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General discussion



Following the developments in advance care planning for patients with an advanced, life-limiting disease, this thesis characterized patients' well-being and preferences near the end of life. This general discussion presents (1) an overview of the main findings of the conducted studies, (2) a brief discussion of methodological considerations and (3) a reflection on patient-centred care and advance care planning near the end of life.

SUMMARY OF THE MAIN FINDINGS

Patients' well-being near the end of life

Part I of this thesis aimed at describing patients' well-being and lived experience near the end of life through a characterization of patients' illness representations (chapter 3), coping (chapter 4) and quality of life (chapter 5).

We found that patients with advanced cancer who hold negative illness representations experience a worse quality of life (chapter 3). This association has previously been described in other patient groups,^{1,2} but the underlying mechanisms were unclear. We were able to decompose this complex relationship and found that symptoms of anxiety and depression mediate the association between illness representations and quality of life (41-87% and 39-69%, respectively). Patients with negative illness representations were at increased risk of developing symptoms of depression and anxiety, which ultimately contributed to a worse quality of life. The mediating effect was stronger for some illness representations than for others. It was strongest for patients who feel that their illness has severe effects and outcomes on their life (illness representation 'Consequences'), for patients who (overly) attribute experienced symptoms to their illness ('Identity') and for patients who are very concerned about their situation ('Concern').

Eventually, patients' illness representations guide their coping efforts.^{3,4} Across six European countries we found that patients with advanced cancer score higher on Acceptance and Problem-focused coping than on Denial (chapter 4). However, rather than using a single coping strategy, patients rely on several coping strategies, such as Acceptance in combination with Problem-focused coping or Problem-focused coping combined with Denial. We also found that the use of coping strategies differs between various sociodemographic and clinical subpopulations and between countries. Older patients tend to use Denial more than their younger counterparts, probably related to a higher tendency of keeping feelings to themselves.⁵ Likewise, we found that patients in Italy and Denmark score higher on Denial than patients in the other countries, which we connected to a general reluctance to talk about death in these countries.⁶ Furthermore, we found that higher educated patients use Acceptance more strongly than patients with lower education. Higher education has been linked to more communication and involvement in end of life decision-making⁷ and we hypothesized that increased involvement in medical decision-making combined with presumably higher cognitive abilities may enable patients with higher education to manage the

multiple demands of a terminal disease better, which contributes to the use of Acceptance. The WHO performance status was the only clinical variable that influenced coping strategies. Patients with a worse WHO performance status (1 or 2) score lower on Problem-focused coping than patients who are fully active and do not experience restrictions. We attributed this finding to the behavioral efforts that are linked to Problem-focused coping,⁸ which might become more challenging when patients' physical abilities decline.

An often used outcome measure for the evaluation of healthcare interventions is quality of life.⁹ We investigated an innovative way of measuring quality of life, using item banks (chapter 5). We found that using questionnaire items that are tailored to patients' individual characteristics gives a more precise and efficient estimate of patients' quality of life. Consequently, the customized questionnaire allows for a smaller sample size without reducing power.

Patients' preferences near the end of life

Part II of this thesis focused on the experiences of patients and healthcare professionals with advance care planning (chapters 6 and 7) and the stability of patients' treatment preferences (chapter 8).

We systematically searched electronic databases for studies on experiences with advance care planning of patients with a life-threatening or life-limiting disease (chapter 6). We found that patients often experience ambivalent feelings during advance care planning conversations. These feelings vary from being distressed and experiencing the conversations as difficult, to perceiving them as informative and helpful. Ambivalence was also observed in patients' level of readiness. While readiness is perceived to be a prerequisite for engaging in advance care planning, readiness has also been observed to increase throughout these conversations. We conclude that advance care planning can be a meaningful experience if patients feel comfortable to open up about their goals and preferences. Patients should feel encouraged to ask questions in order to plan for their current and future medical care.

Our second systematic review focused on advance care planning for patients with chronic respiratory diseases (chapter 7). We found that patients are generally interested in discussing end of life care preferences. Despite of healthcare professionals sharing this interest and seeing the added value of advance care planning, the uptake of advance care planning is low. In an effort to support healthcare professionals in engaging in advance care planning, we identified several barriers and facilitators. An essential, yet complex, factor is the identification of the right moment for having these conversations.

Related to this is the question of the stability of patients' treatment preferences (chapter 8). While we found that most patients with advanced cancer and a life-expectancy of ≤ 6 months have stable treatment preferences, a considerable group of patients change their preferences within a time interval of four months. Change in treatment preferences was not specific into a certain direction (life-prolonging care versus comfort care). Furthermore, change could not be predicted by sociode-

mographic and clinical characteristics or initial treatment preference. However, patients who do not describe their current health status as terminal were more prone of changing their treatment preferences.

METHODOLOGICAL CONSIDERATIONS

Throughout this thesis different methodologies were used to address the aims and objectives, among which the analysis of cross-sectional data collected through questionnaires, prospective observational data and systematic literature reviews. In the following paragraph considerations on these methods will be discussed. This brief discussion is supposed to be understood in addition to and extending the limitations and strengths discussed in the previous chapters.

In chapters 3, 4 and 5 we conducted secondary analyses of cross-sectional data. Secondary analyses refer to the analysis of data that were collected for another primary aim, which makes these analyses very efficient, both concerning time as well as resources.¹⁰ Besides, using these data acknowledges the time and energy patients invested into filling out questionnaires. This is particularly important when conducting research near the end of life, a phase in which participation in research projects can be a burdening experience for patients with a fragile condition.¹¹ Secondary analyses are also socially valuable, considering that many research projects are financially supported by non-profit bodies, such as national governments or cancer societies. Thus, leaving as little unused data as possible through secondary analyses is a responsible and efficient way of increasing knowledge.

In this thesis, the secondary analyses were used to describe the patients' well-being (chapters 3, 4 and 5) and investigate underlying mechanisms (chapter 3). However, while cross-sectional data can provide an accurate and valuable description of certain outcomes, such as illness representations or coping, the main disadvantage is that these analyses do not allow drawing conclusions on causality. Particularly for the study on illness representations (chapter 3) longitudinal studies would enable researchers to extend the findings on observed associations towards causal relationships. We therefore would be interested to see if future research could replicate these findings with longitudinal data and verify the direction of the association we hypothesized. The same applies to the study on coping strategies (chapter 4), which would benefit from looking at the development of coping strategies over time and at coping strategies as an effect of interventions (e.g. on communication near the end of life). Similarly, longitudinal data would enable researchers to validate and extend the findings on the improved way of measuring quality of life (chapter 5) through comparing the questionnaire's ability of detecting changes in quality of life over time.

The study on the stability of treatment preferences (chapter 8) was based on secondary analyses of prospective observational data. One drawback of this study, possibly inherent to conducting research with patients nearing their end of life, is loss to follow-up due to deterioration of the disease and death.^{12,13} High attrition rates can lead to selection bias and may limit the strength of evidence

due to loss of power. Accounting for drop-out in power calculations and making realistic estimations of the response rates of patients is therefore important, particularly in trials with vulnerable patients.

The descriptions of patients' experiences with advance care planning (chapter 6) and practice of advance care planning in chronic respiratory diseases (chapter 7) were based on systematic reviews, supposedly the strongest form of medical evidence.¹⁴ However, systematic reviews depend on the quality of their included studies and are therefore subject to the same biases as their included studies.¹⁴ We tried to account for that by conducting thorough quality assessments of all included studies and highlight the quality of studies in the interpretation of the results. This hopefully aids the reader in forming his/ her own judgment on the strength of the presented evidence.

REFLECTION: CARE AND COMMUNICATION NEAR THE END OF LIFE

While death ultimately occurs due to the cessation of biological functions, dying is certainly not a strictly medical event.¹⁵ A recurring theme during this thesis is the individual and multi-dimensional way patients experience their illness and the last phase of their life. To account for these individual experiences, the National Academy of Medicine recommends that high-quality care near the end of life should preeminently be patient-centered, acknowledging the medical, social, psychological and spiritual dimension of patients.¹⁵

Patient-centered medicine was preceded by disease-oriented medicine, a way of thinking that focused on the localization and diagnosis of a localizable disease.¹⁶ Patient-centered medicine extended this approach towards studying and understanding the person and his or her complaints as a whole in order to reach an 'overall diagnosis'.¹⁶ Related to this way of medical thinking is the biopsychosocial model, which includes interacting biological, psychological and social dimensions that are equally important and necessary for diagnosing and treating the patient.¹⁷ Within the biopsychosocial model, the patient is seen as the expert on the own disease and symptoms.¹⁷ The healthcare professional aims at understanding the patients' lived experience, including their values and preferences. At the same time the healthcare professional fulfills the role of the medical expert.¹⁵ Ideally, the patient and healthcare professional combine their areas of expertise and jointly develop a customized and comprehensive care plan for the patient.¹⁵

While the paradigm of patient-centered care is not a strictly new way of medical thinking, it challenges healthcare professionals, since their training focuses on the biomedical aspects of care rather than psychosocial aspects.¹⁸ Indeed, during consultations with patients newly diagnosed with breast cancer, 88% of all utterances by the oncologists were biomedical. The remaining 12% of utterances were equally divided between administrative and psychological notions.¹⁸ If emotional concerns are not deliberately attended to, they may get lost since patients mainly express their concerns through indirect cues¹⁹ and typically disclose just 40% of their emotional concerns.²⁰

Advance care planning

Physicians are in a key position for communicating with patients about their values and well-being and can ensure that these topics are not undermined by biomedical aspects.²¹ Advance care planning could provide a framework for healthcare professionals that can support them in engaging in conversations about patients' well-being and preferences. Instead of focusing on the disease and medical treatment options alone, advance care planning extends medical encounters towards the patient as a whole, with particular emphasis on the patients' concerns.²² Due to its focus on the exploration of patients' health-related experiences, knowledge, concerns and personal values on the physical, psychological, social and spiritual domain,²² advance care planning can be seen as a patient-centered care conversation.

The ideas and aims of advance care planning have received wide recognition. However, the form and methods of these conversations are not yet universally defined and there is no accepted standard on how and when to perform advance care planning. The right timing for engaging in these conversations also depends on the stability of treatment preferences.²³ We found that most patients with advanced cancer have stable treatment preferences, but for reasons we were unable to unravel some patients still change their preferences. The only influential factor we found was the description or understanding of the current health status (chapter 8). We therefore recommend to integrate questions on patients' illness understanding into advance care planning conversations. This might be even more important, since on average just 11 seconds (less than 1%) of the total patient-oncologist speaking time is spent on checking the patients' understanding of information on prognosis and biomedical issues.²⁴

That being said, stable treatment preferences do not have to be a prerequisite for advance care planning. Most likely, (re)considering preferences and personal values in the light of (disease) progression is a natural and integral part of decision-making. Likewise, our review showed that ambivalence exists in attitudes towards advance care planning and readiness (chapter 6). Ideally, advance care planning is a dynamic and flexible process that creates a space in which patients can reflect openly on their values and preferences. Thinking about the own preferences and wishes may be new for patients and they might benefit from guidance and support during this process. Indeed, there is a discrepancy between feeling comfortable to discuss preferences and wishes and actual conversations; 70% of the general population in the United Kingdom say that they feel comfortable talking about death, however just about one in three respondents actually discusses their wishes.²⁵ Even though this number increases with age when conversations might become more relevant, still just 45% of 75+ years old people discussed their wishes and preferences.²⁵ In our review we found that patients generally preferred healthcare professionals to offer and open these advance care planning conversations (chapter 7). However, introducing advance care planning is a sensitive matter, since we found that patients with advanced, life-limiting diseases can also experience invitations for advance care planning interventions as confronting. In that case, questions and concerns about the severity of their situation and possible disease progression were triggered (chapter 6).

Based on these findings and in the light of patient-centered care, advance care planning might benefit from an approach which it is embedded in usual medical encounters. By doing so, advance care planning would adopt a process character with the goal of getting to know the patients' wishes and preferences through understanding their lived experience, instead of a distinct conversation focused on stating these wishes and preferences. This process approach would take away the barrier of having to start these conversations explicitly (chapter 7) and would allow for the development of and reflection upon individual (treatment) preferences.

Better care through better communication

Understanding advance care planning as a process that unfolds during medical encounters possibly requires a different style and focus of communication. Instead of an interview on preferences, an almost disease-oriented way of medical thinking, these encounters would be characterized by a focus on patients' concerns.¹⁶ It is worthwhile to highlight the importance of this focus, given that fact that in only 28% of observed medical encounters patients were able to complete their initial statements of (health related) concerns towards their family physician.²⁶ The mean time for patients to express their concerns until the first physician redirection was 23 seconds.²⁶ Most redirections occurred after the first concern that was expressed by the patient.²⁶ Patients were mostly hindered from sharing their concerns by closed-ended questions of their physicians, absence of solicitation or physicians' statements (such as "that sounds serious").²⁶ Interestingly, completed and noncompleted patient statements took about the same time.²⁶

The techniques of motivational interviewing might support healthcare professionals during their communication with patients near the end of life.²⁷ In the spirit of patient-centered medicine, the focus of healthcare professionals during motivational interviewing is to listen, rather than to intervene.²⁷ Carl Rogers, the inventor of this patient-centered approach, puts it as follows "*Real communication occurs, (...) when we listen with understanding. (...) It means to see the expressed idea and attitude from the other person's point of view, to sense how it feels for him, to achieve his frame of reference in regard to the thing he is talking about.*"²⁸

Motivational interviewing includes three principles.²⁷ The first principle is collaboration: healthcare professionals and patients work together as partners. The second principle is autonomy: healthcare professionals respect the patients' ability to make their own decisions. Patients are approached as autonomous human beings, with the freedom to make their own choices. The third principle is evocation: This principle includes the healthcare professionals' ability to support patients in reflecting on their internal motivations for a (treatment) preference.²⁷ Introducing these principles during medical encounters may stimulate patients in reflecting upon their wishes and preferences, and the underlying values, and could eventually inform healthcare professionals for developing and proposing a care plan that is consistent with the patients' values.

Acknowledging mortality

In our review on advance care planning in chronic respiratory diseases (chapter 7) healthcare professionals reported an ethos of ‘cure at all costs’ in medicine, which forms a barrier for them to engage in advance care planning.²⁹ Indeed, a recent comment of the Lancet Commission on the Value of Death pointed out that medicine continues to strive to keep patients with life-limiting illnesses alive, often beyond the point of benefit.³⁰ Similarly, healthcare professionals have been found to feel uncomfortable to discuss end of life care topics.³⁰ Two-thirds of general practitioners reported not feeling comfortable to talk to someone about their end of life wishes.³⁰ Interestingly, communication about end of life issues has not been found to be related to patients feeling more depressed or worried, neither to patients losing hope, increased suffering or hastened death.³¹

Medical care strives for improvements in diagnostics and treatment and therefore acknowledging impending death in terminally ill patients might feel contradictory to these intentions. Acknowledging mortality could well be an essential element of successful end of life care and might take away one of the barriers for engagement in advance care planning (chapter 7). Philippe Ariès extensively reflected on the attitudes of people towards death throughout history.³² He argued that death used to be generally accepted prior to the 17th century, when people were aware of their own death and prepared for it.³² Throughout the years, the appreciation of death changed and by the end of the 20th century, society had adopted the concept of ‘forbidden death’, in which death is seen as something shameful and forbidden.³² According to Ariès, we all seem to technically admit that we are mortal, however *“really, at heart we feel we are non-mortals”*.³² In psychology, the so-called ‘terror management theory’ explains this arguable contradiction of knowing that we are mortal but not wanting to admit to it, by relating it to the basic psychological conflict of having a self-preservation instinct, whilst realizing that death is inevitable and cannot be controlled.³³

Accepting the inevitable death of others and ourselves is therefore a complex matter.³³ Self-reflection can help to increase awareness of the personal mortality and mortality of patients. Eventually, this could help healthcare professionals to engage in conversations about treatment preferences in the last phase of life.³⁴

CONCLUSION AND RECOMMENDATIONS

For clinical practice

Advance care planning has the potential to increase the accordance between patient preferences and actual care, and patients’ satisfaction with care. We found that the patients’ lived experience, their understanding of their illness and preferences are highly individual and dynamic. To account for these individual differences, advance care planning might be most efficient and patient-centered if understood as a process, embedded in medical encounters. We would recommend healthcare professionals to be alert for patients’ emotional and health concerns, incorporate them in medical

encounters and repeat these conversations regularly. We found that treatment preferences are not necessarily stable, therefore conversations and decision-making should account for this and allow preferences to develop throughout time. Physicians are in a good position to have advance care planning conversations and might benefit from additional communication skills that are focused on increasing self-reflection as well as a patient-centered way of communicating.

For research

The number of studies in the field of care and decision-making near the end of life has increased throughout the years and the field, both research and practice, has benefitted from many well-conducted projects. For future research, we recommend to invest in longitudinal studies on the development of psychological outcomes (such as illness representations and coping) throughout the illness trajectory. Ideally, outcome measures on the adaptiveness and impact of these psychological concepts are included in the studies. It would also be worthwhile to investigate how advance care planning can best be integrated into medical encounters. It is important to acknowledge and investigate the perspective of healthcare professionals, to focus on experienced facilitators and barriers, to understand the perspectives of patients and their loved ones during this process and to get insight in their needs and challenges.

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