge requires a patient to have taken in a terminal prognosis to a certain point. If a terminal prognosis is rejected outright by the patient, however, defense mechanisms may be employed. Patients may either refuse to engage with the subject of their prognosis altogether, or actively, deny it (Cramer, 2000). They may cling to hope and seek out additional medical information until they get a favorable reply. This may be hard to witness for relatives or health care professionals. Nevertheless, it is important to keep in mind that defense mechanisms are vital tools which enable a person to keep functioning after the tremendous threat a terminal prognosis constitutes. Hence, they should not be counter acted but rather respected. Once the immediate shock has subsided, a person may replace them with more functional coping strategies such as positive reframing and acceptance (Carver, 2007).

It should be noted that the aforementioned mechanisms do not comprise an exhaustive list as other methods include spirituality (McClain, Rosenfield, & Breitbart, 2003), humor, venting, distraction and many more (Carver, 2007; Kvillemo & Bränström, 2014).

2.2 Receiving a terminal prognosis

This section will shed light on what end-of-life communication consists of, what challenges the physicians and patients face and whether there are any guidelines for a best practice scenario.

2.2.1 End-of-life communication. The acronym EOLC used commonly in the literature may refer to either end-of-life (EOL) Communication (such as Brighton et al., 2017) or end-of-life (EOL) Care (such as Nan et al., 2018) depending on the field of research, although the latter is much more common. Neither term has been defined authoritatively yet the body of research associated with these key terms generally refers to caring for patients with terminal illnesses and talking with them about it. Communication often centers on delivering the news that patients are now facing the end of life (Epstein, Prigerson, O'Reilly, & Maciejewski, 2016; Kumar, & Temel, 2013; Mack et al., 2012). Thus, the term EOL communication is often associated with breaking bad news.

Shared decision making would seem to include communicating the information of a terminal prognosis. The subsequent decision to end curative treatment is often difficult for patients to voice, be it for personal reasons, because of the reaction of their oncologists or because of that of their relatives. As it is a decision nonetheless, it ought to be part of the process of shared decision making.

However, research on delivering bad news has shown that physicians are less reluctant to discuss varied options of care and treatments they can provide than they are to discuss palliative care (Fallowfield, & Jenkins, 2004). Mack and Smith (2012) outlined six reasons physicians gave for being reluctant about sharing the news of a poor prognosis:

1. Concern that it will make the patient depressed.
2. Concern that it will take away the patients hope.
3. Concern that the involvement of hospice or palliative care will reduce survival.
4. Concern as to the precision and certainty with which a prognosis can be given.
5. Concern that it is inappropriate to discuss a poor prognosis depending on cultural backgrounds.
6. It is emotionally uncomfortable to have these discussions.

Mack and Smith (2012) invalidated each reason given and provided scientific evidence to the contrary for most of the concerns raised. While they admitted that the concern for certainty is valid, they went on to highlight that this can be communicated as well. As for the last reason, the authors acknowledged the truthfulness of the statement, but concluded that these conversations are still necessary and suggestted that the stress they cause to the physicians may be relieved in different ways (see next section).

Fallowfield, Jenkins and Beveridge (2002) explained the benefits of sharing information about a terminal prognosis. In their landmark paper, the authors gave concrete evidence that the vast majority (over 80% of the participants) wanted "as much information as possible, good and bad" (p298). Despite this desire for information, patients rarely requested it, as they expected their doctors to provide this information when it is relevant to them (Sullivan, Menapace, & White, 2001). Since such findings are usually culturally specific, Rumpold et al. (2015) investigated the information preferences of cure rates and prognosis in Austrian advanced lung cancer patients and found that 76% of patients desired information about either cure rates alone or cure rates and prognosis. Meanwhile, a mere 7% wanted information only when they initiated the conversation, 50% expected the physician to do so and 43% were indecisive, saying it would develop naturally in the conversation. This is further evidence for the need for sensitive and empathic offering of prognosis. However, when neither patient nor physician approach the subject, this may result in a *conspiracy of silence* (Fallowfield et al., 2002, p299). That is to mean that the subject is censored or avoided by both parties, resulting in overall vague and ambiguous language. For a short time, this might even work in the patient's favor, but once the disease progresses further, this silence cannot be sustained without resulting in either a rude awakening or maladaptive coping strategies.

This silence, then, negatively impacts patients, who might continue to hope for remission. The result may be patients dying under circumstances that were not according to their wishes, being prevented from putting their affairs in order or from saying good-bye to loved-ones (Fallowfield et al., 2002). More recently, Mack et al. (2012) showed that early use of EOL communication with cancer patients (before the last 30 days of life) resulted in less aggressive care at the EOL (such as chemotherapy or admittance to an emergency room (Earle et al., 2004)) and a significant increase in receiving hospice care as well as having that hospice care initiated earlier.

Despite this evidence, physicians still practice and in some cases even defend a necessary collusion (Helft, 2005). In his opinion piece, Helft (2005) explained how a physician who wants to preserve hope for a patient may delay giving the information outright until they are invited to do so. However, in his description Helft (2005) failed to recognize that what a physician hints at may not be understood and that patients might subsequently gain the wrong impression (Groopman, 2005; Kalemkerian, 2005). Similarly

Fallowfield et al. (2002) gave an example for a physician and a patient talking at cross purposes. It would seem that ample scientific evidence is not enough to end the lie of omission. Yet, this is unsurprising as open communication regarding a terminal prognosis goes against an established pattern and it remains a very difficult conversation to have.

It should be noted at this point that while Fallowfield et al. (2002) and Rumpold et al. (2015) gave very high numbers for patients desiring information, they were not at 100%, meaning that there are some patients who do not wish to be informed. Bullock (2016) gave an overview of this debate and explained why some patients might wish to opt out of information. Thus, the concerns of physicians reported by Mack and Smith (2012) cannot be easily dismissed for those few patients who do not desire information regarding cure rates and/or prognosis.

2.2.2 Best practice scenario. Considering the information outlined so far, that is the desire of most, though not all patients, to be informed at least to a certain degree, without necessarily communicating the extent of this degree upfront and the concerns raised by physicians as described by Mack and Smith (2012), it becomes evident how any EOL discussion might constitute a tremendous challenge to physicians. The need for effective and sensitive communication raised by the scientific community was met by the health care industry through the implementation of training programs, such as a virtual reality training (Ochs, & Blache, 2016) or simulation exercises (Williams-Reade, Lobo, Whittemore, Parra, & Baerg, 2018), which are often based on step-by-step models or protocols. Some of these are based on culture-specific demands (Abazari et al., 2017), others seek a more general approach (Keefe-Cooperman, Savitsky, Koshel, Bhat, & Cooperman, 2017).

One such protocol is the SPIKES protocol (Baile et al., 2005) which identifies six steps for the clinician to successfully deliver bad news:

S = Setting up the interview: Privacy, presence of family members at the patients request and, if possible, without time constraints or interruptions are important, but also to sit down and connect with the patient.

P = Assessing the patient's perception: This is primarily done to check if the patient has understood their path so far.

I = Obtaining the patient's invitation: A physician is discouraged from sharing information without a signal from the patient that they are ready to receive it. This is likely to be the

most difficult part, as the patient needs to know that there is more information yet they should not be able guess what this information is.

K = Giving knowledge and assessment to the patient: Here the description focuses on warning the patient first and on how to word the information.

E = Addressing the patient's emotions with empathic responses: While patients should not be burdened with excessive emotions, empathy should be displayed.

S = Strategy and summary: Physicians are invited to offer a summary of what was said and a strategy for what comes now.

This SPIKES protocol has been well received and well studied all over the world (Craxì, & Di Marco, 2018; Marschollek, Bakowska, Bakowski, Marschollek, & Tarkwoski, 2018). Several studies since have looked at the training of health care professionals and what can be done to improve their communication skills (Schmitz et al., 2018).

Another model is summarized by the acronym PREPARED (Clayton, Hancock, Butow, Tattersall, & Currow, 2007, pS83): P stands for "prepare the discussion", R for "relate to the person", E is "elicit patient and caregiver preferences", P means "provide information", A "acknowledge emotions and concerns", R stands for "(foster) realistic hope", E is "encourage questions" and D is finally "document". While these short phrases may not serve to highlight the differences to the SPIKES model, the in-depth description provided in the PREPARED guidelines does. The PREPARED model is less theoretical and gives more concrete and practical advice. Despite this, it is less widespread.

Following the literature cited in this section, it can be concluded that while an EOL discussion is difficult for both patient and physician, it is nonetheless necessary. While there are well-established protocols and training programs to support physicians in this difficult task, little is known about the experience of an EOL discussion by patients.

2.2.3 Cultural specifics in cancer and palliative care. Before this study's aims, objectives and relevance can be addressed, one more aspect ought to be considered. Death and dying is a different experience depending on culture and society. From the famous Día de Muertos in Mexico to the moirologists, professional mourners, who still practice in China (Martinsen, 2010), each religion and culture defines life and death in a somewhat different way from reincarnation to ascendancy into Heaven. It follows, naturally, that the approach to shared decision making, EOL communication and information about prognosis is equally subject to societal and cultural preferences. From the gentle, careful, yet truthful and direct

approach evidenced by the sensitive wording from the National Cancer Institute of the US Government (see section 2.1.1 curing cancer, focus on probabilities through hedging techniques such as the recurrent use of *may*, *some* and *can* and use of *you/your*) to the reported discomfort of relatives to share a terminal diagnosis with the patient themselves in Ethiopia (Ayers, Vydelingum, & Arber, 2017).

This cultural diversity is most often addressed by specifically focused studies who often times seek to identify challenges, resources and difficulties stemming from the inter-cultural exchange that occurs when patients, relatives and staff are of different ethnical backgrounds (LoPresti, Demen, & Gold, 2016; Schrank et al., 2016). While it is vital to shed light on these challenges so that they might be overcome, the nuanced cultural differences between western countries should not be omitted. The United States and Ethiopia, compared above, are very different concerning religious, cultural and historical aspects as well as many more. In contrast, the US has a lot more in common with the UK. On closer inspection, however, these two nations are again very different in terms of culture and society. Along those same lines, the health care systems of the UK and the US are more similar than those of Ethiopia and the US, but they are different nonetheless. For instance, Higginson (2005) outlined the differences in palliative care between the US and the UK.

Even within the European Union there is great disparity. One study by Koekkoekk at al. (2014) investigated EOL care processes, perceived quality of care and aspects of quality of care in the EOL phase in The Netherlands, Austria and the UK. The comparison revealed significant differences between the countries. Therefore, findings in a field as culturally diverse as receiving a terminal prognosis cannot be extrapolated from one country to another without careful consideration.

In Greece (Mystakidou, Parpa, Tsilika, Kalaidopoulou, & Vlahos, 2002), only 23% of caregivers favored the disclosure of both diagnosis and prognosis to the patient. Consequently, it is less surprising that Iconomou, Viha, Koutras, Vagenakis, and Kalofonos (2002) found that only 37% of patients were aware of their cancer diagnosis. This trend continues in the opinions of health care providers, since 76% of Greek nurses believe that only some cancer patients ought to be told the truth of their diagnosis and prognosis (Georgaki, Kalaidopoulou, Liarmakopoulos, & Mystakidou, 2002).

In contrast to that stands the literature from northern European countries such as Sweden (Wallberg et al., 2000) and the Netherlands (Rood et al., 2015). Wallberg et al.

(2000) addressed the question of information needs by presenting breast cancer patients with nine types of information and asking them to rank these. There was no item for the refusal of information. The second part of their study investigated patients' role in their treatment and compared this to their desired role. They found great overlap between those two parameters, meaning that patients were content with the amount of their involvement in their treatment. Rood et al. (2015), meanwhile, report that a total of "[82]% would like to have all the available information and would be involved in decision-making" (p89). These study designs and findings are much more in line with the literature cited above (see section 2.2.1).

Geographically, Austria is to the south of Sweden and The Netherlands but north of Greece. From Rumpold et al. (2015), we know that Austrian patients have a specific and detailed desire for an EOL discussion and many even request concrete numbers and statistics. However, the question whether these preferences are being met has not yet been the subject of investigation.

3. Aims and objectives

Very few studies have explored patients' experience of their EOL discussions and no such investigation has been undertaken in Austria so far. Austria is a German-speaking country and the German language offers a unique word: *Aufklärung*. Literally, *Aufklärung* translates to *enlightenment*, although the connotations are quite different when linked to the context of having a conversation with someone. The German word is commonplace and is used to describe transferring information about anything from sexual education to medical information. If a person understands or has been informed about something, they are *aufgeklärt* or *enlightened*. Additionally, German is a language where compounding is prevalent, meaning that two or more nouns can be combined to create a new word. Thus, if the word conversation is added, the word becomes *Aufklärungsgespräch* or *enlightening conversation* and this is interesting for two reasons: First, it is a word widely known and used in medical settings. It denotes the conversation a doctor might have with a patient before they sign an informed consent, for example. Yet, the existence of the word *Aufklärungsgespräch* and the fact that it may also be used for EOL discussions means that there is no unique word for EOL discussion in German. Because of the general meaning of *Aufklärungsgespräch* it does not signal at all that the subject of conversation may be a

patient's approaching death. Secondly, the German term is used primarily in its singular form, suggesting that *enlightenment* ought to happen in one conversation. This would seem to add another level of difficulty to an already daunting task.

The purpose of this study in Austria was to explore the current situation in EOL discussions as perceived by the patients. Due to the lack of research in this area in Austria it could not be assumed that patients definitively had had an EOL discussion or how this would have been set up. It was equally uncertain when such an EOL discussion might have taken place: toward the end of curative treatment or much earlier than that.

Tacking stock of the current situation in Austria through the point of view of the patients is needed to ensure current efforts to improve doctor-patient communication are effective and on point. Consequently, this study aimed to answer three questions:

1. How do Austrian patients experience their EOL discussion (*palliatives Aufklärungsgespräch*)?
2. Which factors contributed positively to the experience?
3. Which factors contributed negatively to the experience?

4. Methodology

4.1 Material and Methods

The explorative nature of this study, ethical considerations as well as the focus on individuals' perception of their EOL discussions contributed to the decision for a descriptive, explorative, qualitative, cross-sectional, mono-centric study design. Specifically, it was decided to approach patients as open-mindedly as possible so as to avoid any confirmation bias. Given the nature of the topic of investigation, participants of this study would be terminally ill with cancer, having been informed about their palliative status and in all likelihood physically weak. Therefore it was of great interest to extract as much information as possible while keeping the strain on participants to a minimum. An interview would allow for this as well as the flexibility to address unforeseen topics and patients' needs (Opdenakker, 2006). Two assessment methods were used: A case report form (see section 8.3) and an interview guideline (see section 8.4). Both will be described in detail in this section regarding the information gathered as well as the procedure to do so.

4.1.1 The Case Report Form (CRF) (see section 8.3). The Case Report Form (CRF) was designed to survey demographic data as well as clinically relevant information regarding the

progression of the disease. Patient ID, age, sex, marital status, children, living situation and the patient's profession were recorded on the first page. Clinically relevant information was noted on the second page. This included the primary diagnosis, its date, the date of the first admittance to the palliative care unit, the types of therapy so far (radiotherapy, surgery, chemotherapy and immunotherapy) as well as current medication.

The first page was filled out together with the participant immediately prior to the interview since it allowed the first opportunity to bond and relate with the patient. The second page of the CRF regarding medical information was filled out after the interview based on the patient file.

4.1.2 The interview guideline (see section 8.4). The interview guideline was designed by the research team of this study based on the literature and the clinical experience of the members of the research team with the specific purpose of answering the above stated research questions. The interview would begin by asking the patient for a recollection of their path since the diagnosis of cancer had been received. This was meant to convey that the interviewer did not know about the medical history of the patient. Additionally, the patient was able to set the pace and instruct the interviewer, thereby gaining a sense of control. After this recollection of the patient's medical history had been completed, the interviewer would ask about the patient's future expectations in order to determine the participant's present state of mind. If they were currently in a state of denial, the interview would be terminated discretely. If the participant exhibited coping strategies or a general openness toward EOL topics the interview would proceed.

Once the interview reached the specific moment of the patient's EOL discussion an open-ended question was asked to elicit a narrative by the participant. This narrative was cross-checked during the interview with a list of factors (e.g. the setting, the time allotted for the discussion or the presence of relatives) deemed relevant to the experience of the EOL discussion compiled by the research team prior to the first interview. If certain factors were not addressed during the narrative, the interviewer would ask about these specifically. This narrative was followed by two direct questions which asked about factors that contributed positively or negatively to the patient's experience. If the patient was still well enough to continue the interview, specific questions regarding support and coping mechanisms would be asked. Having gathered all relevant information, the interviewer would try to activate patient's resources depending on the contents of the interview

(e.g. Your children will be coming for a visit later today, I believe?) and offer psychological support from the on-site staff before thanking them for their time and ending the interview.

4.2 Patient in-/exclusion

Patients were recruited at the palliative care unit of the AKH in Vienna (Klinische Abteilung für Palliativmedizin der Universitätsklinik für Innere Medizin 1 der Medizinischen Universität Wien – Allgemeines Krankenhaus der Stadt Wien). To be included in the study, patients had to fulfill a number of criteria designed to identify those healthy and stable enough for the topic of the interview.

First, patients had to be hospitalized at the above mentioned unit for at least 36 hours so that the personnel could judge the physical and mental state of the patient and recommend either that the patient be included or excluded in the study. In order to be included, patients had to be at least 18 years of age and be fluent in German in order to give consent. Patients had to suffer from terminal cancer (so as to ensure comparability) that was no longer under curative treatment and have voiced this knowledge at least once to medical personnel. Patients who suffered from a psychiatric diagnosis such as dementia or had glioblastoma or brain metastasis were excluded, as unimpaired recollection abilities were vital to the interview process.

4.3 Ethical considerations

Patients who are terminally ill are a particular vulnerable cohort and as such ethical concerns guided the study design from the beginning. First and foremost, it was important to ensure patient's safety and well-being. Therefore, it was decided that the interview would be interrupted immediately should the participant show signs of exhaustion or pain. If necessary, the interview was thus ended prematurely. The qualitative approach allowed for flexibility and adaptions while retaining efficiency.

Prior to participation in this study the interviewer had received training in terminal care (Sterbebegleitungslehrgang für ehrenamtliche MitarbeiterInnen by the Österreichische Buddhistische Religionsgemeinschaft). Supervision was closely meshed and participants were offered psychological support by the on-site staff or a debriefing by the interviewer.

As stated above patients were recruited from the palliative care unit of the AKH – an in-patient setting - thus limiting the efforts necessary to participate in the study. Patients were presented with two copies of an informed consent form (see section 8.2), one to be signed and returned to the interviewer and the other copy for their personal use. Prior to

signing this document, the interviewer explained the process of audio recording, transcribing and information extraction. Only when the potential participant had signaled understanding and agreement were they asked to sign the consent form. This study was submitted to the ethical committee of the medical university of Vienna and received a positive votum in March 2018 (EK Nr.: 1121/2018) (see section 8.1).

4.4 Workflow

Once a patient had been identified as fitting all inclusion criteria and none of the exclusion criteria, they were approached by the interviewer, who introduced herself. During this first conversation she presented the aims and means of the study, gave the potential participant a copy of the informed consent and explained it, if invited to do so. One copy of the informed consent was left with the patient and if they were willing to participate in the study another copy was given to them to sign. Subsequently a time for the interview was agreed upon with the patient.

All interviews were conducted by the same interviewer, so as to ensure comparability. The data was audio-recorded and the transcripts were analyzed using the method detailed by Hopf, Rieker, Sanden-Marcus and Schmidt (1995) based on thematic analysis (Willig, 2013). This method consists of several steps.

First, prior to the first interview, codes were generated deductively from the interview guideline, the literature on the subject and the aims of the study. An example for this is the *positive elements* code. Patients were explicitly asked to give an account of factors that contributed positively to the experience of their EOL discussion. Therefore, all replies to this question as well as any other mentions of positive elements could later be assigned to the code of positive elements.

The interview recordings were transcribed using MAXQDA 2018 (VERBI Software, 2017), licensed by the University of Vienna, in the Mayring system of verbatim transcription (2002), disregarding accents or dialects. The third step of the method by Hopf et al. (1995) consists of a first set of analysis and coding of the first interview transcripts which was carried out in MAXQDA 2018 (VERBI Software, 2017). This led to a minor adaptation of the interview guideline. Once more interviews had been conducted and transcribed, all transcripts were reread and coded with the pre-defined code set from the deductive analysis. In addition, codes were generated inductively out of the participants' answers (i.e. *sources of information*). Eventually, all interviews were transcribed and analyzed deductively

and inductively. Throughout the entire process of data gathering and analysis, the research team used memos, tables and discussions to ensure objectivity and efficiency. The last step of the method (Hopf et al., 1995) includes the in-depth presentation of a particularly interesting or representative participant (see section 5.10).

4.5 Data management and Data security

Given the sensitive nature of the collected data its management and security was paramount. The interviews were recorded with an Olympus digital voice recorder WS-811 in mp3 format and anonymized during the process of transcription, so that no names, locations or other information could be traced back to the identity of the participant.

Participants were given an ID number that was used in all subsequent documents. The only document containing both the name of the participant as well as their ID number is the patient consent form, which was continuously locked away. All digital data, audio recordings, participants' log, transcriptions and codes were stored on a USB flash drive secured with VeraCrypt, an open source encryption program. Only the research team had access to the data at any given point.

5 Results

In this chapter, the results of the analysis of the interviews will be described. In line with the method detailed by Hopf et al. (1995) based on thematic analysis (Willig, 2013), the codes will be reported in individual subsections and a case study will be added for patient 811_0243 (see section 5.10.). The codes are reported in the order in which they seem relevant to aims of the study and thus not necessarily the order in which the questions were put to the participants.

5.1 Sample description

Recruitment of participants lasted from April to August 2018. The palliative care unit of the AKH in Vienna has twelve beds. During the data collection phase, a total of *n* = 64 (*n* = 38 female and *n* = 26 male) patients were hospitalized out of which *n* = 25 (*n* = 14 female and *n* = 11 male) fitted the inclusion criteria and were invited to participate. Some patients declined participation because of personal reasons (*n* = 4), *n* = 4 were physically too weak when the scheduled time for the interview came and *n* = 5 did not participate for various other reasons (i.e. One patient wanted a relative to be present during the interview to help her recollect. Despite explaining the study aims regarding the personal recollection of a conversation, the patient insisted and thus the interview was not conducted.)

The resulting *n* = 12 (*n* = 7 female and *n* = 5 male) interviews lasted between 14min 40sec and 41min 20sec (mean = 27min 48sec). Patients were between 49 and 91 years of age (mean = 68.53), 5 out of 12 were single (widowed: *n* = 3, divorced: *n* = 1, single: *n* = 1), *n* = 10 had children, only one patient reported being entirely without a support system of relatives or friends. On average, patients highest form of education was an equivalent of high school, with only *n* = 2 having graduated from a university. As specified in the in/exclusion criteria (see section 4.2) all *n* = 12 participants were terminally ill with cancer, *n* = 4 having undergone treatment, entered remission and experienced a relapse. Taking that relapse as the new point of reference, patients had been in treatment prior to the interview for an average of 25.83 months (3 to 45 months).

No patient requested in-house counseling or a follow-up meeting with the interviewer after their interview. Since their interview *n* = 7 participants have passed away. The current status of the remaining *n* = 5 participants is unknown. Other data including the medication or side effect could not be gathered for every patient and were therefore not interpreted.

5.2 Progression of the disease

Patients were asked at the beginning of each interview to describe their journey from the cancer diagnosis to their first admittance to the palliative care unit. Regarding the length of the medical history, three variations were observed:

- Less than 9 months (patients 811_0243, 811_0245, 811_0265 and 811_0266)
- Between 16 and 28 months (patients 811_0239, 811_0253, 811_0263 and 811_0264)
- A third group had been diagnosed with cancer, treated, entered remission and suffered a recurrence and thus had a medical history spanning several years (patients 811_0238, 811_0256, 811_0257 and 811_0259)

5.3 Information preferences

The first question with regard to patients' experience of their EOL discussion was whether and how much information they desired. For ethical reasons, this subject was raised only after having assessed what patients recalled from their EOL discussions so that the interview could be adapted to exhibited coping strategies or the patient's individual level of knowledge. This strategy proved successful in that a range of different preferences

concerning information was reported, from deflection and avoidance to active procurement.

5.3.1 Aversion to information. Patient 811_0256 did not wish to engage with the subjects of prognosis or information too closely and thus she reported only the outcomes of her EOL discussions. When asked directly, she would deflect and move on to another topic (patient 811_0256, §§ 37-45 and 69[1]). This behavior is further discussed in section 5.8.1.

A similar strategy was employed by patient 811_0263 who did not wish to engage with medical information or prognosis (patient 811_0263, § 20) and put her children in charge instead (patient 811_0263, §§ 64-68). This wish was apparently respected by her physicians and she reported it as a positive aspect.

Consequently both patients passively received the information given to them and did not assume an active role in its procurement. Nevertheless, patient 811_0263 felt that she was informed against her will. She stated this explicitly in § 96:

> Ich wollte nicht darüber sprechen. Aber das weiß ich von diesem Bestrahlungsarzt. Dass der Zustand nicht so gut ist. [I did not want to talk about it. But I know it from this radiation doctor. That the situation is not so good.]

Immediately after this statement, the participant moved on to talk about medication (a common way for patients to track the progress of their disease) and then to her sorrow over being dependent on nurses and her children. While she did not categorize the physician's behavior outright, she stated prior to this recollection why she avoided information:

> Ich habe hier auch mit dem Bestrahlungsarzt gesprochen. Und er hat mir gesagt, ich kann nicht sprechen, wissen Sie, weil… wenn ich das spreche, dann geht es mir noch schlechter. Er hat mir etwas gesagt, damit ich weiß, dass es mir schlecht geht. [I talked with this radiation doctor here. And he told me… I cannot talk, you know, because… If I say it, I will be worse off. He told me something, so that I know, that I am badly off. patient 811_0263, § 92].

[1] All paragraph references refer to the individual transcripts. Each turn-taking during the interview was numbered individually by the transcription program MAXQDA 2018 (VERBI Software, 2017). Sometimes, very long turns would be split into more than one paragraph.

Thus it can be inferred, that the patient was informed against her will which attacked her coping strategy (see section 5.8.1) and left her vulnerable.

What happens when patients receive information before they are ready to receive it is described by patient 811_0265. Prior to the interview, she had spent three months in the hospital being transferred between units. She said: “Nein, also erst hier konnte ich richtig… Vielleicht weil ich auch klarer denken konnte.” [“No, only here could I really… Maybe because I could think more clearly.” patient 811_0265, § 76] referring to the palliative care unit where she had been admitted two weeks prior to the interview. This suggests that she had not been able to process the information so far.

5.3.2 Passive reception of information. Patient 811_0239 reported a more positive reception of information that was not sought out actively. She described that physicians at the palliative care unit would prescribe medication and explain to her what it was meant to do. The patient contrasted this experience to that at other units: “Also man kriegt das schon hier erklärt. Das ist nicht so, dass… ‘Das müssen Sie nehmen und Basta!’” [“So you do get this explained, here. It’s not like… ‘You have to take this and that’s it!’” patient 811_0239, § 49]. Following up on this, she was asked whether she was happy with the information she received to which she replied: “Na! Also auf jeden Fall! Also… auf jeden... ich sage ja, wäre es nur überall so.” [“Well of course! So… of… like I said, if only it were like this everywhere.” patient 811_0239, § 51].

Thus, even if patients do not actively seek information from physicians by asking questions, it cannot be concluded that they would not like to receive them, as patient 811_0257 further demonstrates. When asked if she would have wanted additional information regarding the significance of bone metastases, she responded: “Ja, gerne. Eigentlich schon, ja.” [“Yes, gladly. Actually, yes. Certainly.” patient 811_0257, § 90]. However, the questions she would actively ask a physician were centered solely on medication (patient 811_0257, §§ 79-80).

5.3.3 Active procurement of information. Two patients turned to the internet rather than their physician for information. Patient 811_0243 wanted some information as evidenced by her seeking it out online and through conversations with acquaintances and other patients (patient 811_0243, §§ 32 and 40), but she chose not to ask her physicians as they never offered any EOL discussion (patient 811_0243, §§ 35-44). When she googled

what the word *palliative* meant, which she had seen on a painting at the unit, she experienced shock (patient 811_0243, §§ 52-54 and 65-68).

Of particular interest is the case of patient 811_0238 who desired information but did not ask his physician for it. Instead, he turned to the internet: “Was mich interessiert, schau ich im Internet. Lesen und schauen, da finde ich genug” [“What interests me, I look up on the internet. Reading and looking, I find enough.” patient 811_0238, § 32]. This strategy allowed the patient to obtain exactly the desired amount of information, but not more.

A more active stance toward their physician was reported by four patients, incidentally all of them male. Patient 811_0253 describes a very intense need for information:

> Na freilich! Ich wollte alles wissen. Ich wollte genau wissen, wie lange lebe ich noch oder wie lang kann es noch gehen, weil genau kann sie es mir ja nicht sagen. Aber… da legen sie sich halt nicht gerne fest, die Ärzte, nicht? [Naturally! I wanted to know everything. I wanted to know in detail, how long I have to live or how long it can go on, because she can’t tell me precisely. … they don’t like to specify, the doctors, right? patient 811_0253, § 50].

However, when the time came to ask questions, he reported being overwhelmed by the speed of events and would later regret not having asked questions despite his best intentions (§§ 22, 46 and 60).

Meanwhile patients 811_0264, 811_0245 and 811_0259 all had the same strategy wherein they would request honesty and directness from their physician upfront. This request was generally granted and consequently positively reported by participants (patient 811_0245, §§ 47, 53, 67 and patient 811_0259, §§ 50 and 67-72). When the requested information was not forthcoming, patient 811_0264 enlisted the help of a second physician. He had prepared beforehand by reading up on his disease on the internet and then used this knowledge to discuss his prognosis with his physician (patient 811_0264, §§ 16, 27-32).

It can thus be summarized that patients’ needs for information are quite diverse. While most patients seem to be able to get as much (or as little) information as they desire, they all describe that it required effort to get there, either by shielding themselves with relatives or negotiating a basis for truth. Information (or desired lack thereof) does not come effortlessly.

5.4 Source of information (*Aufklärung*/enlightenment)

As some statements from patients in the last section suggest, patients' source of information regarding their curative to palliative transition status was not limited to EOL discussions with their primary physicians. A closer look at the range of sources is therefore warranted.

5.4.1 EOL discussions with a physician. As expected most patients (*n* = 8) had an EOL discussion with a physician, at least to some degree (patients 811_0245, 811_0253, 811_0256, 811_0257, 811_0259, 811_0264, 811_0266 and patient 811_0263 by proxy through her children as well as directly). However, the reported quality of these conversations varied greatly, as will be shown by the discussion of physicians' wording that some patients were able to recall.

As reported by the patient, the worst choice of words was: "Ich kann nichts mehr für sie tun." ["I can't do anything for you anymore." patient 811_0256, §§ 41, 47 and 75]. The participant was taken aback to have heard those exact same words from two different physicians and continued to look for (better) care. Phrasing the terminal diagnosis in such a manner, gives the impression that the patient is left alone. Thus, it is possible that the wording added to the patient's reluctance to accept the message (see section 5.8.2). Yet, the wording "Bitte verzeihen Sie, wenn ich so ehrlich bin, dann reden wir von eingeschränkter Lebenszeit." ["Please excuse me for being so frank, but then we are talking about a limited life time." patient 811_0264, § 47] is a much gentler way to phrase the end of curative options and still the patient had similar difficulties accepting the message (see section 5.8.2).

Some physicians seemed to have phrased the terminal prognosis rather bluntly: "…dass ich Lungenkrebs habe und dass er nicht heilbar ist." ["…that I have lung cancer and that it is not curable." patient 811_0245, § 49]. Or: "…dass alles ausgeschöpft wurde." ["…that every option had been exhausted." patient 811_0253, § 44]. However, in this last instance, the impact of the message was reportedly softened by an apology of the physician: "…dass es ihr halt leid tut." ["…that she is sorry" patient 811_0253, § 44].

Patient 811_0257 heard her doctor say: "Der Arzt sagt dann nur, dann hö… machen wir Pause [von der Chemotherapie]." ["The doctor just says, then we st… let's take a break [from chemotherapy]" § 42].

Interestingly, patient 811_0259 gave the impression that he was ready to accept his palliative status when his doctor was not:

> Also für mich war sofort klar, dass ich sterben werde. Bis mir dann der Arzt gesagt hat: "Na, wir geben noch nicht auf. Wir probieren ja alles. Bis zum Schluss und wenn das auch nichts nutzt, dann können wir immer noch aufgeben." [So it was clear for me from the get go, that I would die. Until my doctor said: "Well we don't give up. We will try everything. Until the last moment and when that doesn't help, then we can still give up." § 84].

Generally speaking, patients conveyed that physicians opted to move on from the difficult subject as quickly as possible and tried to shift the focus onto more manageable topics such as pain and quality of life. This is in line with the good practice guidelines cited in section 2.2.2.

When appointments for EOL discussions with a physician were made, it was at the initiative of the doctor (patient 811_0259, § 38; patient 811_0253, §§ 51-56). This seems natural, given that physicians are the ones who have access to the medical knowledge that the patient can no longer be cured and that it is part of their responsibility to relay this information. However, sometimes physicians had to be asked repeatedly (patient 811_0264, § 16) or the truthfulness of the conversation had been negotiated upfront (see section 5.3). This strategy seemed efficient as both patient 811_0259 (§ 68) and patient 811_0245 (§§ 68-69) reported that they had no need to look for additional information elsewhere.

Patient 811_0253 explicitly stated that he would only accept this type of information from a physician and no one else: "[…], aber sie ist halt kein Arzt. […], aber das muss halt der Arzt sagen." ["[…], but she is not a physician. […], but the physician must say this." patient 811_0253, § 62]. Similarly, an offer for an EOL discussion by the on-site psychologist was refused by patient 811_0263 (§ 100). In fact, she chose to re-interpret his offer in a non-threatening way, namely that he had misunderstood her intentions and then went on to discredit him, by blaming his work load (patient 811_0263, § 102).

5.4.2 The internet. Several patients reported to have at some point looked up their disease or prognosis or other key words such as *palliative* on the internet (e.g. patient 811_0243, §§ 32 and 40). Patient 811_0238 decided to use the internet in lieu of discussing it with a physician (§ 32), patient 811_0264 did this prior to his (EOL) discussions with physicians to be on more solid ground in the conversations (patient 811_0264, § 28). It is

not entirely clear at which point patient 811_0259 decided to google the word *palliative*, but there was a conversation with a physician later (§patient 811_0259, § 84). He did not report distress but rather that the information on the internet was not exhaustive as the word *palliative* also includes "Leben mit Krebs" ["living with cancer" patient 811_0259, § 84].

5.4.3 Other sources. Based on the timing when the word *palliative* was first heard as well as the preconceptions surrounding it, admittance to the palliative care unit or mention thereof was a another source of information regarding a patient's individual prognosis (patients 811_0239, 811_0243, 811_0259, 811_0263 and 811_0265).

Some patients reported getting (additional) information regarding their disease and prognosis from individuals such as acquaintances, who either died from cancer (patient 811_0243, §§ 32 and 40) or lived through remission (patient 811_0264, § 26), although the type of cancer of the acquaintance was not mentioned. Another source of information were other patients who the participants met throughout their disease, for example in waiting areas (patient 811_0238, §§ 22-26 and patient 811_0263, §§ 40 and 70). One patient reported that her experience as a nurse helped her understand what was happening in addition to the EOL discussion with her physician (patient 811_0266, §§ 40 and 59-62).

Patient 811_0257 stated that her knowledge about her disease was largely based on what she picked up from TV, newspapers and conversations with her acquaintances (patient 811_0257, §§ 60 and 88). She also mentioned reading through her medical reports prior to giving them to her physician, yet not fully understanding what they were saying (patient 811_0257, § 88). Out of these, she constructed a theory of how she was doing that was rather on point, yet she did not fail to mention that she would have preferred to receive this information from her physician (patient 811_0257, §§ 89-90).

The exact source of information for patient 811_0239 remained equally vague. She stated that her treatment had become all but a delaying tactic (patient 811_0239, § 37) yet that she was not told this by a physician (patient 811_0239, §§ 38-39). She then went on to explain that no one can foresee the future and that every organism reacts differently, a phrase commonly used by physicians (patient 811_0239, § 41). She mentioned that the morphine she received for her pain was another indicator (patient 811_0239, § 45) and that, when she heard the word *palliative*, she was distraught (patient 811_0239, § 43). When prompted how she had come to know what the word *palliative* meant, patient 811_0239

replied that it was in the emergency room (ER) but did not specify how (patient 811_0239, § 59).

5.5 Palliative – what does it mean to you?

Apart from patient 811_0256, who first demonstrated understanding that she was currently admitted at the palliative care unit (patient 811_0256, §§ 60-63) and then immediately went on to deny that she had ever heard the word *palliative* (patient 811_0256, §§ 64-69), all patients were able to give some form of definition for the word *palliative*, when prompted. Due to her coping strategy (see section 5.3.1) patient 811_0265 refused to acknowledge explicitly that she was at the palliative care unit or even what the word meant, but demonstrated understanding nonetheless through the use of an emotionally charged negative label: “Katastrophenstation” [“disaster unit” patient 811_0265, § 52].

Originally most patients had negative attitudes towards palliative care units, with some patients linking them explicitly to dying (patient 811_0253, § 94 and patient 811_0239, §§ 43, 45 and 47). Especially vocal about this was patient 811_0263, who stated: “Ich habe gedacht, ich werde überall… um mich herum sterbende Menschen sehen.” [“I thought, I would see everywhere… dying people all around me.” patient 811_0263, § 74]. This preconception seemed unaltered despite the fact that she had now been admitted to a single room, as she said: “Damit wäre ich nie einverstanden. Aber was bleibt mir übrig. Bei meinem Sohn.” [“I would never agree to this, but what can I do with my son?” patient 811_0263, § 70] (Referring to her admittance to the palliative care unit, which had been authorized by her son. She had put him in charge of her medical decisions prior. patient 811_0263, §§ 65-70).

If the word *palliative* was not associated with dying, it was at least perceived to be the end of treatment: “Nicht als richtiger Palliativpatient, weil ich ja noch in Behandlung bin, und nicht, dass du sagst, austherapiert.” [“Not as a real palliative patient, because I am still in therapy and not, as you would say, beyond treatment.” patient 811_0264, § 38]. Patient 811_0257 was puzzled by the conflict of her preconception and her experience: “Nur was man so allgemein weiß. Dass palliativ keine Behandlung mehr gibt… Obwohl Schmerztherapie ja auch eine Behandlung ist, nicht?” [“Just what you know in general. That palliative is no more treatment… Although pain therapy is treatment too, no?” patient 811_0257, § 56]. This notion that *palliative* means the end of treatment was propagated by

the fact that some patients experienced the admittance to the palliative care unit as somewhat of a last resort to help, where all other units had failed (patient 811_0243, §§ 60-64; patient 811_0256, § 63 and patient 811_0265, § 44).

Some physicians seemed to be aware of the preconceptions of patients toward the word *palliative* and had decided to use euphemisms and speak of how positively other patients responded to palliative care. Patient 811_0264 reported his physician explaining to him: "[...], wir haben eine Palliativstation, so dass, die Sie aufpäppeln. Das kommt unheimlich gut an, die sind sehr nett, kompetent und und und." ["We have a palliative care unit, where you will be pampered. Patients enjoy it a lot, they are very nice, competent and so on." patient 811_0264, § 38]. Another patient reported her physician stating that there were no empty beds in the oncology unit which is why the patient would be admitted to the palliative care unit: "[…], da ist es sehr schön und da wird es mir sehr gut gehen und…" ["[…] where it is very nice and were I will be well cared for" patient 811_0257, § 54]. The physician did not, however, explain either the concept or the purpose of a palliative care unit, thus the patient had to draw her own conclusions (patient 811_0257, §§ 55-60).

Later, patients would usually become aware through varying sources that it was not the purpose of a palliative care unit (in Austria) to care for patients until their death. Such information was provided, for example, by physicians at the palliative care unit (patient 811_0253, §§ 94-98) or the internet (patient 811_0243, § 68 and patient 811_0259, § 84).

Recollection when the word was heard for the first time could not be achieved by all patients (patient 811_0253, § 89-92 and patient 811_0266, §§ 96-97). Nonetheless, some patients were able to recall this moment quite clearly (e.g. patient 811_0253, §§ 59-60). For example, patient 811_0239 had been told in the ER, late at night, moments before admission (patient 811_0239, § 59) and patient 811_0243 googled the word *palliative* moments before being led to her room (811_0243, §§ 65-68). Others could not pinpoint the exact moment as they had been aware of the concept prior even to their own disease (patient 811_0264, §§ 58-63 and patient 811_0266, §§ 63-72).

Participants were also asked to report on their experience at the current palliative care unit. Patients were grateful to have been admitted (patient 811_0253, § 84) and satisfied to the point of delight (patient 811_0238, § 30; patient 811_0239, §§ 47, 51-53 and 59; patient 811_0243, § 88; patient 811_0253, § 82 and patient 811_0265, §§ 44-46) even stating that they had no wish to leave (patient 811_0259, § 90 and patient 811_0265, § 44).

A particular striking way to phrase his praise was found by patient 811_0259: “Ja. Ja. Ja. Das passt. Der Schutzmantel funktioniert.” [“Yes, yes, yes. It’s alright. The protective cloak is working.” patient 811_0259, § 92].

5.6 Alleviating elements

The alleviating elements reported in this section refer to the EOL discussion and/or the realization of the transition from curative to solely palliative, not to coping with a cancer diagnosis.

5.6.1 Relatives. As expected most participants mentioned their relatives as a form of support (patient 811_0245, §§ 70-71; patient 811_0253, §§ 33-36 and 61-62; patient 811_0257, §§ 61-68; patient 811_0264, §§ 52-53; patient 811_0265, §§ 65-72 and 83-90 and patient 811_0266, § 26). As mentioned above, one patient decided to filter all information and decision making through her children (patient 811_0263, §§ 7 and 20). When this was respected by her physicians, it was reported positively by her (patient 811_0263, §§ 65-68). However, it should be noted that some patients decided not to involve their relatives. This behavior might be surprising, given physicians’ explicit requests to see relatives, but patients seemed to be very apt in making this decision for themselves, as they reported (patient 811_0256, §§ 78-85 or patient 811_0259, §§ 39-44).

5.6.2 Physicians’ behavior. Several patients noted positively various aspects of their physician’s behavior: humor (patient 811_0259, § 64 and patient 811_0264, § 16), continuous and helpful demeanor (patient 811_0259, § 75-78), being matter-of-fact (patient 811_0253, §§ 67-70; patient 811_0264, §§ 16 and 45 and patient 811_0266, § 60), kind (patient 811_0266, § 60), empathic (patient 811_0253, §§ 44 and 102 and patient 811_0264, § 34), competent (patient 811_0253, §§ 67-70 and 102 and patient 811_0264, §§ 16, 34 and 67) and open (patient 811_0264, § 45).

Those patients who had requested truth and honesty were glad to have received information, but even some who did not actively pursue information were later glad to have received it (patient 811_0239, §§ 48-51) even stating that “Information beruhigt” [“information soothes” patient 811_0239, § 57]. This is especially interesting in the case of patient 811_0243 (see section 5.10) who at first suffered shock upon learning what a palliative care unit is: “Wenn man es aber weiß, ist besser.” [“When you know it, it is better.” § 72]. When prompted, she reinforced it (patient 811_0243, §§ 72-74).

5.6.3 Shared decision making. The ability to take decisions regarding the therapeutic process and to engage in shared decision making was reported positively throughout (patient 811_0257 §§ 37-40 and 111-112; patient 811_0263, §§ 20 and 36 and patient 811_0264, § 36). This was particularly pronounced in patient 811_0266, who had watched her brother suffer through aggressive care at the end of his life: “Ich muss sagen, das Wort ist Sünde, aber wirklich. Er ist wie verreckt. So elend zu Grunde gegangen.” [“I have to say; the word is sinful, but really. He died a wretched death. Such a miserable end.” patient 811_0266, § 89] This, along with her experience as a nurse, led her to forego all treatment options upon her first diagnosis. This she discussed with both her physician and her son, who both went along (patient 811_0266, §§ 27-28). She continued to say: “Und das… da habe ich mir vorgenommen, nicht um jeden Preis diese Verlängerung, weil nein. Und ich bereue es auch nicht, […].” [“And that… I decided, this prolongation not at all costs, because…no. And I don’t regret it, […].” patient 811_0266, § 89].

5.7 Detrimental elements

The interview guideline aimed to elicit factors patients perceived as detrimental in reference to their EOL discussion and their transition from curative to solely palliative. Thus, like in the previous section, the reported elements below are not in reference to a cancer diagnosis in general.

5.7.1 Physicians’ behavior. Although physicians being matter-of-fact was reported several times in a positive way (see section 5.6.2), there are times when it seemed inappropriate or was negatively perceived (patient 811_0264, § 16). Furthermore, leaving things unsaid or phrasing them in an ambiguous manner was also experienced negatively (patient 811_0265, §§ 34-36). One physician threw a negative information regarding the patient’s medical report while walking past the patient in the hallway on her way out (patient 811_0257, §§ 105-110). Another physician never made eye contact during appointments (patient 811_0257, §§ 71-76). Building a personal relationship was thus impaired (patient 811_0257, § 70).

Some patients reported that physicians’ demeanor changed after the EOL discussion in a rather upsetting way: “Der hat sich so weit weg gestellt von uns, er hat uns beim Verabschieden nicht einmal die Hand gegeben […].” [“He positioned himself so far away from us, he didn’t even shake our hands when we said goodbye […].” patient 811_0264, § 51]. Patient 811_0256 was more subtle in her recollection, but stated that:

> […], aber die sagen nichts. Die sagen nur: “Es tut mir leid, ich kann nichts mehr für Sie tun.” Jeder dieselben Worte. Wirklich, das hat mich gewundert.” [“[…], they don’t say anything. They just say: “I’m sorry, I can’t do anything for you anymore.” Everybody the same words. Really, that puzzled me.” § 75]

She drew a rather bleak picture overall (§§ 75-77). For a closer look at physicians’ reported wording in EOL discussions see section 5.4.1.

5.7.2 Information procurement. Another negative aspect was when patients desired information, but had to work hard to get it. Patient 811_0264 used a common figure of speech which refers to something particularly cumbersome: “Dem habe ich alles aus der Nase ziehen müssen” [“I had to tear every piece of information from him” patient 811_0264, § 16]. Later, the same patient reported that he would have to remind his physicians during morning rounds that he was in the room with them and that when they were talking about him, he wanted to know what was being said (patient 811_0264, § 32). An elderly patient also stated that she had difficulty understanding what doctors’ were saying to her during rounds because they kept talking to each other as well as to her and that this made it difficult for her to follow (patient 811_0266, § 16).

A very interesting point was raised by patient 811_0257, who explained that she received information from her physician, but that its meaning and implications were not explained to her:

> Ich habe zwar alle drei Monate eine Computertomografie wo eben drinnen steht: “Keine Fraktur”. Also ich weiß nicht, besteht die Gefahr, dass die Knochen leichter brechen? Also da wurde ich überhaupt nicht aufgeklärt. [“I have a CT every three months which says: “No fracture”. So I don’t know, is there a danger that the bones break more easily? I have received no information. patient 811_0257, § 88]

The same pattern was repeated for other symptoms, such as water in the lungs (patient 811_0257, § 96 and 100). This left the patient nescient and was clearly a source of great distress as she kept bringing the interview back to this topic and spent a lot of time discussing it (patient 811_0257, §§ 24, 70-76, 88 and 91-120). Eventually the patient reported that she resigned herself to not getting what she wanted and, after discussing it with other patients, learned that they had had similar experiences (patient 811_0257, §§ 120-122).

Other patients stated explicitly that they expected their physicians to take the lead (patient 811_0253, § 48) or explained that it was very laborious to ask questions:

> Früher habe ich mir ja gar nicht gemerkt, was ich alles fragen soll. Da hat [mein Verlobter] gesagt, man muss schon fragen. Das war aber so anstrengend. Unglaublich. [Earlier I didn't even remember what I was supposed to ask. But [my fiancé] said, you have to ask. But that was so exhausting. Unbelievable. patient 811_0265, § 78]

Patient 811_0243 reported having received no offer for information or EOL discussions by any physician, and since she did not request it herself, no EOL discussion took place (patient 811_0243, §§ 35-46 and 83-84).

The internet might have been the source of information for several patients as stated in section 5.4.2, however this was often reported as being negative (patient 811_0243, §§ 65-70; patient 811_0259, § 84 and patient 811_0264, § 28).

5.7.3 Time. Several patients reported being overwhelmed by the speed of events and quantity of information (patient 811_0243, §§ 83-86; patient 811_0253, §§ 22 and 46-48; patient 811_0256, § 41 and patient 811_0265, § 42). Often the conversation proceeded immediately after a patient had been given a terminal prognosis (patient 811_0253, §§ 57-60) or the subject was shifted onto therapeutic options, despite the patient's desire for an EOL discussion (patient 811_0257, § 24). Especially pronounced was the perception that doctors' were overwhelmed and overworked and that this resulted in very limited time for the patients (patient 811_0239, §§ 53-57; patient 811_0243, § 76; patient 811_0253, §§ 28 and 42 and patient 811_0256, §§ 90-97), sometimes leading to patients' fearing for their care (patient 811_0239, § 55).

Furthermore, time was also mentioned as a negative factor in relation to the general hospital setting, for example when patients would come in for an appointment and wait for several hours (patient 811_0253, §§ 42 and 77-80 and patient 811_0257, § 70). Patient 811_0253 further explained that while an appointment might last only minutes, this often led to a half-day or more being taken up not just for him, but also his caregiver due to transportation needs (patient 811_0253, § 80). This puts additional stress on patients (patient 811_0239, § 71).

When patients visited physicians' in their private practice outside of the hospital, time appeared to be less of an issue (patient 811_0256, §§ 76-77 and 84-85). This might

seem like a positive element, however, this time is billed differently in Austria and usually results in higher costs for the patients, which also leads to different expectations: “[Wenn man] für eine dreiviertel Stunde 250 € zahlt, dann erwarte ich mir diese Basics.” [“[When you pay] 250€ for 45min, then I expect these basics.” patient 811_0264, § 51, referring to the physician not shaking their hand goodbye].

5.7.4 Organization and logistics in the health care system. Another detrimental element reported by patients was insufficient interconnectedness between physicians in Austria, especially between those working in hospitals and the general practitioners (patient 811_0264, § 40). For patient 811_0264, this also led to a lack of information regarding additional therapeutic options such as rehabilitation which the patient subsequently had to procure on his own (patient 811_0264, § 41).

Patient 811_0253 found himself in a situation where he had taken as much pain medication as his prescription allowed, but was still in great physical distress. The only solution that seemed available to him was going to the ER, a place notoriously unsuited for palliative patients (patient 811_0253, § 64). A similar experience was described by patient 811_0239, who faced an EOL discussion in the ER (patient 811_0239, §§ 56-62). The information was not integrated by the patient until it was repeated in the palliative care unit (patient 811_0239, § 57).

Hospital organization was negatively perceived as well, when it came to being transferred between units several times within a short time frame. Some patients were unable to recall where they had been exactly, suggesting a loss of control (patient 811_0243, §§ 60-64 and patient 811_0265, §§ 39-44).

5.8 Observed coping mechanisms

The coping mechanisms relayed in this section may refer to the disease as a whole (i.e. not solely to the EOL discussion) or the transition from curative to solely palliative treatment, as patients might not be able to differentiate clearly or use similar mechanisms for both.

5.8.1 Defense mechanisms. Some patients described in various ways that they decided consciously not to engage with the word *palliative* or the terminal diagnosis, such as patient 811_0263: “Ich wollte nicht darüber sprechen.” [“I did not want to talk about it.” patient 811_0263, § 96]. Patient 811_0256, who continuously avoided questions regarding

the term *palliative* or concrete recollection of her terminal prognosis (patient 811_0256, §§ 58, 69 and 89) explicitly stated:

> [Meine Tocher und ich] haben darüber nie viel gesprochen. Weil ich wollte nicht krank sein und sie wollte mich nicht krank sehen. [[My daughter and I] never discussed it much. Because I did not want to be sick and she did not want to see me sick. patient 811_0256, § 111]

One patient (811_0265, § 52-62) exhibited defense mechanisms to her cancer diagnosis throughout the entire interview. When asked when she had first been diagnosed, she responded with: "Von Krebs war gar keine Rede." ["We did not speak of cancer." patient 811_0265, § 18]. It was not until fairly late in the interview (patient 811_0265, § 70) that she used the word *cancer* and this was the only occurrence in the interview. The patient alluded twice more to her disease by using the words *chemo* (patient 811_0265, § 80) and *radiation therapy* (patient 811_0265, § 94). Yet, any follow-up question was met with middle knowledge (patient 811_0265, § 82) or positive thinking (patient 811_0265, § 98). Paired with the use of emotionally charged words such as "Katastrophenstation" ["catastrophe unit" patient 811_0265, § 52] referring to the palliative care unit or the expression "Ich will da gar nicht her. Mit dem setze ich mich jetzt momentan überhaupt nicht auseinander." ["I don't want to go there. I do not want to deal with that at all." patient 811_0265, § 54], this gave the impression that the patient was still in a state of shock over what had happened to her.

5.8.2 Denial and second opinion seeking. On several occasions, patients described seeking out other physicians for a second opinion. Some patients reported this openly and freely, such as patient 811_0263 (§§ 20-22), patient 811_0256 (§ 87) or patient 811_0264:

> Bin aber irgendwann, nach einigen Monaten weggegangen, weil ich eine Diagnose bekommen habe, die nicht gut war. Dann habe ich mir gedacht, jetzt hole ich mir eine Zweitmeinung ein und seither bin ich im AKH. [But eventually, after several months, I left because I had received a diagnosis, that wasn't good. So I thought, I'll get a second opinion and since then I have been at this hospital. patient 811_0263, § 16]

If this behavior persists, however, until a doctor is found who will provide the answer or the treatment desired, this might be detrimental to the coping process as it facilitates denial, as evidenced by patient 811_0263's statements: "Nicht als richtiger Palliativpatient, weil ich ja

noch in Behandlung bin und nicht, dass du sagst, austherapiert." ["Not as a real palliative patient, because I am still in therapy and not, as you would say, beyond treatment." patient 811_0263, § 38] and: "Ich muss auch sterben. Aber nicht jetzt." ["I have to die as well. But not now." patient 811_0263, § 47].

5.8.3 Middle knowledge. On some occasions, utterances that, at first glance, seemed to indicate denial revealed themselves to be part of middle knowledge after closer inspection. In the case of patient 811_0265 this was only expressed implicitly. She had been with her partner for thirty years, but only recently had she expressed a desire to marry him, because she wanted "things settled" ("Aber ich habe gesagt, ich will dann alles unter Dach und Fach haben." patient 811_0265, § 68). At the beginning of the interview, the patient responded to the question regarding her marital status by saying "not yet" and that it would change "soon" (patient 811_0265, §§ 2, 4 and 6). However, this was qualified when she said she wanted to get married before her 50th birthday, still several years away at the time of the interview.

Another, albeit much more explicit example was given by patient 811_0239 when she said:

> Na sagen Sie es ruhig heraus. Ich weiß, dass ich schlecht dran bin. Sie brauchen keine Hemmungen haben. Also ich weiß eh, was es geschlagen hat. Wie ich gehört habe, Palliativstation habe ich mir gedacht: „Na Servus. Endstation." Aber es ist ja nicht so. ["You can say it. I know, I am badly off. Don't be shy. I know what's what. When I heard, palliative care unit, I thought: "Oh boy. End of the line." But that is not how it is. patient 811_0239, § 43]

In the first half of the utterance, it seems as though the patient accepts her prognosis, but with the last few words she qualifies her proposition to an extent where it is no longer possible to discern whether she is coping or misinformed.

5.8.4 Positive thinking and reframing. In addition to the exhibited denial (see section 5.8.2), patient 811_0264 also used positive thinking:

> Das heißt, ist der Kopf gut, wird die Sache gut. Ist er nicht gut, dann wird es nicht. Wie sagt der Bob, der Baumeister? Wir schaffen das! Schaffen wir. [That means, if the mind is okay, the matter will be okay. If it is not, then it won't be. How does Bob, the builder put it? Can we make it? Yes we can." patient 811_0264, § 51).

Patient 811_0238 opted to focus on the positive side of things and listed the things he was still able to do and enjoy (§ 28). He was well aware that this was a temporary consolation as he immediately went on to say: “Das Schlimmste ist, wenn man immer nur im Bett sein kann. Und wenn das kommt… Haben wir ja noch Zeit.” [„The worst would be to be bed-ridden. And when that comes... We still have time.“ patient 811_0238, § 28]. He summarized his perspective using a football analogy:

> Ich weiß eines, die Krankheit ist schwer, das ist nicht einfach, aber kämpfen muss man. Wer nicht kämpft verliert. Das Fussballmatch ist vorbei, jetzt ist Verlängerung. Dann kommt Elfmeterschießen. Das ist alles. [I know one thing: the disease is though. That’s not easy, but you have to fight. Who doesn’t fight, looses. The football match is over, now we have overtime. And after that comes penalty. That is all. Patient 811_0238, § 34]

5.8.5 Acceptance. Several patients in this study exhibited acceptance for their reduced lifespan and imminent deaths, such as patient 811_0257: “Ich habe zwar gewusst, es ist unheilbar, aber… es ist mir gut gegangen.” [“I knew it was incurable, but… I was fine.” patient 811_0257, § 8]. The same patient said that she would not accept chemotherapy if it only served to prolong her life: “Ob jetzt die Chemo bringt, dass ich drei Monate länger lebe… Also auf das lege ich keinen Wert. Ich will nur keine Schmerzen haben.” [“Wether the chemo allows me to live three more months… I don’t care about that. I just want to be pain-free.” patient 811_0257, § 38].

Three other patients accepted their situation through the use of life review (e.g. patient 811_0245, § 25). For example, patient 811_0266 recounted her entire biography throughout the interview in a very positive manner. She described her job as having been “born for it” (patient 811_0266, § 42), her life-time project was fulfilled (patient 811_0266, § 44) and after retirement she continued to volunteer which was a source of joy to her (patient 811_0266, § 56). With regard to her cancer diagnosis (for which she refused any treatment, see §§ 29 to 40), she recounted: “Habe ich mir gedacht, egal, einmal fährst du noch mit der Straßenbahn. Einmal noch über den Ring. Abschied zu nehmen.” [“I thought to myself, no matter, take the tram one more time. Once more over the Ringstraße. Saying goodbye.” patient 811_0266, § 20].

As patients 811_0245 and 811_0266 were 79 and 91 years of age respectively, the life review approach may seem like a foregone conclusion, but it was also employed by

patient 811_0259, who was just 55 years old. To the interviewer's question what had led to his relaxed perspective on death and dying the patient responded:

> Nein, schauen Sie, wenn du eine Vergangenheit gehabt hast, wie ich, dann überrascht dich nichts mehr. 60er Jahre, Sex, Drugs und Rock'n Roll. Tatsächlich. Also, ja." ["Look, when you have a past like me, nothing surprises you anymore. Sixties, sex, drugs and rock'n roll. For real. So, yeah." patient 811_0259, § 60]

5.9 Psychological counseling

Three patients reported using psychological services offered by the hospital (811_0243, 811_0259 and 811_0263). Patient 811_0259 refused psychological counseling when first offered, but decided to take advantage once admitted to the palliative care unit (patient 811_0259, §§ 52 and 80). In the case of patient 811_0243, psychological services were called to intervene, when she could not be consoled after finding out what the word *palliative* meant (patient 811_0243, §§ 94-100). This counseling was discontinued (patient 811_0243, §§ 105-112).

Three other patients (811_0253, 811_0257 and 811_0245) were offered psychological services, but refused them. This was reportedly due to the patient's feeling that it was not needed (patient 811_0253, §§ 71-76 and patient 811_0257, § 82) or psychology being discarded as "ridiculous" (patient 811_0245, § 73).

Patient 811_0256 never received an offer for psychological counseling (patient 811_0256, §§ 112-123).

Regardless of whether patients had refused, accepted or never mentioned (as in the case of the remaining five patients) psychological counseling, a number of personal and individual grievances were brought up during the interviews. They are reported here for the sake of completeness.

As expected, due to the typical progression of cancer, patients were burdened by their physical deterioration or side effect of treatment. Patient 811_0265 stated this explicitly (patient 811_0265, §§ 94-98) while patient 811_0264 described it in a more humoristic, subtle way: "[…], was willst du den da noch großartig massieren? Wenn es nur noch Haut und Knochen sind." ["What do you want to massage if there is only skin and bones." patient 811_0264 § 40]. During a procedure when the nurse said she had hit muscles with the needle he replied: "Na klar! Ich, der Muskelprotz!" ["Sure! I'm such a beefcake!" patient 811_0264, § 41]. Another recurring theme was that of being rendered

helpless by the disease (patient 811_0239, §§ 62-65 and patient 811_0263, § 96). Knowing what might lie ahead was equally troublesome for patient 811_0266 who was scared of an ileus (patient 811_0266, § 89) as well as aggressive care at the end of life after having witnessed her brother's death (patient 811_0266, § 87). Throughout the interview patient 811_0245 regretted a decision taken about his treatment and patient 811_0256 was frustrated by the fact that no primary tumor location could be found, leaving her with a diagnosis of metastasis disease (patient 811_0256, § 34).

On a more personal level, patient 811_0263 blamed her son for her admittance to the palliative care unit against her will (patient 811_0263, § 70). An impaired son and his special needs weighed heavy on patient 811_0265 (§ 74) as well as relatives trying to motivate her to eat (patient 811_0265, § 92). The view from her hospital bed was a singular hardship on patient 811_0243 as she could see the track she had been running prior to her diagnosis (patient 811_0243, § 100). She said to herself: "Du wirst dort nie wieder hinkommen." ["You'll never get back there." patient 811_0243, § 52].

5.10 Case study of patient 811_0243

Aged 55, patient 811_0243 was married, without children, living with her partner and prior to her cancer diagnosis had been a swim teacher for middle school. A friend of hers noticed that she was no longer able to process alcohol the way she used to and told her to see a doctor, which led to her diagnosis of pancreatic cancer (patient 811_0243, § 16). This was in September 2017 (patient 811_0243, § 20), the interview took place in mid April 2018.

From her demeanor, the patient seemed to be still adjusting to the events as well as their speed (patient 811_0243, §§ 20-28). She was familiar with her type of cancer as three or four of her acquaintances had died of it. Despite this, she went online and looked up "what it all meant" (patient 811_0243, § 32). Afterwards she discontinued this behavior in favor of a "step-by-step" (patient 811_0243, § 32) approach wherein she would react to what was currently happening.

According to the patient, her physicians never offered information (patient 811_0243, §§ 35-38) and she never inquired with them (patient 811_0243, §§ 41-42). She did, however, get in contact with the people of her congregation and the relatives of the acquaintances who had passed away (patient 811_0243, § 40).

When she was transferred to the palliative care unit for the first time in early April 2018, the decorations put up to lighten the mood and create an atmosphere of warmth had the reverse effect on her as they reminded her of the decorations at her father's nursing home. Patient 811_0243 reported this as a difficult experience (patient 811_0243, § 50), although it remained unclear whether the difficult experience was her father's stay at the nursing home or being transferred to a unit with similar decorations.

During the admission process, she had to wait in the communal area of the palliative care unit in which a painting, created by a former patient, features the word *palliative*. She then googled the term and realized for the first time where she was (patient 811_0243, §§ 65-68). A few minutes later, she was brought to her room and there, from the window, she could see the track she had been running up until last summer and realized she would never get back there (patient 811_0243, § 52). This sent her into a state of shock. She cried uncontrollably and could not be consoled for what felt to her to be a very long time (patient 811_0243, §§ 52, 84 and 94-100).

Eventually, she processed the information of her terminal prognosis and then held the belief that "it was better to know" (patient 811_0243, § 72). By the time she was admitted to the palliative care unit a second time (in mid April 2018, when the interview was conducted) she was more relaxed (patient 811_0243, § 88) but this was due to changes in her person (patient 811_0243, § 90). She had not received continuous counseling (patient 811_0243, §§ 105-108) but relied on her social network (patient 811_0243, § 114).

5.11 Additional Findings

Based on the literature cited in chapter 2, it was expected that all patients would report having had an EOL discussion. During this discussion, they would have realized that they were no longer receiving curative treatment and that a new phase had begun. It was expected that patients would remember this conversation and report on positive and negative aspects ranging from the physician's choice of words to the setting as a whole. As has been shown in detail, these expectations were only partially met (see section 5.4) However, even those patients who reported having an EOL discussion with their physician did not integrate this information into the reality of their life at the time when they received it (save for patient 811_0259).

In order for patients to begin dealing with the news that their cancer is no longer considered curable, they would first have to receive this news; not just hear it, but actually

receive and process it. The difference is perhaps best illustrated by patient 811_0264, a communications trainer (patient 811_0264, § 10), who said: “Gesagt ist nicht das was gesagt wurde, sondern immer das was gehört wurde.” [“What has been said is not what was said, but what was heard.” patient 811_0264, § 67]. Similarly patient 811_0253 highlights that once a terminal prognosis has been communicated there is still a lot of work to be done as people need time to register and process what had been said:

> Interviewer: Und als die Ärztin das gesagt hat, haben Sie das wirklich auch gehört gleich, oder hat das ein bisschen gedauert? [So, when the doctor said that, did you hear that right away or did you take a while? patient 811_0253, § 45]
>
> 811_0253: Nein, das hörst ja nicht. Das... brauchst zwei, drei Tage... Das kommt dir immer wieder in den Kopf und dann denkst dir: "Ach, das hätte ich noch fragen können, das hätte ich noch fragen können!..." Aber selber... Du bist mit der Krankheit überfordert. [No, you don’t hear that. That… takes two or three days… It comes back to your mind and then you think: “Oh, I could have asked that. That’s something I could’ve asked too!...” But yourself… you’re overwhelmed with the disease. patient 811_0253, § 46]

Consequently the research team decided to broaden the scope of analysis from how patients experienced their EOL discussion, to how and when they managed to subjectively integrate the information at their disposal – from EOL discussions or other sources – into the reality of their lives, their personal narrative and thus their transition from being curative to solely palliative patients. As this process is highly individual and cannot be generalized, the next section will give a brief summary of each patient’s process of integration (in the order in which the interviews were conducted) before consequences for clinical practice will be discussed in the chapter 6.

5.11.1 Patients transition from curative to solely palliative

Patient 811_0238 drew his conclusions mostly from other patients (patient 811_0238, § 26) and from the internet (patient 811_0238, § 32). He did not report negative feelings about either his lack of an EOL discussion or his transition.

Patient 811_0239 suffered so heavily from the side effect of her treatment that she reached the conclusion “Ist eh schon wurscht, woran ich sterbe. An Krebs oder an den Nebenwirkungen.” [“It’s irrelevant, what I die of: of cancer or from the side effect.” patient 811_0239, § 33]. She reported having had no EOL discussion with a physician and drawing

her own conclusion that her treatments had moved on to mere “delaying tactics” (patient 811_0239, §§ 37-41). This conclusion was based mostly on her admittance to the palliative care unit (patient 811_0239, § 43). More than her transition, her social isolation weighed heavily on her (patient 811_0239, §§ 61-65).

Patient 811_0243 whose case was highlighted in section 5.10 got a first glimpse when she googled her diagnosis (patient 811_0243, § 32) and responded with retreat. She never brought up the subject with her physicians. When she could no longer escape the truth, she was entirely unprepared and reacted with shock. Since the opportunity to support and prepare this patient had gone by unused, the psychologist, the physician or the volunteer were not able to console her in the moment when she integrated the information.

Patient 811_0245 was a peculiar case in that he professed acceptance of his impending death (patient 811_0245, § 25), but spent the entire interview focused on the regret that he should not have accepted radiotherapy for the cancerous growth in his lung. Rather, he thought now, he should have given his body time to grow stronger to be able to withstand an operation (patient 811_0245, § 23). He reached the integration of his situation after an EOL discussion, but it was not possible to determine when exactly.

Patient 811_0253 had experienced an EOL discussion, but stated explicitly that everything happened too fast to be processed immediately (patient 811_0253, §§ 22 and 46). Drawing on past experience, namely that his cancer progressed despite all treatments (patient 811_0253, § 26), he integrated the information on his own over the following days.

Patient 811_0256 had a similar experience in that she heard what her physicians said to her. She repeated this several times during the interview and was reportedly “puzzled” (patient 811_0256, § 75) by their choice of words (see section 5.7.1). Upon being prompted how she reacted or felt after these EOL discussions, she replied:

> Ich bin hinaus gegangen, habe ich mir gedacht: „Na gut, also der kann nicht, schaust dorthin.“ Gar nichts mehr… Was soll ich mir unheimlich denken? [I went out and I thought to myself: “Alright, so he can’t, I’ll go elsewhere.” Nothing more… What am I supposed to think? patient 811_0256, § 87]

The moment when she integrated the information of her transition was not revealed during the interview, most likely due to her coping mechanism of avoidance (see section 5.8.1).

Patient 811_0257 had an array of hints ranging from fragments gleaned from her medical reports to general knowledge picked up from TV, magazines and acquaintances,

which led her to conclude that her cancer could not be cured (patient 811_0257, § 88). An EOL discussion was not a source of information for her, yet she reported accepting her transition (patient 811_0257, §§ 38 and 82).

Patient 811_0259 was the only participant of the study who reported the best practice journey of having had an EOL discussion with his primary and trusted physician. This EOL discussion was well received and enabled the immediate integration of the information. The patient came to accept his situation and concluded the interview by saying: "Ja. Ja. Ja. Das passt. Der Schutzmantel funktioniert." ["Yes. Yes. Yes. It's alright. The protective cloak is working." patient 811_0259, patient 811_0259, § 92].

Patient 811_0263 was informed about her situation against her will (see section 5.3). As she did not report this incident in detail, no conclusion can be drawn regarding how exactly this was done. It might be that the physician in question tried to gently ease her into the truth or that he was blunt and abrasive. Regardless of the fashion, the patient was not ready for the information at the time she received it.

Patient 811_0264 heard from his doctor: "Bitte verzeihen Sie, wenn ich so ehrlich bin, dann reden wir von eingeschränkter Lebenszeit." ["Please excuse me for being so frank, but then we are talking about a limited life time." patient 811_0264, § 47]. His reported response was:

> Also das war klipp und klar am Tisch, das ist in dem Moment: Da musst du schlucken und sagen: "Was heißt das jetzt für mich?" Das checkt man erst am nächsten Tag. Wie das halt so ist bei solchen Informationen, aber man weiß woran man ist und ich habe gesagt: Sicher nicht! Ich weiß, dass… Jeder Mensch muss sterben. Ich muss auch sterben. Aber nicht jetzt. [So that was crystal clear, in that moment. You have to take a step back and say: "What does this mean for me?" You only get that the next day. That is how it is with these things, but you know where you stand and I said: Hell no! I know, that… Everybody has to die. I have to die too. But not now. patient 811_0264, § 47]

Very clearly and explicitly, the patient stated that he heard the information during his EOL discussion. He then processed it over the next days, but since he did not approve of the implications, he rejected the physician's statement. What is interesting here is that the moment of integration was not during the EOL discussion, but after. When exactly it

happened, who might have been there to support him or indeed who was absent was not revealed.

Patient 811_0265 was still reeling from the speed of the events surrounding her at the time of the interview. Her coping mechanisms (see section 5.8.1) barred her from recounting the precise timing of her realization that she was no longer under curative treatment. Given her focus on her physical deterioration evident throughout the entire interview, it can be concluded that this was her strongest indication.

Patient 811_0266 received her cancer diagnosis and, together with her experience as a nurse (patient 811_0266, § 62) and her personal history of watching her brother suffer an agonizing end of life (patient 811_0266, § 89), she concluded that she would refuse treatment (patient 811_0266, §§ 29-36). She did not regret this decision and reported accepting her situation (patient 811_0266, §§ 20 and 89).

6. Discussion

6.1 Synthesis of the study's results

Overall, patients reported a wide range of information preferences. Regardless of their preference, patients were (mostly) successful in procuring as much or as little information as they desired. Nevertheless, this often required effort and tenacity and was thus reported negatively (see section 5.7.2). Contrary to the expectations of the research team, four out of twelve patients had experienced no EOL discussion at all. Instead, and in the other eight cases additionally to an EOL discussion, patients relied on the internet, other media, relatives and other patients as sources of information regarding their prognosis. It could be hypothesized that this constitutes another coping strategy: information from unqualified sources need not necessarily be trusted and can be easily dismissed if unfavorable. Considering that the reported preferred source of information is the trusted physician, however, an offer for an EOL discussion should be extended to patients regardless. This is further emphasized by patients reporting positively on having received unsolicited information from their physicians (see section 5.3.2).

When patients were asked what the word *palliative* meant, an underlying misconception became apparent. Participants of this study reported that understanding what *palliative care* actually stood for and hearing the word for the first time were two distinct moments in time. Initially, almost all patients believed palliative care unit and

hospice to be synonymous and assumed that admittance to the palliative care unit meant that they were about to die. This partial misconception was also evidenced by the fact that admittance to the palliative care unit was a central source of information for some patients that their prognosis had deteriorated (see section 5.4.3). Becoming aware of the actual purpose of a palliative care unit after admittance (see section 5.4.1) is not a best practice scenario, as it precludes patients from giving informed consent regarding admittance to the unit to begin with.

The task of a palliative care unit in Austria is, among others, the alleviation of suffering without targeting the underlying disease and to discharge the patients once the acute situation has been resolved (Federal Ministry of Labor, Social Affairs, Health and Consumer Protection, 2014). Thus, contrary to patients' statements, palliative medicine should not be seen as the end of the line of conventional medicine and a last resort for terminally ill patients. As the literature suggests (see section 2.1.2), curative treatment ought to be administered conjointly with palliative medicine as early in the medical history as possible.

It could be argued that the misconception held by patients regarding the purpose of a palliative care unit is detrimental to both patients and physicians: Patients may be unsettled or afraid and palliative physicians might have a difficult time to illicit compliance. Presenting the admittance to a palliative care unit as overly positive and euphemistic in order to overcome this misconception, as was reported by several patients, is similarly negative. Patients might go from one misconception to another and, once the truth becomes obvious, acceptance might be impeded. Therefore it might be advisable to address the misconception regarding the objectives of a palliative care unit in the general population.

The reported alleviating and detrimental elements to EOL discussions and the transition from being a curative to a solely palliative patient are summarized in the next sections.

6.2 Implications for current clinical practice

In order to adequately assess the implications of the outcomes of this study for daily clinical practice, it is important to reiterate that to be included in this study, patients had to fulfill a number of criteria, three of which are of particular interest here:

- Patients had to have exhibited understanding of their situation at some point to the medical staff.
- Patients had to have been deemed stable by the medical staff.
- Patients had to consent to the interview and be willing to engage with the subject of EOL discussions.

This selection process was designed to protect those most vulnerable, patients whose coping strategies had proven ineffective and those who could not bear to talk about their transition (see sections 4.2 and 4.3). Consequently, the participants of this study represent an echelon of patients whose transition was – at least to some extent - successful. In this light, the finding that patients often only integrated the information about their transition well after any EOL discussion (if indeed there had been one) and that, in many cases, the EOL discussion was reportedly far from ideal is a strong indication that the current situation could be improved.

6.2.1 Level of health care professionals. Shared decision making regarding treatment or the refusal thereof was always reported positively. Therefore, its integration into daily practice should continue to be fostered.

Physician's demeanor was reported either in a very positive light (see section 5.6.2) or, on the contrary, as a cause of distress (see section 5.7.1). This dichotomy is unsurprising as physicians are patients' gateway to treatment. Physicians will make a lasting impression on patients, regardless of the polarity of the experience. While the quality of reported EOL discussions varied greatly (see section 5.4.1), EOL discussions were never reported overtly negatively. However, as the EOL discussion is the corner stone of a smooth transition from being a curative to a solely palliative patient (Fallowfield & Jenkins, 2004), it will be considered in more detail.

Given patients' emphasis throughout all interviews, it bears repeating that patients' preferred source of information is the physician (except for patient 811_0238). While section 5.7.1 highlighted that there is room for improvement, it is clear that patients keep turning to their physicians for answers. Despite this overt preference, patients often piece together their state of knowledge from a variety of sources of which the physician might not even be one. This discrepancy between the preferred and the actual source of information warrants further attention, since an EOL discussion with a trusted physician cannot and should not be substituted.

Patients were also burdened by the effort it required to get information. Surprisingly, there seemed to be a perceived need for patients to negotiate honesty and directness with their physicians upfront (see section 5.3). No patient reported having been asked how much information they desired. Given that patients are reluctant to ask for information themselves (Rumpold et al., 2015), the offer of additional information should be extended to every patient. The description of how laborious it can be to request information (see section 5.7.2) demonstrates that physicians would ideally offer information repeatedly, not just once, in order to make sure patients can act upon this offer once they are ready to do so.

Furthermore, the internet has become a general source of information in our everyday lives and thus, unsurprisingly, patients have taken to researching their diagnosis and prognosis online. However, they might not be prepared for what they find. This can be particularly harrowing with regard to the word *palliative* as in the case of patient 811_0243. This is not to say that information on the internet is per se untrustworthy, but rather that it cannot do justice to an individual's case. A patient's personal physician is not only up to speed with medical information but can – during an EOL discussion – adapt to the patient's demeanor and expressed whishes. The only patient who reported having been warned about information on the internet by his physician was patient 811_0264 (§ 28). The findings of this study suggest that this practice should be strongly encouraged.

Some of the alleviating elements mentioned in section 5.6, such as the support provided by relatives, are outside the realm of influence of health care professionals. However, they may still serve as indicators for those patients who require more attention than others.

6.2.2 Level of hospital organization. In addition to voicing criticism and praise concerning their EOL discussions, participants were explicitly asked for, they reported further discontent with regard to waiting times in the hospital in general. Specifically, the discrepancy between waiting times and actual interaction with the health care professionals angered patients. Upon further analysis of the interviews, several key aspects underlying this dissatisfaction could be identified.

Participants highlighted the often unseen adversity that getting to the hospital presents in and of itself. Patients who are seriously ill may not be able to drive themselves and the use of public transportation is arduous. Thus, they often have to rely on relatives or

special transportation services, which each bring new issues. Relatives might have to take time off from work and accumulating parking fees at the hospital can get expensive. Special transportation services may not be able to specify when exactly they might come to pick up the patient, which can be worrisome if an important appointment needs to be kept (see section 5.7.3). While these concerns do not present insurmountable obstacles, they do contribute to the mindset with which patients enter the building.

Once at the hospital, patients will need to register with the administrative staff, fill out paperwork, maybe have their blood drawn and then not rarely wait for several hours. During this waiting period patients (and potential accompanying relatives) are left to themselves. In practice, this often means sitting around, perhaps among other patients. As mentioned in section 5.4.3, this can lead to conversations regarding diagnosis and prognosis. Whether this is beneficial or detrimental to the interlocutors is up to chance. Escapism such as portable entertainment like reading is often too demanding and may thus not be an adequate resort for many cancer patients. Furthermore, the activity of sitting on hard chairs can itself be quite strenuous for seriously ill patients and can cause not just discomfort but physical pain.

The interaction with the physician that follows this waiting period will then determine how patients perceive it in hindsight. Whether it was worth enduring these adversities is based mostly on the conversation patients have been waiting for, its content, form and length. It may not be a surprise that this evaluation was rarely in the hospital's favor. Patients did not place blame with the physicians, but with the hospital. They expressed understanding for overworked physicians but also worry that this might result in worse care or even mistakes (see section 5.7.3). Revisiting the logistical necessities within the organization of the hospital which lead to long waiting periods for terminally ill patients might thus be appropriate.

A first suggestion could be to visit the palliative care unit during ambulatory hours. Currently the palliative care unit at the AKH is open for consultations without admittance only on select Wednesday mornings. These are used by former inpatients for the most part. Expanding these hours to other days, but also to patients from other units (such as oncology or radiotherapy) would serve multiple purposes.

First, it might constitute a way for patients to come in contact with the objective of a palliative care unit well before their curative options are exhausted. Thereby, the word

palliative might lose some of its stigma. Consequently, the misconception of the tasks of palliative care units (see section 6.1) might be addressed pre-emptively. The early introduction of patients from other units through their physicians might help to decrease the taboo that seems to be linked to the word *palliative* and the palliative care unit.

Incidentally, this might also prevent patients from receiving an EOL discussion rather late in their medical history or in the ER as in the case of patient 811_0239. Palliative care, which includes EOL discussions, is built upon the concept of giving comfort along with medical care. It is therefore a time-consuming process that cannot be rushed. In contrast, the ER is a hectic place and health care personnel are in crisis management, which is why admittance to an ER within the last days of life is usually a marker for aggressive care (Earle et al., 2004). EOL discussions or even care in the ER should thus be avoided (Chan, Macdonald, Carnevale, & Cohen, 2018).

Furthermore, easier access to the palliative care unit might serve to inform patients and provide on-point palliative interventions without necessarily admitting patients for longer periods of time. Palliative visits to other units are a possible next step. All of these measures would work to establish trust toward palliative physicians. Given the ample evidence in the literature that the onset of palliative care as early as possible is beneficial to the patient in a variety of ways (Greer at al., 2012; Temel et al., 2010), expanding the ambulatory hours of the palliative care unit can be seen as a first step in this direction.

6.3 Long term implications

Even before patients receive a cancer diagnosis, they have been in contact with a large number of health care professionals from their general practitioner to the physician actually delivering the diagnosis. Oncologists, radiologists, nurses, physical therapists, nutritionists, social workers and more all try to work together to support the patient. The range of offers from different professionals can sometimes be overwhelming and requires of the patient to take in and retain a lot of information. It is not uncommon to see patients or relatives with thick folders filled with medical reports, newspaper clippings and other information regarding the disease. This was recognized as a manageable issue and answered with the introduction of case managers in countries like the US (Snoddon, 2010) and The Netherlands (Van der Plas et al., 2015). In these countries, a person, mostly a nurse, is tasked with guiding the patient through the health care system and ensuring that they will receive the best care possible. The objectives of the case manager are primarily focused on

logistical and organizational support. As Van der Plas et al. (2015) report, the introduction of case managers leads to less hospitalization at the end of life, the general practitioner is more likely to know patient's wishes regarding their preferred place of death and patients are more likely to die at home. There is no similar job or function in Austria today.

The results of this study suggest that such a position would be in the best interest of cancer patients and health care personnel in Austria. Based on the results of this study, the case manager model might also be developed further in some aspects. From the moment a cancer diagnosis is given to a patient, the case manager would monitor and support this patient. They would get to know them, learn about their social support system and, in time, their coping strategies. Ideally, the case manager would have received psychological training or be a trained psychologist. Throughout the progression of the disease, the case manager would be a constant companion. The patient's emotional well-being would be addressed either by providing psychological counseling directly or by introducing a psychologist. If the psychologist is a person who introduces themselves instead of an abstract mention during an otherwise challenging conversation (see section 5.9), patients might be more inclined to make use of this service.

As of now personal information is gathered independently by each unit the patient comes in contact with and there is no system to store personal or emotional information about patients. The case manager would have access to medical reports and be in contact with physicians and other health care personnel on the case. They would have been trained to have a basic understanding of the disease, the treatments and their side effect. Bringing together both personal and medical information might enable a case manager to provide assistance to both patient and physicians. This could improve quality of life, care, compliance or even streamline hospital processes.

An example for the benefits this might have is the history of patient 811_0265 who talked about her physically impaired son in the interview. This information only came to light during the interview. The personnel at the palliative care unit were unaware of this issue up to that point. The patient was very focused on being released, so as to relieve her partner from the stress of having to take care of both her and their son. When the son was admitted to the same hospital as his mother for his own condition, no intervention was planned by health care personnel. Since the staff did not know about these circumstances, the patient was unable to see her son and her partner had to split his visiting hours between

the two. A case manager knowing the family might have alerted the hospital to this situation. Perhaps a shared room for mother and son could have been organized. At the least some form of accommodation for the partner/father might have been found.

The situation given in this example is, of course, highly specific and individual. Section 5.11.1 shows that the needs of every patient are highly specific and individual. For instance, patient 811_0245 had expressed regret several times during his interview that he had taken the wrong decision. He felt that he should have postponed a surgery until he was strong enough to endure it, rather than – as he had – opted for chemotherapy. A case manager might have been able to set up conversations between the patient and his physicians to address this matter. Meanwhile, patient 811_0257 was struggling to understand the implications and consequences of the findings in her medical report. Her physician merely relayed the contents without contextualizing them for her. In this instance, a case manager, building on experience and training, could have asked the patient if she was content with the information. Consequently, they could have worked to improve it, together with the physician. The list could be completed for each participant in this study, but perhaps the most persuasive argument is the case of patient 811_0243 detailed in section 5.10.

A case manager for patient 811_0243 might have known that she had gathered information on her prognosis and gotten scared, which led to her shunning away from all conversations on the matter. A physician might now have informed this case manager that the woman might not be able to afford looking the other way for too long, as the progression of her disease was aggressive and rapid. The case manager might then have taken steps to provide psychological counseling for the patient. Ideally, the case manager would have had the opportunity to discuss with the patient her prior experience with nursing homes and incentivized a visit to the palliative care unit during ambulatory hours (section 6.2.2) before the patient needed to be admitted. Thus, patient 811_0243 might have been much better prepared and perhaps might have been spared the shock upon realizing what unit she had been admitted to that she described in the interview.

With regard to the integration of information, a case manager could provide assistance to the patient. They could help with their transition from being a curative to a solely palliative patient either directly or via the early inclusion of psychological counseling. However, the case manager and their tasks, as outlined in this first conception, are not

solely psychologically oriented. Costs can be reduced when patients' needs are effectively and adequately met before situations become unmanageable and time-consuming. Ideally, case managers would be financed and employed not by the hospital, but by health care providers for two reasons. First, this would allow sharing information between hospitals as patients might opt to pursue care in a different hospital (see section 5.8.2). Secondly, case managers would not be tied to a specific unit or specialty, so that when patients are being treated for other complaints (such as patient 811_0239, who was treated for a macular degeneration) their allotted case manager can assist there as well.

The interactions necessary for the work of the case manager to be effective and productive could be fitted into the hospital routine. Meeting the patients as they receive the news that they might have cancer, case managers would be involved even at a time when patients might not need to be admitted. Some of their work might be done during waiting hours, which are currently cumbersome and might be used more productively (see section 6.2.2).

Overall, the introduction of case managers in Austria with a special focus on personal assistance might be beneficial to both patients and health care personnel, although additional information would be of interest (see section 6.5.4).

6.4 Limitations

The limitations of this study primarily concern the amount of data gathered. It would have been preferable to interview more participants, for a longer duration and, at best, at repeated intervals throughout the progression of their disease. The single point of interviewing was partially due to the palliative care unit comprising only twelve beds and the fact that the study was mono-centric. However, this approach was chosen to boost comparability between reported EOL discussions. A response rate of 50% (see section 5.1) is certainly satisfactory given the study's topic and a general tendency to avoid the subject of death and dying. Often the interview was terminated, so as not to overstrain patients. The interest of patients' well-being was given preference over any additional scientific gain.

Interviews prior to the EOL discussion or the integration of the transition as well as afterward would have been highly interesting. Due to this being a master thesis and as such subject to university regulations regarding the length of execution, this was not possible.

Many of the patients who could not be included in this study did not speak German on a sufficiently skilled level to participate in a semi-structured interview. Ethical concerns

further restricted participant inclusion. Thus, patients whose coping mechanisms had failed to support integration of the information of their terminal prognosis were excluded.

6.5 Outlook

The primary purpose of this study was exploratory and the options for further continued scientific research are accordingly broad.

6.5.1 Link between length of disease and coping effectiveness. The small number of participants precluded quantitative analysis of the data regarding the correlation between the time from initial diagnosis to the end of curative treatment and patients' ability to cope with the transition**.** As mentioned in section 5.2, three general variations regarding the progression of the disease were observed: less than nine months, less than two years and several years with recurrence after remission. When these three groups are compared with regard to the effectiveness of their coping mechanisms, a trend seems to emerge.

Out of the four patients with a progression from initial cancer diagnosis to terminal prognosis of less than nine months, three had substantial difficulty coping and one had refused treatment primarily on the basis of her prior experiences as a nurse. Of the four patients whose progression lasted between 16 and 28 months, two had adjusted well and two were struggling. The four patients who had experienced recurrence after remission were doing well emotionally, except for patient 811_0256, who never spoke of her disease.

It would appear that patients who have had more time to adjust to their diagnosis were generally psychologically more successful in their transition. The length of a medical history cannot be influenced to allow patients time to come to terms with their terminal prognosis. However, it could serve as a warning sign to alert health care professionals that these patients might require more support.

Additionally it would be interesting to investigate longitudinally how various treatment lines influence coping. Once traditional treatment options have failed to cure a patient, they might opt to participate in experimental studies. Probabilities and possible outcomes would be unknown to both patients and researchers, but hope might still prevail. Knowing how patients experience this context, especially in relation to letting go, could serve to improve psychological counselling or even informed consent forms.

6.5.2 Link between coping mechanisms and actual transition experience. Another aspect of interest that could not be investigated with this study design was patients' progress in terms of coping over time. It bears repeating that, in the palliative setting,

exhibited coping mechanisms can be in flux. Patients were only approached for this study if they had expressed understanding of their terminal prognosis at least once to medical personnel. Nonetheless, during the interviews some participants exhibited denial (see sections 5.8.1 and 5.8.2). Therefore, conclusions as to the success of coping mechanisms or transitions cannot be fully inferred from a single interview.

The investigation of coping mechanisms was not the focus of this study. Nevertheless an interesting avenue of research emerges from the findings. Somewhat unexpectedly, patients' moment of integration of the transition process was a different moment than their EOL discussion, even if one had taken place. Furthermore, little is known about the experience in the moment itself, as patients were often unable to recollect it precisely (see section 5.11.1).

Additional studies focusing primarily on coping strategies and the moment of integration would be highly beneficial. Psychological counseling as well as the proposed case manager model and hospital processes in general might be improved. Finding successful means of support could help to assist patients in choosing, developing and using effective strategies to manage this difficult task. Furthermore, a longitudinal approach (as suggested in section 6.5.1 as well) would allow monitoring patients' coping abilities. At a time when they are open to discuss it, patients might then be interviewed on the subject of when and how exactly it became clear to them that their cancer was no longer curable.

This would serve to explore what can be done in order to aid patients in this transition. As was mentioned by several patients, EOL discussions should be a step-by-step process and should not be expected to happen within a single conversation (see section 5.11). The current reported situation of providing patients with information fragments (i.e. "You have water in your lungs") needs to make way for an iterative approach that allows patients time to learn what medical reports mean and entail. It should be investigated whether the transition from a curative chemotherapy to a palliative one being a gradual and subtle process is beneficial to the patient's integration or whether it might merely postpone adverse experiences.

The question raised in section 6.5.1 and this one might together be investigated in one longitudinal study with a primary focus on coping mechanisms, the moment of integration of the transition from curative to solely palliative patient and the experienced medical journey.

6.5.3 Psychological counseling in Austria. One more aspect that was alluded to by the participants in this study, but which could not be fully answered at this point, is the role of psychological counseling. Numerous studies have been published which conclude that psychological counseling is highly benefical to oncological patients' quality of life (Goodwin et al., 2001; Spiegel, Bloom, Kraemer, & Gottheil, 1989; Wang et al., 2018). Yet, the participants of this study tended to refuse counselling even when it was offered to them (see section 5.9).

At this point, three causes for this might be hypothesized: prejudice, timing and manner of the offer. Patient 811_0245 dismissed psychology in its entirety as ludicruous and unnecessary. In the case of patient 811_0259, who at first refused, but then gladly accepted counseling, the timing of the offer was key. At first, the offer was extended during the EOL discussion, as with many other patients. The EOL discussion is itself a taxing experience that overwhelms patients (see section 5.11). Offering psychological support at this time might be dismissed before being fully considered. Additionally, psychologists are, at this point, nothing more than a mention. Being face-to-face with a psychologist, who might make the offer themselves, would be a different experience. The psychologist might also begin with a light conversation and dismantle preconceptions.

It is possible that psychological counseling might also be impeded by the organizational level as psychologists are part of the staff of a specific unit. Thus, when the patient is transferred to a different unit, the connection with the psychologist is severed. Given that psychological counseling is primarily dependent on an interpersonal relationship between psychologist and client (Lambert & Barley, 2002), this might be an additional factor in patients' reluctance. It is also the reason why the proposed case manager model would ideally be independent of individual units and personnel management (see section 6.3).

However, these theoretical considerations need to be investigated in further studies before any conclusions might be drawn. Regardless, it would be extremely advantageous to find out why the current services offered do not seem to meet patients' needs.

6.5.4 The Case Manager. Last, but not least, additional research is warranted with regard to the proposed case manager model. Main areas of interest would be financial and logistic feasibility, potential benefits to patients, physicians and hospitals and a more detailed and concrete plan for workload and training.

6.6 Summary

This study was designed to explore patients' experience of their EOL discussion. The qualitative semi-structured interviews resulted in findings regarding the alleviating and detrimental elements. However, it was also discovered that these EOL discussions did not always take place. If they did, they constituted only one element of information. Eleven out of twelve patients integrated the knowledge about their terminal prognosis at a different and unique moment in time. This moment could not be recollected precisely by patients and thus elludes further investigation for now. Supplementary research in this area would be highly desirable in order to develop a better understanding for what it is that patients experience. These conclusions would be the foundation for the improvement of psychological counseling and EOL discussion models and training programs in Austria.

Additionally the findings of this study suggest first steps which might be undertaken to improve patient experience today. Of particular interest would be the full conceptualization of the case manager.

7. References

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8. Appendices

8.1 The vote of the ethics committee of the medical university of Vienna

ethik kommission
Medizinische Universität Wien

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ethik-kom@meduniwien.ac.at
http://ethikkommission.meduniwien.ac.at/

Votum:

EK Nr: 1121/2018
Projekttitel: Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes
Antragsteller/in: Frau Alina El-Hagin
Institution: Universität Wien - Psychologie
Sponsor: Medizinische Universität Wien

Teilnehmende Prüfzentren:

Ethik-Kommission	Prüfzentrum	Prüfärztin/arzt
Ethikkommission der Medizinischen Universität Wien	Medizinische Universität Wien - Universitätsklinik Innere Medizin I (17K)	Frau Ass. Prof. Priv. Doz. Mag. Dr. Eva Masel

Die Stellungnahme der Ethik-Kommission erfolgt aufgrund folgender eingereichter Unterlagen: Fallbericht-Formular (CRF)

Name	Version	Datum
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Case Report Form	1.0	05.02.2018

Lebenslauf (CV)

Name	Version	Datum

Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - CV Masel	1.0	05.02.2018

Sonstige

Name	Version	Datum
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Verpflichtungserklärung	1.0	02.02.2018

Patienteninformation

Name	Version	Datum
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Informed Consent	1.0	05.02.2018
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Informed Consent - Clean Version	2.0	22.03.2018
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Informed Consent - Track Version	2.0	22.03.2018

Studienprotokoll (Prüfplan)

Name	Version	Datum
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Studienprotokoll	1.0	05.02.2018
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Studienprotokoll - Clean Version	2.0	22.03.2018
Das Erleben des Aufklärungsprozesses im Rahmen der subjektiven Realisierung des terminalen Krankheitsverlaufes - Studienprotokoll - Track Version	2.0	22.03.2018

Die Kommission fasst folgenden Beschluss (mit X markiert):

X	Es besteht kein Einwand gegen die Durchführung der Studie. ACHTUNG: Unter Berücksichtigung der "ICH-Guideline for Good Clinical Practice" gilt dieser Beschluss ein Jahr ab Datum der Ausstellung. Gegebenenfalls hat der Antragsteller eine Verlängerung der Gültigkeit rechtzeitig zu beantragen.

Ergänzende Kommentare der Sitzung am 13.03.2018:

Zum Antrag:

Alle im Protokoll angeführten Studienmitarbeiter sind auch im Antrag im Reiter Zentren anzuführen (z.B. fehlt Dr. Lötsch).

Die Angabe in Punkt 10.8 ("Facharzt für...") scheint nicht korrekt.

Zur Patienteninformation:

Punkt 6: Der Begriff "anonymisiert" sollte durch "verschlüsselt" ersetzt werden bzw. erklärt werden.

Zur Versicherung:

Die Ethik-Kommission hält fest, dass der Abschluss einer Versicherung für diese Studie nicht erforderlich ist.

Die Ethik-Kommission ersucht die Antragsteller, bei der Wiedervorlage von geänderten Unterlagen ein Exemplar mit hervorgehobenen Änderungen beizulegen.

Ergänzende Kommentare:

Nachtrag vom 23. März 2018:

Die Antragsteller legen am 22.03.2018 überarbeitete Unterlagen vor, die von der EthikKommission akzeptiert werden.

Die aktuelle Mitgliederliste der Ethik-Kommission ist unter folgender Adresse abrufbar: http://ethikkommission.meduniwien.ac.at/ethik-kommission/mitglieder/

Mitglieder der Ethik-Kommission, die für diesen Tagesordnungspunkt als befangen anzusehen waren und daher laut Geschäftsordnung an der Entscheidungsfindung/Abstimmung nicht teilgenommen haben: **keine**

Dieses Dokument ist für berechtigte Benutzer/innen in digitaler Form unter folgender Adresse abrufbar: https://ekmeduniwien.at/vote/14095/download/

SIGNATURINFORMATIONEN	**Unterzeichner**	Dr. Martin Bernhard Brunner
	Datum/Zeit-UTC	2018-03-27T12:36:08Z
	Prüfinformation	Informationen zur Prüfung der elektronischen Signatur finden Sie unter: https://www.signaturpruefung.gv.at

8.2 Informed Consent Form

Patienteninformation und Einwilligungserklärung zur Teilnahme an der psychologischen Studie

Palliativer Aufklärungsprozess an der Universitätsklinik für Innere Medizin I

Sehr geehrte Patientin, sehr geehrter Patient!

Wir laden Sie ein an der oben genannten psychologischen Studie zum palliativen Aufklärungsprozess teilzunehmen. Die Aufklärung darüber erfolgt in einem ausführlichen Gespräch.

Ihre Teilnahme an dieser psychologischen Studie erfolgt freiwillig. Sie können jederzeit ohne Angabe von Gründen aus der Studie ausscheiden. Die Ablehnung der Teilnahme oder ein vorzeitiges Ausscheiden aus dieser Studie hat keine nachteiligen Folgen für Ihre medizinische Betreuung.

Unverzichtbare Voraussetzung für die Durchführung einer psychologischen Studie ist jedoch, dass Sie Ihr Einverständnis zur Teilnahme an dieser psychologischen Studie schriftlich erklären. Bitte lesen Sie den folgenden Text, als Ergänzung zum Informationsgespräch, sorgfältig durch und zögern Sie nicht, Fragen zu stellen.

Bitte unterschreiben Sie die Einwilligungserklärung nur

- wenn Sie Art und Ablauf der psychologischen Studie vollständig verstanden haben,
- wenn Sie bereit sind, der Teilnahme zuzustimmen, und
- wenn Sie sich über Ihre Rechte als TeilnehmerIn an dieser psychologischen Studie im Klaren sind.

Zu dieser psychologischen Studie sowie zur Patienteninformation und Einwilligungserklärung wurde von der zuständigen Ethikkommission eine befürwortende Stellungnahme abgegeben.

1. Was ist der Zweck der psychologischen Studie?

Jede/-r PatientIn erlebt die eigene Erkrankung individuell und so gestalten sich auch die Bedürfnisse und Erlebnisse sehr unterschiedlich. Während einige PatientInnen den Ungewissheiten einer Krebserkrankung mit möglichst detaillierten Informationen über den weiteren Krankheitsverlauf begegnen möchten, versuchen andere das Thema weitgehend zu vermeiden. Die Kommunikation zwischen ÄrztInnen und PatientInnen ist hier von besonderer Bedeutung und wird häufig von beiden Seiten als Herausforderung wahrgenommen.

Zweck dieser psychologischen Studie ist es, Ihr persönliches Erleben der Aufklärungsgespräche über den Krankheitsverlauf zu erfragen sowie eventuelle Einflussfaktoren darauf zu finden. Mit Ihrer Teilnahme helfen Sie mit, die Kommunikation zwischen ÄrztInnen und PatientInnen zu verbessern und in Zukunft ein individuelleres Eingehen auf unsere PatientInnen zu ermöglichen.

2. Wie läuft die psychologische Studie ab?

Diese psychologische Studie wird an der Universitätsklinik für Innere Medizin I des Allgemeinen Krankenhauses Wien durchgeführt; es werden insgesamt ungefähr 15 Personen daran teilnehmen.

Folgende Maßnahmen werden ausschließlich aus Studiengründen durchgeführt:

Ihre Teilnahme an dieser psychologischen Studie umfasst ein Interview während Ihres stationären Aufenthaltes auf 17K an der Universitätsklinik für Innere Medizin I.

Ihre Teilnahme an dieser psychologischen Studie wird voraussichtlich 30-60 Minuten dauern. Auf Ihren Wunsch kann das Gespräch auch weniger oder mehr Zeit in Anspruch nehmen bzw. jederzeit abgebrochen oder verschoben werden.

Das Interview beschäftigt sich mit der Frage, wie Sie die Aufklärungsgespräche hinsichtlich Ihres Krankheitsverlaufes erlebt haben: Welche Faktoren in der ärztlichen Gesprächsführung und –beziehung haben diesen Prozess sowohl erleichtert/unterstützt als auch erschwert/behindert.

3. Worin liegt der Nutzen einer Teilnahme an dieser psychologischen Studie?

Ihre Teilnahme an dieser psychologischen Studie kann zu einer Verbesserung der Kommunikation zwischen ÄrztInnen und PatientInnen führen, welche dadurch noch spezieller auf die Bedürfnisse und Erwartungen der PatientInnen ausgerichtet werden kann. Ihre Angaben geben uns dafür wertvolle Hinweise.

4. Gibt es Risiken, Beschwerden und Begleiterscheinungen?

Durch die Teilnahme an dieser psychologischen Studie sind keinerlei Risiken, Beschwerden oder Begleiterscheinungen zu erwarten. Sie bezieht sich ausschließlich auf Ihre persönliche Meinung und hat keine Auswirkungen auf Ihre weitere Behandlung an der Universitätsklinik. Bei Bedarf steht Ihnen jederzeit das psychologische Team der Abteilung 17K für Beratungsgespräche zur Verfügung.

5. Wann wird Ihre Teilnahme an der psychologischen Studie vorzeitig beendet?

Sie können jederzeit auch ohne Angabe von Gründen Ihre Teilnahmebereitschaft widerrufen und aus der psychologischen Studie ausscheiden, ohne dass Ihnen dadurch irgendwelche Nachteile für Ihre weitere medizinische Betreuung entstehen.

Ihr/e PrüfarztIn wird Sie über alle neuen Erkenntnisse, die in Bezug auf diese psychologische Studie bekannt werden, und für Sie wesentlich werden könnten, umgehend informieren. Auf dieser Basis können Sie dann Ihre Entscheidung zur **weiteren** Teilnahme an dieser psychologischen Studie neu überdenken.

Es ist aber auch möglich, dass Ihr/e PrüfarztIn entscheidet, Ihre Teilnahme an der psychologischen Studie vorzeitig zu beenden, ohne vorher Ihr Einverständnis einzuholen. Die Gründe hierfür können sein:

- Sie können den Erfordernissen der psychologischen Studie nicht entsprechen;
- Ihr/e PrüfarztIn hat den Eindruck, dass eine weitere Teilnahme an der psychologischen Studie nicht in Ihrem Interesse ist.

6. In welcher Weise werden die im Rahmen dieser psychologischen Studie gesammelten Daten verwendet?

Das Interview wird auf Tonband aufgezeichnet. Nach der Niederschrift des Tonbandes, wird dieses umgehend gelöscht. In der Niederschrift wird Ihr Name nicht ausgeschrieben, sondern verschlüsselt. Sofern gesetzlich nicht etwas anderes vorgesehen ist, haben nur die Prüfer und deren MitarbeiterInnen Zugang zu den vertraulichen Daten (Tonband), in denen Sie namentlich genannt werden. Diese Personen unterliegen der Schweigepflicht. Die Weitergabe der Daten erfolgt ausschließlich zu Auswertungszwecken und Sie werden ausnahmslos darin nicht namentlich genannt. Auch in etwaigen Veröffentlichungen der Daten dieser psychologischen Studie werden Sie nicht namentlich genannt.

7. Entstehen für die Teilnehmer Kosten? Gibt es einen Kostenersatz oder eine Vergütung?

Durch Ihre Teilnahme an dieser psychologischen Studie entstehen für Sie keine zusätzlichen Kosten. Ein Kostenersatz oder eine Vergütung erfolgen nicht.

8. Möglichkeit zur Diskussion weiterer Fragen

Für weitere Fragen im Zusammenhang mit dieser psychologischen Studie stehen Ihnen Ihr/e PrüfarztIn und MitarbeiterInnen gern zur Verfügung. Auch Fragen, die Ihre Rechte als PatientIn und TeilnehmerIn an dieser psychologischen Studie betreffen, werden Ihnen gerne beantwortet.

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9. Einwilligungserklärung

Name des Patienten in Druckbuchstaben: .....

Geb.Datum: ..... Code: .....

Ich erkläre mich bereit, an der psychologischen Studie zum palliativen Aufklärungsprozess teilzunehmen.

Ich bin von Herrn/Frau.....

ausführlich und verständlich über die Studie zur medizinischen Entscheidungsfindung, mögliche Belastungen und Risiken sowie über Wesen, Bedeutung und Tragweite der psychologischen Studie und den sich für mich daraus ergebenden Anforderungen aufgeklärt worden. Ich habe darüber hinaus den Text dieser Patientenaufklärung und Einwilligungserklärung, die insgesamt 4 Seiten umfasst gelesen. Aufgetretene Fragen wurden mir vom Prüfarzt verständlich und

genügend beantwortet. Ich hatte ausreichend Zeit, mich zu entscheiden. Ich habe zurzeit keine weiteren Fragen mehr.

Ich werde den ärztlichen Anordnungen, die für die Durchführung der psychologischen Studie erforderlich sind, Folge leisten, behalte mir jedoch das Recht vor, meine freiwillige Mitwirkung jederzeit zu beenden, ohne dass mir daraus Nachteile für meine weitere medizinische Betreuung entstehen.

Ich bin zugleich damit einverstanden, dass meine im Rahmen dieser psychologischen Studie ermittelten Daten aufgezeichnet werden. Um die Richtigkeit der Datenaufzeichnung zu überprüfen, dürfen Beauftragte des Auftraggebers und der zuständigen Behörden beim Prüfarzt Einblick in meine personenbezogenen Krankheitsdaten nehmen.

Beim Umgang mit den Daten werden die Bestimmungen des Datenschutzgesetzes beachtet.

Eine Kopie dieser Patienteninformation und Einwilligungserklärung habe ich erhalten. Das Original verbleibt beim dem/der PrüfarztIn.

.....

(Datum und Unterschrift PatientIn)

.....

(Datum, Name und Unterschrift PrüfarztIn)

8.3 Case Report Form

Case Report Form

PatientInnen ID: _____

Alter: _____

Geschlecht: ☐ Weiblich ☐ Männlich

Familienstand:
☐ ledig
☐ verheiratet / verpartnert
☐ Lebensgemeinschaft
☐ verwitwet
☐ geschieden
☐ getrennt lebend

Gibt es Kinder? ☐ Ja ☐ Nein
Wenn ja: Wie viele und in welchem Alter?: _____

Wird alleine gelebt? ☐ Ja ☐ Nein

Wenn nein, mit wem leben Sie zusammen?
(mehrere Antworten möglich)

☐ mit PartnerIn
☐ mit Kind(ern)
☐ mit Eltern
☐ mit FreundIn(nen)
☐ im Heim lebend

Welche(n) Beruf(e) wurden ausgeübt?

_____

_____

_____

Welche Ausbildung(en) wurden abgeschlossen?

_____

_____

_____

Primäre Diagnose: _____

Krankheitsstadium TNM: _____

Lokalisation bei M1: _____

Datum Erstdiagnose: _____

Datum Erstkontakt Palliativabteilung: _____

Therapie(n):

- Radiotherapie: _____
- Chirurgie: _____
- Chemotherapie: _____
- Immuntherapie: _____

Aktuelle Symptome / Nebenwirkungen:

_____

_____

_____

Schmerzen VAS

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Aktuelle Medikation: _____

_____

_____

8.4 Interview Guideline

Gesprächsleitfaden für die semi-strukturierten Interviews auf 17K

Ich habe von der Ärztin gehört / in Ihrer Akte gelesen, dass Sie verheiratet sind / Kinder haben etc – stimmt das?

Können Sie sich noch erinnern, wieso Sie ganz zu Beginn zum Arzt / zur Ärztin gegangen sind? Wie Sie gehört haben, es ist [Krebs]?

Was hat Ihnen der Arzt / die Ärztin gesagt, ob das wieder weggeht? / Wann ist Ihnen klar geworden, dass das nicht mehr weggeht?

Wie war das für sie?

- ✓ Wann hat das Gespräch statt gefunden
- ✓ Wer war bei dem Gespräch dabei?
- ✓ Wer hat die Informationen vermittelt – ÄrztIn, KrankenpflegerIn, AngehörigE
- ✓ Wie war das bisherige Verhältnis zum NachrichtenüberbringeR?
- ✓ War das ein iterativer Prozess, oder ein einzelnes Gespräch?
- ✓ Wer hat das Gespräch initiiert?
- ✓ Wer hat das Thema Heilungschancen angeschnitten?
- ✓ Wie war die Sprache? Klar? Fachausdrücke?
- ✓ Wo hat das Gespräch statt gefunden?
- ✓ Konnte das Gespräch ungestört statt finden?
- ✓ Wie lange hat es gedauert?
- ✓ Können Sie sich noch an die Wortwahl des Nachrichtenüberbringers erinnern?
- ✓ Wie ist es Ihnen emotional dabei ergangen? An welche Gefühle können Sie sich spontan erinnern?
- ✓ Hat die Nachrichtenüberbringerin Emotionen gezeigt? Welche und wie wirkte das auf Sie?
- ✓ Gab es innerhalb des Gespräches Gelegenheit das Gehörte zu verdauen?
- ✓ Gab es Gelegenheit für Fragen?

Gab es in diesem Gespräch / Prozess etwas, das Sie als besonders belastend empfunden haben?
Gab es in diesem Gespräch / Prozess etwas, das Sie als besonders hilfreich erlebt haben?

Gesprächsende hier möglich, wenn der Patient / die Patientin anzeigt, dass es genug ist. Andernfalls wird nach Rückfrage fortgesetzt.

Wussten Sie vor dem Gespräch was auf Sie zukommt? Woher?

Wenn die Patientin / der Patient vorbereitet war: Haben Sie das positiv erlebt, dass Sie vorher schon ein bisschen wussten, was auf Sie zukommt? Haben Sie sich irgendwie auf das kommende Gespräch vorbereitet?

Optional: Haben Sie sich eigenständig Informationen über Ihren Krankheitsverlauf geholt? Wie sind Sie daran gegangen?

Optional: Wollten Sie Angehörige dabei haben? War das möglich? Wie haben Sie deren An/Abwesenheit erlebt?

Optional: Wie haben Sie Ihren Angehörigen von dem Aufklärungsgespräch berichtet?

Was haben Sie unmittelbar nach dem Gespräch gemacht?

Was haben / hätten Sie in diesem Moment gebraucht?

Haben Sie ein ärztliches Folgegespräch erhalten? Von wem (OnkologIn, PalliativärztIn)? Was können Sie mir darüber berichten?

Optional: Sind später noch Fragen bei Ihnen aufgetaucht? Konnten Sie diese stellen? Wem?

Haben Sie psychologische Unterstützung angeboten bekommen oder genutzt? Seelsorgerische Begleitung?

8.5 Abstract (Deutsch)

Ist eine Heilung, beispielsweise einer Krebserkrankung, mittels kurativer Therapien nicht mehr möglich, kann jedoch die Palliativmedizin weiterhin dafür sorgen die Lebensqualität zu steigern beziehungsweise zu erhalten.

Die terminale Diagnose wird PatientInnen in palliativen Aufklärungsgesprächen vermittelt. Sie stellen eine enorme kommunikative Herausforderung für ÄrztInnen wie auch für PatientInnen dar. Während es auf Basis intensiver Forschung Trainingsmodelle für ÄrztInnen gibt, ist hinsichtlich des Erlebens der PatientInnen fast nichts bekannt.

Um diese Lücke zu schließen, wurde eine qualitative, explorative, mono-zentrische, deskriptive Querschnittsstudie durchgeführt. Mit 12 PatientInnen wurden semi-strukturierte Interviews durchgeführt, die anschließend transkribiert und ausgewertet wurden, was zu Erkenntnissen in folgenden Bereichen führte: Informationspräferenzen, Quelle(n) der Aufklärung, Bedeutung des Wortes „palliativ“, positive und negative Elemente, Copingstrategien sowie die psychologische Betreuung.

Die subjektive Realisierung des terminalen Krankheitsverlaufes fand in elf von zwölf Fällen nicht während eines ärztlichen Aufklärungsgespräches statt. Vielmehr markiert die Integration der Informationsfragmente in den persönlichen Narrativ einen eigenen Zeitpunkt im Erleben. Daraus lässt sich ableiten, dass das derzeitige Angebot an palliativen Aufklärungsgesprächen ausgebaut werden kann.

Derzeitig gibt es an vereinzelten Mittwochvormittagen Ambulanzstunden auf der Palliativstation, die vorrangig von ehemalig palliativ-stationären PatientInnen in Anspruch genommen werden. Eine Ausdehnung auf andere Tage und für PatientInnen anderer Stationen könnte helfen, Vorurteile zu verringern und PatientInnen früher mit Palliativmedizin in Kontakt zu bringen.

In den USA und Niederlanden werden PatientInnen „Case-Manager“ an die Seite gestellt, die durch den Krankenhausbetrieb führen. Eine solche Position könnte auch für österreichische PatientInnen überaus positiv sein, insbesondere wenn die Aufgaben auch auf psychologische und soziale Bereiche ausgedehnt würden.

8.6 Abstract (English)

An end-of-life discussion is the term for any communication between a physician and their patient which concerns the patient's end of life. Thus, a patient first needs to be told of their terminal diagnosis. In Austria this is done during so-called palliative *Aufklärungsgespräche*. While there is research on how this can best be achieved, information regarding the patient's experience is lacking. Therefore a qualitative, explorative, mono-centric, descriptive, cross-sectional study was done. Twelve semi-structured interviews, which were transcribed and analyzed, led to conclusions concerning information preferences, sources of information, meaning of the word *palliative*, positive and negative elements, coping mechanisms and psychological counselling.

The subjective realization of the terminal nature of the prognosis was not achieved during the EOL discussion in eleven out of twelve cases. Rather the integration of numerous fragments of information into the personal narrative marked a distinct event in time. This is evidence that the current offer of EOL discussions could be improved.

Currently the palliative unit is open for ambulatory consultations on select Wednesday mornings. Expanding this to other days and to in-patients of other stations as well, might help to reduce bias and misconceptions as well as get patients in contact with palliative care earlier in the progression of their disease.

In the US and The Netherlands patients are assisted by *case managers* who help guide them through the hospital process. Such a position would be in the best interest of Austrian patients as well, especially if tasks are extended to psycho-social areas.