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Palliative non-oncology patients' wish to die. Final scientific report

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Full project title: **Palliative non-oncology patients' wish to die.**
The attitudes and concerns of patients with neurological diseases, organ failure or frailty about the end of life and dying.

1. Objectives of the research project

This qualitative interview-based research has been the second part of a twin study, which has investigated the subjective understanding, and in particular the diachronic and relational characteristics of a wish to die in palliative care patients with advanced incurable disease. Recruitment took place in the region of Basel, Switzerland. While the first part of the study was dedicated to patients with tumour disease, this second part of the study, investigated the phenomenon of wishes to die in the experience of non-cancer patients: patients with organ failure, degenerative neurological disease and frail people.

The data from both studies allowed for the comparative analysis of the phenomenon of a wish to die in the context of the subjective experiences of diverse illness trajectories.

The study aimed to explore the subjective phenomenon of a wish to die, i.e. the content and dynamics of the experience of a wish to die in patients who (a) wish to die but who do not wish to interfere in the course of illness in comparison to patients, who (b) explicitly express a wish to hasten death with either passive or active measures, and (c) with patients who are confronted with the situation to be near death without an explicit wish to die. As we knew from the oncology study, a wish to die and a wish to die statement can have different reasons, meanings and functions for the patient and the caregivers, depending on a wide range of factors in the context of their life histories, including the particular experience of illness. The differences / in-depth knowledge of reasons, meanings and functions have an impact for the decisions and best practice in end-of-life care.

In the research proposal we raised the following questions as subquestions for research:

- Which are the implicit and explicit concerns, values, factors or constellations that patients themselves perceive as relevant and influential for the emergence of a WTD?
- How do these factors change over time (diachronic aspects of the WTD) and
- How do patients and relatives perceive the significance of the influencing factors (relativity and relationality of the WTD)?

These questions were broken down to the following, more concrete **questions** (from the research proposal) to be tackled in the interviews:

- (1) What is the **meaning the patient attributes to his or her own dying**?
- (2) Are there different **“levels” of a WTD** and how can these levels be identified in a patient?
- (3) How can **advance directives** be involved? **How are they handled in practice**, in relation to a WTD?
- (4) Which factors are important in the perception of patients regarding their WTD - as **triggering/risk** factors; Are there characteristic constellations/clusters of factors if seen through the subjective accounts of patients? **How do patients evaluate** the factors against each other?
- (5) Which **ethical implications** do these informations bear, in particular to ethical decision making in end-of-life care?
- (6) How is the WTD related to the **patient’s image of the self** as an embodied being?
- (7) Are the patients' decisions **affected by the possibility for legal assisted suicide**, and, if so, to what extent?
- (8) Do patients perceive **palliative sedation as an alternative to hasten death**?
- (9) How are typical disease **trajectories** represented in the patients', caregivers' and relatives' **anticipations about the end of life**?

Objectives of the PhD project of Nina Streeck. During the first year of the study, the PhD project of Nina Streeck was integrated as an additional subproject to explore an aspect of wishes to die that had been proven relevant both during the first part and during the beginning of the second part of the twin study, namely the social dimension of wishes to die and dying in general (Working title: “Authenticity as an Ethical Ideal in Dealing with Wishes to Die”). The PhD project participated in the qualitative-empirical approach of the main study and, above that, accomplished a theoretical analysis to contribute to a deeper understanding of what is socially at stake for people at the end of life. The PhD project aims at contributing to a deeper understanding of the social dimension of dying and at informing current debates within end-of-life ethics and efforts to establish an appropriate “culture of dying”.

2. Research design, theoretical framework, methods and data

Theoretical Framework: The method of our research relies on a phenomenological-hermeneutic framework and is based on *Interpretative Phenomenological Analysis* (IPA) and *Grounded Theory* (GT). The idiographic approach of IPA enables in-depth investigation of how patients make sense of their personal experiences and the meanings they personally attribute to them. GT enables analysis of the data on a higher sociological level of abstraction. This approach is conceived to be as open as possible to the participants' subjective views and avoids moral judgments about controversial end-of-life practices.

Sampling: We did qualitative semi-structure interviews with terminally ill non-cancer patients. If they agreed, we interviewed also a close family member of their choice, a physician and a nurse. The patients were situated in various palliative care facilities: a hospice, a ward of palliative care, internal medicine or geriatrics, a rehabilitation center for neurodegenerative diseases, several nursing homes and patients at home.

Inclusion criteria: We interviewed persons who matched the following inclusion criteria: persons

1. with advanced neurological diseases (ALS/Multiple Sclerosis MS), organ failure or frailty at old age,
2. in a palliative situation (defined by the Gold Standard Framework),
3. who were already aware of the incurability of their condition or palliative state,
4. whose primary physician had consented to their enrolment in the study (patient protection),
5. who had sufficient language skills to participate in the interview, and
6. who were cognitively in a condition to participate in an in-depth interview
7. who consented in one or more interviews and analysis of their records.

Each patient was tested for depression (anamnesis and screening by Robinson’s mini-screen for depression and Beck-Depression Inventory in suspected depression). Existence of a persistent mild or moderate depression was not an exclusion criteria. We included not only patients who had expressed a WTD, because we also wanted to investigate the genesis of WTD or situations in which a WTD was not known to others and because we supposed hidden wishes to die. We deliberately investigated broader on WTD in general. We believed that there were various forms of WTD, with unknown degree of burdening, and that WTHD statements should be interpreted in the larger context of present wishes and concerns of patients.

Participant enrolment happened simultaneously to the on-going process of data interpretation. In line with the idea of ‘theoretical sampling’, we included in the beginning patients broadly, with and without known WTD according the above-mentioned criteria. In the course of the study interviewees were increasingly selected for theoretical reasons, involving more persons who had already expressed a WTD.

This report regards the second part of a twin-study on non-cancer patients. It included 32 patients, belonged to three groups: neurological diseases (mainly ALS and MS) (n = 10), organ failure (especially lung and heart disease) (n = 11), as well as frail elderly (n = 11).

Interview process: The semi-structured, face-to-face interviews lasted between 30 and 120 minutes and focused on the experiences, ideas and wishes of the patients with regard to their dying. The interview guide was tested in an initial pilot study (2007), was then applied in the study on cancer patients (2008-2011) and since then was refined throughout the entire interview period, as it is foreseen by our methodology. For the interview guide for the first patient interview, see Annex I. The interview guide for the follow-up interview with the patient was an adapted version of this first interview guide, as well as the interview guides for the relatives and health professionals that focused mainly on the patient experience as well (for more information on the other interview guides, please contact us). The interviews with nurses, doctors and relatives took place shortly after the patients’ interview and were based on an adapted interview guide focusing on the patients’ experiences and wishes and communication about it.

Interview feedbacks. From the view of interviewed patients and relatives the interviews were well tolerated, although they took place in a difficult context (burdensome life situation, unknown perspective, physical weakness). Most patients were grateful to be heard and to tell “their whole story to somebody”. The same counts for the interviewed relatives. Critical incidents did not happen. The cautious patient selection by physicians and the thorough preparation of the setting seemed crucial.

Recruitment of relatives. In 12 Patient cases, no relative could be interviewed. Reasons: 1 patient suffered from advanced dementia, 4 patients refused interviews with their relatives and 5 relatives renounced themselves, because they feared the interviews to be too burdensome. In one case the patient died soon after the interview and for reasons of piety the relative could not be asked any more. In 1 case, the reason for refusal remained unclear. Compared to the former interview-study on cancer patients, the burden on relatives was striking.

Table 1: Number of patients recruited

Inclusion and Exclusion Process	N	Remarks
Patients asked by attending physicians in institutions, nursing homes and at home	unclear	
Patients interviewed	34	
Patients excluded after interview process	2	P10: Dementia more severe than expected P27: Frailty. Dementia and depression with severe indecisiveness, both more severe than expected. Patient not able to decide to sign informed consent.
Patients included	32	

Interviews analysed	142
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Table 2: Characteristics of study patients (n=32)

Parameter	Details	N	Comments
Sex	M	18	
	F	14	
Age		58-97	(mean 82)
Place of Care	Home Care	3	13
	Nursing Home	10	
	Palliative Care Unit / Hospice	5	
	Rehabilitation	4	
	Acute hospital	10	
Type of Disease	Organ Failure	11	
	Neurologic Disease	10	
	Frailty	11	
Mood at Time of Interview	No Depression	22	2 patients with antidepressants for affective lability (P1, P31) 1 patient with antidepressant for unknown reason (P4)
	No depressive mood. Depression controlled by drug.	3	P15, P19, P29
	Active depressive episode.	4	3 mild (P17, P24, P28), 1 medium (P5)
	Mixed syndrome picture. Depression cannot be clearly distinguished from other mental impairment.	3	ALS with frontal dementia (P2, P8), or frailty (P30)
	Advanced Care Planning (ACP)	Yes	16
	No	16	
Member of Right to Die Organisation	Yes	4	
	No	25	
	Unclear	3	
Patients died**	No	21	
	Yes	11	Median interval between last interview and death: 53 days (range 3-480 days)

NH: Nursing home

** per December 31, 2015

Table 3: Key measures of the twin study (oncology and non-oncology patients).

	Cancer	Non-cancer
Number of cases	30	32
Age	34-87 Median 82	58-97 Median 82
Sex M/F	12/18	18/14
Deceased	28	11
Interval between last interview and death	5-237 Median 23	3-480 Median 53
Depression mild to moderate	3	4*
Interviews with caregivers	18	20
Total of interviews	116	132

*In 3 out of 4 patients depressive mood overlapped by cognitive impairment

A total of 248 interviews were conducted (116 in Study I (cancer), 132 in Study II (non-cancer)). 62 patients were interviewed, 30 oncological patients (Study I) and 32 non-oncological patients (Study II). Characteristics of the study patients are listed in Table 3.

Analysis. The interviews were audio-taped and fully transcribed. The transcripts were first read and openly coded by all authors individually. Analysis was sustained by the use of MaxQDA11. The main themes found in individual analysis were then discussed among all authors in shared discussions of a 'single case' (including the interviews with the patient, relatives, doctors, nurses). In-depth discussion of individual interpretations in the research group lasted as long we found for most cases a shared interpretation of a case. The analysis lead to the elaboration of the following emerging and set themes (the later coming out of the research questions).

Set and emerging themes in the second part of the twin-study

The **emerging themes** that came up in the second study were: E1 Subjective estimation about ones' own illness trajectory; E2 Feeling to be a burden to others; E3 Negotiating one's dying; E4 Acceptance of dying (has been an important aspect in the last project, but raised again as emerging theme in the interviews of the second study).

The list of **set themes** that have been used in analyzing the data included: G1 subjective meaning of one's dying; G2 factor time; G3 advance directives; G4 factors that trigger, influence or delay a wish to die; G5 image of body and self; G6 sedation; G7 how others are moved, touched or challenged by a wish to die; G8 significance and definition of a wish to die from the perspective of caregivers and relatives; G9 Anatomy of the WTD (intentions, motivations social interactions); G10 Ambivalence; G11 influence and significance of the Swiss regulation and attitude regarding assisted suicide to personal attitude.

Once the analysis advanced, some emergent or set themes were then deepened through axial coding in constant comparative analysis. Themes we undertook an axial analysis:

- Influence of diversity of dying trajectories on the WTD
- Acceptance of dying
- Feeling to be a burden to others

The interviews of relatives, doctors and nurses were interpreted insofar as they provide a perspective on the patients' situation, on the relationship to the patient, and on her/his views on dying. Though related, they are however independent perspectives from the patient and also served to gain a more nuanced interpretation of patient statements.

In addition to individual memos during coding, theoretical case memos based on the discussions in the research group were prepared for each case analysis, and that contained the interpretation of the team on important key themes, especially the interpretation of the WTD. In addition, we wrote memos for the axial coding. Both parts of the study (tumor and non-tumor) were approved by the Ethics Committee of Both Basel (EKBB).

The integration of N. Streeck's subproject led to the following extensions of the research design:

- In the first phase of the second study, it became clear that for a comprehensive understanding of wishes to die it is crucial to analyse their social dimension which so far had been insufficiently investigated. Therefore, questions regarding broader socio-cultural factors (beyond family relationships and the healthcare professional-patient relationships) were added, i.e. the perception of the possibility of assisted suicide, or facing up to social norms of dying. The questions aimed at exploring how patients experienced attitudes toward dying in their personal and social environment.
- Part of the PhD project addresses the analysis of the ethical ideal of authenticity and its application within end-of-life ethics so that a systematic approach had to be added to the qualitative-empirical methodology of the main project. It draws on different traditions such as hermeneutics, phenomenology, and critical social theory.

3. Results

3.1. Results of the main study

Overview over the results regarding the main research question and subquestions and where to find them in our publications:

- Which are the implicit and explicit concerns, values, factors or constellations that patients themselves perceive as relevant and influential for the emergence of a WTD?
- How do these factors change over time (diachronic aspects of the WTD) and
- How do patients and relatives perceive the significance of the influencing factors (relativity and relationality of the WTD)?

- In all our publications

Our results regarding the implicit and explicit concerns, values, factors or constellations that patients themselves perceive as relevant and influential regarding their WTD can be found throughout all our publications. The main paper that summarizes the results of the second part of the study is:

- Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: **“Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study.”** (in progress; to be submitted to PlosOne)

We described the typical patterns, similarities and differences in the subjective experiences of patients of the four illness and dying trajectories that we investigated. See more in detail below (Subquestion 9 and Theme III). We also described our findings regarding the diachronic aspects of WTD. For each patient group, we identified decisive turning points within the illness and dying trajectory that patient stated as important in the development of their WTD. These moments were different in each of the four trajectories and are relevant in the care for these patients. The complex diachronic structure of wishes to die that we already identified in the first study, was confirmed by the data of the second study also for the other patient groups. For this, we refer to our articles in the OUP-book on WTD we edited and contributed to in articles:

- Rehmann-Sutter C, Gudat H, Ohnsorge Kathrin (Editors). **The Patient's Wish to Die**. Oxford University Press. 2015.

The relational aspects also were tackled in nearly all of our publications; more specifically we analyzed it in our publications on the feeling to be burden to others and its relations to WTD. (see under Subquestion 4 and Theme IV).

- Gudat H, Ohnsorge K, Streeck N, Rehmann-Sutter C.: **Palliative care patients' feelings to be a burden to others can motivate a wish to die. An empirical ethics analysis of the moral challenges in clinical work** (work in progress; to be submitted to BIOETHICS call for special issue on burden-feeling).
- Rehmann-Sutter C: **Moral implications of self-perceived burden to others and wishes to die. A conceptual analysis** (work in progress; to be submitted to BIOETHICS call for special issue on burden-feeling).

There we show that complex inter-subjective considerations in caring relationships lead persons to feel to be a burden to others. These feelings are mostly nurtured by feelings of responsibility and moral considerations towards the other on both sides (patient and carer) and are triggering as well as preventive for a WTD.

Besides the below mentioned research articles, which are the main outputs of our research, we (Gudat, Rehmann-Sutter, Streeck, Ohnsorge) will publish separate articles in a book edited by Christoph Rehmann-Sutter on the meaning of dying. There we will explain some of our findings to a more general public. The 14 articles in the reader (most of them from other authors) want to connect the subjective perspective of persons close to dying with more social and philosophical reflections and stipulate reflection about the meaning of dying. Submission of articles until May 2017 (for more information on the content of the book, see Annex III).

Results regarding the subquestions:

(1) What is the meaning the patient attributes to his or her own dying?

- See our main publication of the results: Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: **“Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study.”** (in progress; to be submitted to PlosOne)

In this study, we identified various meanings patients attribute to their WTD that came up in the subjective experience of illness in the non-cancer patients and which are partly different from those of cancer patients. In the above-mentioned publication, we describe them and explain their differences respectively to the four patient groups (non-cancer and cancer) that we investigated in this and the previous study.

(2) Are there different “levels” of a WTD and how can these levels be identified in a patient (i.e. WTD as ‘being at ease with death’, to fulfill one’s life circle; WTD, because life is too burdensome, **refuse of life-sustaining treatments; WTD as wish to hasten death; other**)?

- Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: **In end-of-life care, consider the inner complexity and diversity of patients’ wishes to die.** (submitted to BMJ)
- Ohnsorge K, Rehmann-Sutter C, Streeck N, Widdershoven G, Gudat H: **Was bedeutet es, das eigene Sterben zu ‚akzeptieren‘? Ergebnisse aus einer qualitativen Studie mit 62 Palliativpatientinnen und –patienten** Zeitschrift für Palliativmedizin 18(2017): 144-151.

In this study, we found the same aspects of intentions that we identified in the previous study on non-cancer patients (see below). We got however more aware about the implications of thinking in ‘levels’ of escalation of WTD (from wishes to go to the ‘other side’ for spiritual reasons or mild wishes to hasten death to very strong desires to die and attempt to suicide). This thinking in ‘levels’ is quite common in the literature on WTD, even among empirical literature. Mostly, it serves to differentiate between wishes to hasten death that – is suggested – need attention in care and research, and wishes to die that do not lead to desires to hasten death and that are therefore often not considered as important clinical factors or aspects relevant for patient care. In the paper **“In end-of-life care, consider the inner complexity and diversity of patients’ wishes to die”** we argue that for understanding wishes to die, one has to acknowledge the inner complexity of these statements and that it is not helpful or even sometimes misleading to focus predominantly on desires to hasten death, instead of acknowledging the complexities that make up such a wish at the end of life. In this as in the previous study, we found most wishes composed of various different intentions (WTD next to wishes to live or

acceptance of dying or different wishes to die next to each other, i.e. hypothetical WTD next to actual wish to hasten death). In both studies (cancer and non-cancer) we also saw WTD that changed even shortly in time or after a long time being held in place. In our article, we tried therefore to raise attention of practitioners as well as researchers to perceive WTD in more complex way and to conceptualize WTD not through levels of escalation, but to acknowledge and detect these wishes in their complexity. We hold this differentiated understanding of WTD to be utmost important, when we want to understand patients' wishes and preferences for care and in providing the best care possible for a particular patient.

The analysis yielded three emergent themes that are related to acceptance. The analysis can be found in the paper **Was bedeutet es, das eigene Sterben zu ,akzeptieren'?**: (1) The subjective meaning of the acceptance or non-acceptance for the persons concerned, (2) how accepting occurs as a process and (3) acceptance as a normative claim, with which patients are confronted or which they pose to themselves. The interviewees understood their acceptance as an unstable balance that had to be continually re-established. We noticed that the acceptance of dying, a wish to live or a wish to die can coexist. Conclusions: Accepting or not accepting contains complex, multifaceted meanings which often do not represent the end point of considerations for those concerned. It represents the attempt to integrate something that seems inevitable into one's own attitude.

(3) How can **advance directives** be involved? **How are they handled in practice**, in relation to a WTD?

We did not further investigate on this topic. The material gave not enough results in this regard, even though all patients were asked in the interview whether they had an advance directive and what it meant to them. This does not exclude a more theoretical reflection on this in future based on the general material we found.

(4) Which factors are important in the perception of patients regarding their WTD - as **triggering/risk** factors; Are there characteristic constellations/clusters of factors if seen through the subjective accounts of patients? **How do patients evaluate** the factors against each other?

- Answered in our main publication of the results: Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: **"Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study."** (in progress; to be submitted to PlosOne).
- Gudat H, Ohnsorge K, Streeck N, Rehmann-Sutter C.: **Palliative care patients' feelings to be a burden to others can motivate a wish to die. An empirical ethics analysis of the moral challenges in clinic and families** (work in progress; to be submitted to BIOETHICS call for special issue on burden-feeling).
- Rehmann-Sutter C, Ohnsorge K, Onwuteaka-Philipsen B, Widdershoven G (eds.): **'Being a burden to others' and wishes to die. An ethically complicated relation. Bioethics; Special issue.** Closing date for submission 2nd May 2017 (see Call for publication, Annex II).

The main results for this question can be find in our article: **Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study."** There we describe for all three non-cancer patient groups the trigger and risk factors we found in the subjective accounts of our interviewees in comparison to the cancer patients (previous study). We identified indeed for each dying trajectory characteristic constellations or cluster of factors that are more frequently reported from patients as underlying their WTD. Next to the risk factors, we also identified decisive turning points (often moments of crisis) during an illness or dying trajectory that triggered a WTD or in which patients reported to have experienced more frequently a WTD.

As the issue of self-perceived burden emerged significantly in all four patient groups, we undertook an axial coding only for this theme that included both studies. In order to investigate this subject in more detail, we organized an international workshop in September 2015. This gave rise to the idea of a jointly submitted special issue in the journal 'Bioethics', which has been accepted and has the call running until May, 2nd. Christoph Rehmann-Sutter and Kathrin Ohnsorge will be together with Bretje Onwuteaka-Philipsen and Guy

Widderhoven the editors of this special issue. Our research on this topic was also presented in 9-11th June 2016 at the 9th World Research Conference of the European Association of Palliative Care (EAPC) in Dublin.

(5) Which **ethical implications** do these information bear, in particular to ethical decision making in end-of-life care?

- All our publications.

There are multifold ethical implications arising from the results of our two studies:

1. **Understanding WTD as ethical task:** WTD statements should never naively be taken at face value without appreciating their deeper intentional content. Without detailed understanding of the specific intention of a WTD, and without insight into its specific meanings, reasons and functions, it will be difficult to understand what a patient wants and why wishing it is important to patient. An in-depth understanding of the concerns and challenges of the subjective experience of WTD takes time (and can – we assume on base of our data - eventually not be done in a punctual contact with a patient, as some right-to-die organization offer it). It can facilitate the communication about end-of-life wishes and be helpful in assessing more accurately and responsively particular patients' needs and fears, if the patient wants so.
2. **Acknowledging complexity of WTD:** Professional caregivers should understand patients' expressions of a WTD as complex and dynamic constellations of intentions and meanings, and should be hesitant to label patients as 'contradictory' or 'depressive'. WTD statements can be occasions to probe and better understand the patients' subjective experience. The fact that WTD statements sometimes fluctuate does not justify seeing them as 'inauthentic'.
3. **Narrativity:** Patients' narratives around WTD are complex and personal. Foremost, they are narratively structured, meaning told by patients in such a way that they make sense to themselves. Reacting in a responsive and caring way to wish to die statements implies engaging with the underlying narrative structure of these statements. Caring responsibly for someone with a wish to die cannot be done without thoroughly investigating what people think about when they express such a wish and what meanings, fears, thoughts, and moral understandings in relation to themselves and others have brought them there. Patients need confidence and trust in order to state what is personally important to them. Clinic professionals should therefore have the appropriate hermeneutic and communicative skills in order to investigate such personal narratives together with the patient.
4. **Doing justice to patients with different forms of WTD:** Focusing exclusively on wishes to hasten death is unhelpful, since it hinders the detection of other forms of wishes to die. If wishes to die are only taken seriously if they are expressed as wishes to hasten death, one might fail to do justice to the complexity of patients' concerns, or misunderstand them. Not only those who express a wish to hasten death might need support. Patients' wishes to die of all sorts should be addressed proactively and should be mindfully explored
5. **Exploring Trajectories:** A better understanding of the concerns and challenges and the particular setting in an illness and dying trajectory in which a WTD arises can facilitate the communication about end-of-life wishes and be helpful in assessing more accurately and responsively particular patients' needs and fears. The awareness on critical points in time important in certain trajectories and that might trigger a WTD, on typical social issues as feeling to be a burden to others or on the needs to plan ahead and find solutions how to arrange dying in the most dignified way, is important and most needed for improving care for patients with WTD in end-of-life care.
6. **Acceptance:** Acceptance of dying and non-acceptance of dying contain complex, multifaceted meanings, which often do not represent the end-point of considerations for those concerned. Both, acceptance and non-acceptance can have a profound meaning for patients. Non-acceptance does not necessarily mean that a patient is 'removing' his or her dying. Health professionals should not impose pressure on patients to strive for acceptance of dying.

7. **Feeling to be a burden to others:** Self-perceived burden is frequently stated by patients as a reason for a wish to die. But depending on what is important it can also counterbalance a wish to hasten death, when the wish not to cause harm is more important than what one wishes for oneself. So, it is important to acknowledge that the feeling to be a burden to others not necessarily leads to a wish to die, but in some cases even prevents it being put into action. Without doubt, a self-perceived burden expresses often a deep existential suffering that might be alleviated at least partly by careful and open communication and intensified support, especially for family caregivers that are frequently really overburdened. But it is wrong to assume that self-perceived burden can or even should always be resolved. We need to recognize that this feeling also expresses strong personal bonds, loving care, and recognition of the other persons' commitment. In this sense, it affirms also personal moral values and moral understandings of oneself in relationship. While it is important to see where support can be offered, it is equally important to see where this feeling makes sense in a persons' moral world.

8. **Tailored response to patients' need and preferences:** Once the intentions, motivations and interaction of wishes to die are clarified, further questions may be asked more easily, to help respond compassionately to the actual needs of the patient at a given moment: What can be done medically, psychologically, through spiritual care or social support to ease the grounds of the wish to die, and the sufferings connected to this particular constellation of wishes? Being aware of wishes to die in a detailed and comprehensive way, in the context of possible wishes to live, has important implications for clinical practice. It helps to detect unmet needs early, ideally before a wish to hasten death is developed.

9. **Social interactions in health care around WTD:** It is an ethical imperative that patients should not be 'talked into' or 'talked out of' something that does not belong to their own understanding of themselves or does not reflect their own narrative account. It requires rigorous self-observation to detect the subtle influences that one's own values and convictions (i.e. in favor for or against assisted dying) can have within the dialogue that persuades patients directly or indirectly towards the 'better'. Between imposing one's own moral understandings on the patient and offering creative counter-stories that support him or her to arrive at a fresh and yet authentic interpretation of his or her experience, there is a thin ethical line.

(6) How is the WTD related to the **patient's image of the self** as an embodied being?

- Gudat H: **Erzählen am Lebensende im Kontext von Palliative Care.** In: Andreas Mauz, Simon Peng-Keller (Hrsg.), *Sterbenarrative. Hermeneutische Erkundungen des Erzählens am und vom Lebensende* (accepted for publication).

On the ground of the study interviews it is shown how people come to terms with chronic or incurable illness, with moments of transition, and breaking points in their life story, when telling "their story" to other people. The narrative act allows to maintain a social connection to the other and to (re)construct a social Self in times of instability and existential threat. Whereas physical and emotional symptoms were told in a direct language, attitudes, moral beliefs and concerns were embedded in stories. There were unnarrated aspects about disappointed expectations or personal failure associated with guilt or shame (addiction, disrupted relationships) and disnarrated aspects, as the high dependency from others or unbalanced relationships between patients and family caregivers, that were narrated with less importance than it would deserve. Some patients did not find any language to give words to their suffering. Others gave a picture of different concerns and wishes that stood in tension to each other, with or without feelings of ambivalence. Different narration strands, the unnarrated or disnarrated was only understandable when listening thoroughly. Narrative medicine should be fostered for a patient centered decision making and tailored care planning, especially in complex disease where patients have to find their individual solution among various therapeutic options. The society creates its own narrative about death and dying by how it recommends life prolonging therapies and how it deals with end of life issues. Probably a more creative approach would be helpful for patients and their families concerned by severe illness.

We also partly captured this aspect in our main publication of the results, but more as part of the subjective experience of the dying trajectory in relation to the WTD: **“Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study”** (in progress).

(7) Are the patients' decisions affected by the possibility for legal assisted suicide, and, if so, to what extent?

The data we generated does not allow for any conclusions in this regard. All patients were asked in the interviews about their ideas and opinions regarding the possibility of assisted suicide in Switzerland. Some patients were positive about the possibility for assisted suicide for the general population, but would not consider it for themselves. Those who thought about assisted dying for themselves through a right-to-die organization, of course were able to do so, because it is a legal option in Switzerland. Four out of 32 patients of study II were known to be members of a right to die organization, but did not take any action concerning assisted suicide. There were however also interviewees in the study who were not aware about the legal possibility of assisted dying or those who considered hastening death, but did not want to ask help of an organization. No one of the 62 patients (non-cancer and cancer study) committed assisted suicide.

Therefore, the question should be reframed to focus on how the patients and other participants see the existence of right to die organizations and the possibility to use their services, not on the extent of influence. A further analysis of our data in regard to this issue could be done, however exceeded the capacities of the present project.

(8) Do patients perceive palliative sedation as an alternative to hasten death?

We collected some interesting data about this issue and plan for further publication on this topic, which, we believe, is highly important. It is currently well discussed in the international literature and urging for further investigation also in the Swiss context as recent literature suggested surprisingly high numbers of palliative sedation in Swiss end-of-life practice. What the patients, we interviewed, thought about palliative sedation seemed to depend to a good degree on the amount and quality of information given by their physicians. Some patients were not aware of the option of palliative sedation at all. The neurological patients, however, were very well informed about palliative sedation, since they had standardized information procedure by their specialist or an ALS nurse. They all knew that it was an option for them in case they would experience advanced breathlessness or in alternative to the choice for respirator support. The same was true for the patients with COPD. While many patients said that simply knowing about the possibility of a palliative sedation at the end-of-life was a release to them, some understood palliative sedation indeed in closeness of or as an alternative to hastening death (putting for sleep for killing like an animal, “einschläfern”). Here it is not clear whether this comes through misunderstanding in the process of information with the physicians or because it is not always easy for the persons concerned to distinguish these practices in their symbolic content. More research is needed on this issue.

(9) How are typical disease trajectories represented in the patients', caregivers' and relatives' anticipations about the end of life?

- See our main publication of the results: Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: **“Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study.”** (in progress; to be submitted to PloseOne)

In the subjective accounts among persons going through the same illness or a condition of old age, we found recurring considerations and experiences connected to the particular illness or health status next to other more personal concerns that were deployed by the interviewees to explain the presence of their WTD. These considerations do not explain the WTD in total, but give important information on both, the challenges for

particular patients groups that might lead to a WTD and on what to investigate more in detail once a WTD is experienced.

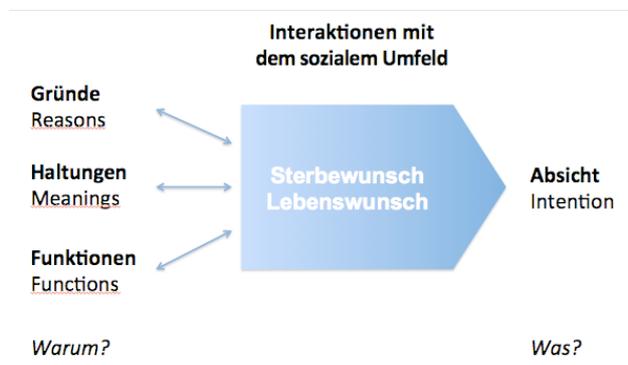
In all patients groups except the frail elderly who have a less predictable dying trajectory, there were clear moments that triggered a WTD: In neurological patients, these moments were when they had to consider starting tube feeding or respirator support. Advanced breathlessness, spastic paresis that importantly compromised quality of life and indicated closeness of dying, and moments of choices for initiating palliative sedation were other important breaking points for neurological patients. Patients with organ failure experienced time-restricted WTHD during acute highly burdensome crisis' and with regard to similar situations in future. Patients with tumor often reflected about a WTD in timely closeness to the first diagnosis ("shock of diagnose"), the first relapse, significant aggravations, and during the move from curative into palliative care (if understood as a clear cut in patients-physician-communication; 'there is nothing we can do'; "then I stopped fighting"). One can hypothesize that for the frail elderly, moments as giving up ones' home and moving into care facilities, losses of important relationships or physical capabilities might be similar breaking points that trigger a WTD. In health care regarding all pathologies, these critical moments definitively deserve particular attention and increased communication in the process of patient care.

For the following themes we did more in-depth analysis or axial coding:

Theme I: The Anatomy of the Wish to Die

- Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: **In end-of-life care, consider the inner complexity and diversity of patients' wishes to die.** (submitted to BMJ)
- Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: **"Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study."** (in progress; to be submitted to PlosOne)

From the findings of the first study, we have developed a model that distinguishes between intentions, motivations (reasons, meanings, functions), and social interactions (see Table below). In medical practice, the model is intended to help analyzing a WTD to better understand its meaning for those affected, and to refine patient-physician-communication.



in: Ohnsorge K, Gudat H, Rehmann-Sutter C: **Intentions in wishes to die: analysis and a typology – A report of 30 qualitative case studies of terminally ill cancer patients in palliative care.** *Psycho-Oncology* 23: 1021-1026 (2014). DOI: 10.1002/pon.3524.

In the current study, we tested this model and further elaborated on it in non-cancer patients. The data of the current study confirms the three-fold structure of the model. We refined the model however with respect to the hypothetic wishes to die and found some more motivations, especially meanings, in the interviews with non-cancer patients

Hypothetical WTD were expressed in all patient groups, but were differently situated and were diversely laden in the different trajectories. In all of them, we noticed that the hypothetical WTD of patients who considered themselves close to dying, were formulated in a way that felt emotionally closer or more realistic than

hypothetical WTD of patients, who thought themselves to be still far from dying. These lasts were formulated more abstractly, and seemed to reflect the patients' idea of a "good death" or of what they tempted to avoid. In assessing these hypothetical WTD, it seems to be important to evaluate how patients see themselves in the progress of their illness and how far they consider themselves to be from dying. However, for illnesses as ALS, MS or cancer, time and circumstances were better foreseeable than for patients with organ failure or frailty.

Motivations, additional meanings: The following *additional* meanings were found in the groups of non-cancer patients:

Wanting to die

- to avoid that others remember oneself as an ill person. (P32-II)
- to avoid a situation that one perceives as degrading/without dignity
- to avoid having to go again through the next life-threatening health crisis (i.e. patients with COPD)
- to get released from a more and more complex, burdensome daily life
- to end a life bound to institutional care,
- to act against suffering from alienation, loneliness or mistreatment

All of them are described in detail in our publication: "**Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study.**"

This model will help to understand the subjective meanings of WTD and refine patient-physician-communication. In our paper "**In end-of-life care, consider the inner complexity and diversity of patients' wishes to die**" we describe it more in detail.

On basis of the model Kathrin Ohnsorge and Heike Gudat have given a Meet-the-Expert-Workshop under the title: "Exploring and understanding wish to die statements" at the 15th Conference of the European Association for Palliative Care in Madrid in May 2015.

Theme II: Acceptance of dying

- Ohnsorge K, Rehmann-Sutter C, Streeck N, Widdershoven G, Gudat H: **Was bedeutet es, das eigene Sterben zu ,akzeptieren'? Ergebnisse aus einer qualitativen Studie mit 62 Palliativpatientinnen und –patienten.** Zeitschrift für Palliativmedizin 18(2017): 144-151.

In the previous study, we identified acceptance of dying as one possible attitude or intention next to the WTD. It is a frequent expectation in palliative care that the acceptance of dying is a desirable attitude. As in the previous study also in the current study, patients frequently spoke about their accepting attitude, also in distinction of their WTD. For a clearer view on the WTD and to refine the model of the 'Anatomy of the WTD', we undertook an in-depth analysis of the subjective experience of acceptance in the interviewees' accounts in our study. The axial analysis of this theme yielded three emergent themes: (1) The subjective meaning of the acceptance or non-acceptance for the persons concerned, (2) how accepting occurs as a process and (3) acceptance as a normative claim, with which patients are confronted or which they pose to themselves. The interviewees understood their acceptance as an unstable balance that had to be continually re-established. We noticed that the acceptance of dying, a wish to live or a wish to die can coexist. We concluded that accepting or not accepting contains complex, multifaceted meanings, and often do not represent the endpoint of considerations for those concerned but the attempt to integrate something that seems inevitable.

Theme III: Wishes to die and differences in the subjective experience of dying trajectories

- Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H: "**Wishes to Die at the End of Life in Four Typical Dying Trajectories. A Qualitative Interview Study.**" (in progress; to be submitted to PloseOne).

We analyzed the subjective account of the WTD for each of the three dying trajectories and compared it to the accounts of cancer patients and elaborated for each of these four trajectories according to our 'Anatomy Model' typical aspects regarding the intention, motivations and social interactions. Looking at the WTD through trajectories shows that people dealing with similar trajectories are often confronted with similar questions and concerns due to similar challenges. For each dying trajectory we found typical patterns, similarities and differences that are to be considered when talking with patients about their WTD.

For example, many of neurological patients expressed a hypothetical WTD, thus a WTD for the future for the case, if conditions would become unbearable (while there were also other WTD and concrete WTD in this group). Hypothetical WTD in neurological patients expressed a need for security, fear of complete dependence and loss of control.

Persons with organ failure instead stated their WTD in the context of an up and down between life threatening health crisis and re-stabilization. Their WTD often reflected this situation: all of them had expressed a WTD during a life-threatening crisis and many of them had hypothetical WTD for the future in case of a next crisis. They spoke of their WTD as a means of control. They did not want to go again through the unwanted experiences and pain.

Older, frail persons situated their WTD in the experience of perceiving their inner and outer reality as increasingly complex and feel overburdened by that. Feelings of alienation (to places and in between generations), physical deterioration, increasing dependence, institutionalization and loss of friends and relatives led to the feeling of alienation and a reduced life-world that underlined their WTD.

Persons with tumor diseases, finally, expressed a WTD often in a situation of a high physical burden and psychological suffering. They wished to die to let death put an end to severe suffering, to put an end to a situation that was seen as an unreasonable physical or psychological demand or to end a life they felt was now without value. A lack of perspective and hopelessness due to the clear awareness of the approaching death was frequently mentioned by the interviewees with cancer patients as reasons for their WTD.

For each patient group, we also identified decisive turning points within the illness and dying trajectory that seemed important in the development of a WTD. These moments were different in each of the four trajectories. Health professional should be aware of an increased risk to develop WTD during these breaking points of these illness and dying trajectories.

Illness-related considerations alone do not give a comprehensive insight into the WTD in total, but give important information on both, a) the challenges that particular patients groups frequently live and that might lead to the formulation of a WTD and b) on what can be investigated to understand an existing WTD of a particular patient. These challenges belonging to the subjective experience of different dying trajectories set the conditions in front of which WTD are articulated.

Theme IV: Feeling to be a burden to others

- Rehmann-Sutter C, Ohnsorge K, Onwuteaka-Philipsen B, Widdershoven G (eds.): **'Being a burden to others' and wishes to die. An ethically complicated relation.** *Bioethics; Special issue.* Closing date for submission 2 May 2017 (extended to 2 October 2017).
- Gudat H, Ohnsorge K, Streeck N, Rehmann-Sutter C.: **Palliative care patients' feelings to be a burden to others can motivate a wish to die. An empirical ethics analysis of the moral challenges in clinic and families** (work in progress; to be submitted to BIOETHICS call for special issue on burden-feeling;).
- Rehmann-Sutter C: **Moral implications of self-perceived burden to others and wishes to die. A conceptual analysis** (work in progress; to be submitted to BIOETHICS call for special issue on burden-feeling).

In our study, self-perceived burden was a frequently named issue by patients with a WTD and without. Only some related it also to wish to die statements.

Patients' explanations: Patients were concerned to impose physical hardship, deprivation of sleep, limited private time or emotional burden on others. Associated emotions (guilt, shame, self-hate etc.) were related to moral values that patients felt violated. Patients adopted strategies to avoid being a burden, such as choosing for institutionalized care, avoiding burdensome communication, not calling for help or deciding for or against certain treatments.

Burden-feelings and wishes to die: For some, the feeling to be a burden was the predominant reason for their wish to die. Others with a wish to die, instead, worried that expressing this wish would burden others. Frequently, patients refrained from executing a wish to hasten death arguing that they did not want to create suffering for others by hastening death. Feelings to be a burden were deeply connected to personal moral understandings and self-concepts, but were as well generated in social interactions, through tacit assumptions or verbal and non-verbal communication.

We concluded that while feelings to be a burden can lead patients to state a wish to die, these feelings can also counterbalance a wish to hasten death. In caring for these patients, it is important to understand which of their or others' moral values patients perceive to be violated.

The ethical implications of the phenomenology and the cognitive content of the emotions seem to have a dialogical structure: It is not only the actual caregiver burden that motivates the feeling (or fear) to be a burden; it is rather the patient's *belief* about the burden the others carry. Using a relational analysis proposed by Ronald D. Laing (and "Jack and Jill" as model names), Jack's feeling to be a burden to others can contain several relational elements, such as: (i) Jack fears to be such a burden to Jill; (ii) Jill fears that Jack thinks he is such a burden to her; (iii) Jack fears that Jill thinks he thinks to be such a burden to her. So, the perspectives are intertwined, even in one mind. Ethical implications of this are discussed in Rehmann-Sutter C: Moral implications of self-perceived burden to others and wishes to die. A conceptual analysis (submitted to Bioethics call for special issue on 'Being a burden to others').

3.2. Results of the PhD thesis of Nina Streeck

The subproject of Nina Streeck led to the following results:

1) Social influences on individual reflections of dying and death: Results from the qualitative study

- Streeck N: **Das Lebensende gestalten. Soziale Anforderungen und individuelle Umgangsformen mit dem Sterben.** Psychosozial 40 (1), 2017, 93-104.

The article addresses the question how individuals at the end of life prepare for their imminent death and how they deal with making plans for their dying process. It focuses on how social conditions, norms and requirements translate into individual ways of approaching one's own dying. First, the paper introduces and discusses what characterizes current dying processes. The possibility of individually determining one's dying is identified as a crucial feature that is associated with various challenges for the dying person. Based on the description and interpretation of two cases it is then shown how these challenges affect individual reflections on the end of life and the planning of one's own dying.

- Streeck N, Rehmann-Sutter C, Ohnsorge K, Gudat H: **Contemplating the good death: views of terminally ill and frail patients on death and dying** (in preparation)

2) The social dimension of dying: Current ideals of death and dying under scrutiny – theoretical analysis

- Streeck N: **Ende gut, alles gut? Sterbeerzählungen und Entscheidungen am Lebensende.** In: Mauz A, Peng-Keller S (Hrsg.), *Sterbenarrative. Hermeneutische Erkundungen des Erzählens am/vom Lebensende.* Berlin: DeGruyter (accepted).

The book chapter focuses on narratives of dying from a narrative ethics perspective. The concept of narrative coherence is discussed as 1) people at the end of life can feel the need or the desire to establish narrative coherence in their life stories, and 2) some narrative ethics approaches operate with a normative concept of coherence. It is argued that narrative coherence neither is suited to clarify moral issues nor can it function as evaluative criterion within theories of the good life. On the contrary, striving for narrative coherence at the end of life can turn into a problematic demand being imposed on the dying.

- Streeck N: **Sterben, wie man gelebt hat. Die Optimierung des Lebensendes.** In: Jakoby N, Thönnies M (Hrsg.), *Zur Soziologie des Sterbens. Aktuelle theoretische und empirische Beiträge.* Wiesbaden: Springer VS 2017, 29-48.

The good death is subject of vigorous debate today but it is not always clear what is being discussed: good death or good dying? The paper develops the argument that it characterizes current approaches to end of life to subject the dying process to certain distinct forms of optimization. Primarily, the optimization of dying follows the influential ideals of „good death“ represented by Palliative Care (PC) and the Right-to-Die movement. The analysis of the provision of terminal care by PC and of assistance in dying by Right-to-Die organizations, respectively, sheds light on how optimization processes of dying are currently being realized.

- Streeck N: **„Leben machen, sterben lassen“: Palliative Care und Biomacht.** *Ethik in der Medizin* 28(2), 2016, 135-148.

Definition of the problem The article takes a critical look at the current theory and practice of palliative care (PC), how it deals with death and dying and which ideal of good dying orientates PC. On that account, Foucault's concept of bio-power is utilized. *Argument* Since PC aims at facilitating a good death, manifold criteria and measures have been developed that help plan interventions and control for their success. In the light of the concept of bio-power certain problematic aspects of this development become manifest that are usually not thought of within the bioethical discourse. *Conclusion* As PC wants to improve the quality of life of the dying and therefore not only treats physical symptoms but also psychological, social and spiritual suffering it commits itself to maximising life in a way that can become overdemanding for the individual and possibly does not satisfy his real needs.

- Streeck N: **Nicht für immer. Ars moriendi nova – Sterbekunst ohne Jenseitsperspektive.** *Hermeneutische Blätter, Themenheft „Für immer“*, 2016, 150-160.

The medieval notion of „ars moriendi“ has gained attraction in discourses on the good death. It opens a way to discuss current concepts of good death and establish an „ars moriendi nova“ as a modern culture of dying. The paper discusses approaches of such a new „ars moriendi“ and asks for the consequences of introducing a modern art of dying that gives up on religious conceptions of the afterlife.

- Streeck N: **Sterbewünsche – medizinethisch-empirische Zugänge.** In: Hilpert K, Sautermeister J (Hrsg.), *Selbstbestimmung – auch im Sterben? Streit um den assistierten Suizid.* Freiburg: Herder 2015, 17-29.

The book chapter gives an overview of the current state of research on wishes to die and discusses ethical implications of empirical insights in wishes to die.

- Streeck N: **Selbstbestimmung als Element der Vorstellung vom guten Tod.** *Bioethica Forum* 7, 2014, 136-138.

The comment discusses the concept of autonomy as an element of current ideals of dying.

3) Authenticity as an Ethical Ideal at the End of Life

In addition to the papers and book chapters presented, the actual PhD thesis (monograph) will be completed (this year) and published (presumably 2018). The thesis addresses the question of good dying and aims at contributing to current endeavours to come to an understanding of a common culture of dying. It focuses on an analysis of dying ideals and suggests to interpret them as being motivated by the ethical ideal of authenticity that thus gives answers to the question of how to reach a good death. A critical concept of authenticity is constructed that can help identify problematic practices at the end of life and guide attempts to enable a good death.

The monograph will be delivered to the SNF after publication.

4. Recommendations for policy makers and experts from the practical realm

Health care professionals: To acknowledge wishes to die at end of life as an important issue. There must be a change of perception, that WTD are inherent part of patients' coping with severe illness and dying. The awareness for and handling of wishes to die must include those without the desire to *hasten* death. Acknowledge that wishes to die in severe illness are complex, dynamic constructs, consisting of different strands of wishes, in which partial wishes may stay in tension to each other, that they show a temporal course and maybe chagement of prioritisation, and that they have a strong social, interpersonal dimension.

Proactive and reflexive communication of health professionals: Encourage an open and respectful discussion on the topic, on professional, public level and in the professional-patient-relationship, and give a voice to the persons concerned (patients, families, but also experienced professional caregivers). Approach the discussion on wishes towards life and death in a broad sense, without limiting the discussion on wishes to hasten death. Approaching WTD should occur without judging patient's attitudes morally. Talk about hastening death (for example on assisted suicide) in the most objective and (self-)reflexive terms to minder a polemic, non-constructive level of discussion. Unburden patients from feelings that they plan and act in an unmoral way.

Enable professionals, especially physicians of primary care, to deal with terminally ill patients' wishes to die: Professionals in primary care are said to care for about 80% of all patients in advanced palliative care situations. Within these professionals, general practitioners are of outmost importance: as the physician of trust, mostly in a long-lasting relationship, offering family oriented medicine and being case-manager in complex and instable illness. Also important are nurses of ambulatory services, social workers, but also specialized physicians, since the Swiss health care system is known as a markedly specialist-orientated health care system.

Knowledge, competencies and skills concerning palliative medicine, care, psychosocial issues and communication have to be fostered by implementing them in regular medical education and formation.

Palliative units in hospitals could be better integrated into medical curricula or formation programmes, especially for future general practitioners.

Develop easy and well accessible tools to assess the patients' wishes. Professionals should be better sensitized for characteristic breaking points in illness and dying trajectories, that let a wish to die arise (to know the "red flags").

Assessment tools should be practicable for primary care settings. Development of tools preferably include inputs of professionals caring for patients. The heterogeneous situations should be considered (different diseases and comorbidities, social and cultural setting).

Strengthen narrative medicine in education, formation and practical work.

Experts promoting narrative medicine are team members of today palliative care teams, but are insufficiently financed (for palliative care units mandatory, but insufficiently paid for the service on demand, "Vorhalteleistung").

Find alternatives for patients, who are not capable to use language as a tool of communication (patients who do not feel at ease to frame their needs by words, cognitive impaired patients, patients with migrant background).

Improve early access of patients to palliative care, since the inner dialogue on wishes toward life and death may start with diagnosis of an incurable disease.

- The palliative approach includes a dialogue on psychosocial and spiritual aspects. Acknowledge that wishes to die can disappear under tailored palliative care, but respect that they may also persist.
- Use early appropriate advance care planning (content and communication adjusted to the phase of disease) to empower patients and family caregivers in moments of crisis and supposed complications when illness aggravates (fear for pain, terminal suffocation, loss of control, fear to be a burden due to insufficient care net)
- create settings for the elderly that let them feel welcome to society and pay attention to their need for biographic work and recognition.
- promote and offer psychosocial support for patients with incurable disease from diagnosis on, especially for patients with stigmatized illness (cancer, ALS, multiple sclerosis), so that they keep agency and emotional stability.

Support the care unit of patient and informal caregiver (family members). Unbalanced situations enhance suffering of patient and caregiver, the patients' feeling to be a burden or a wish to die (spelled or suppressed in front of others). In this context the backing of caregivers has to be enhanced in practical life, in financial aspects, and on emotional and spiritual level. Acknowledge informal caregivers as a crucial part within the care, decision making and wellbeing of the patients. Include them in evaluation of the patients' situation and planning. Improve financial support and reduce their financial shortcoming due to loss of earnings. Improve the caregivers' support by peer groups, self help groups and communication platforms.

Strengthen research in palliative care and especially at end of life, that takes the perspective of patients and caregivers as a starting point or which at least integrates it.

- to detect the characteristic breaking points within disease trajectories: research on the patients' perspective during the temporal course of characteristic trajectories.
- Strengthen research for vulnerable patients in this context (under flanking measures): patients with cognitive impairment, with psychiatric (co)morbidities, with migrant background, socially deprived patients.
- Include the perspective and special needs of caregivers (psychosocial and spiritual support, financeable relief of care round the clock)
- Define sensitive points within disease trajectories that trigger wishes to die; give special consideration to illness trajectories with recurrent decompensations (for example organ failure).

Acknowledge as society the ethical and social dimension of wishes to die in severe illness (incurable disease, chronic care) **and frailty, when patients feel like a burden.** Respect that patients develop feelings to be a burden to others and utter WTD, but give as society the signal to patients that they are welcome and appreciated. This touches also the discussion of limited resources within the health care system, which is important, but has to be held prudently and respectfully.

5. Implementation activities

Award

HEMMI-PREIS 2016

The HEMMI-foundation has dedicated the award for outstanding research in oncology 2016 to our research group. The price of CHF 15'000 will be used for a project, that transfers research knowledge into practice.

Teaching: Continuous academic, postgraduate and specialized training for health professionals that present our research findings:

Workshop: „Wenn Menschen sterben möchten. Die Bedeutung von Sterbewünschen bei Menschen in schwerer Krankheit“. Takes place 1-2 times a year at the HOSPIZ IM PARK. By Christoph Rehmann-Sutter and Heike Gudat.

Zertifikatslehrgang "Palliative Care in der Grundversorgung" von SBK und HOSPIZ IM PARK (level B1 of palliative

ch, 10 days): Input, case study and discussion of 2 hours on the topic wishes to die. Takes place twice a year. By Heike Gudat.

Within the Zertifikatslehrgang (CAS) „Interprofessionelle spezialisierte Palliative Care“ of the palliative care unit, Inselspital, Berne. Takes place every 2 years, with start 2017. By Heike Gudat (presentation of or model of WTD) and Simone Münger.

Within the “Basler Lehrgang für Psychosomatik” 2 hours of theory, case study and discussion on the topic wishes to die. By Heike Gudat.

Within the “Forum für medizinische Fortbildung FomF“, Technopark Zürich: Within the lecture for palliative care in the ambulatory setting presentation of the model for WTD and of key questions within a patient-physician-dialogue. By Heike Gudat.

Within the curriculum “Psychoonkologie” of the Swiss Cancer League. 2-3 hours of theory, case study and discussion on the topic wishes to die. By Heike Gudat.

Within the different professional settings the findings of our study and our model of analyses are presented.

Seminar and Workshop “Wishes to die at the end of life. Empirical findings and ethical interpretation.” At the University of Padua together with prof. Corrado Viafora. By Kathrin Ohnsorge.

Seminar “Desideri di morire in persone con malattie terminali o età avanzata” within the Corso di Perfezionamento di Bioetica (yearly 2013-2017). Postgraduate training. University of Padua, Italy. By Kathrin Ohnsorge.

Student Seminar: „Assistiertes Sterben und die Vorstellungen vom „guten Tod“ - ethische Fragen am Ende des Lebens“, Institut für Mendizingeschichte und Wissenschaftsforschung der Universität zu Lübeck. Normally by Christoph Rehmann-Sutter, in 2016 by Kathrin Ohnsorge.

Presentations/Conferences

19.5.2017 Ohnsorge K, Gudat H: Meet the expert (session): “Exploring and understanding wish to die statements”, 15th Congress of the European Association for Palliative Care, Madrid.

15.-16.03.2017 Streeck N. Zwischen Gestaltungswunsch und Geschehenlassen. Der heutige Umgang mit dem Sterben. Frühlingstagung der Übungsgruppe für geistliche Begleitung, Luzern.

13.3.2017 Rehmann-Sutter C. Ethics at the end of life - biopolitics of dying. Vortrag im MA-Programm, Modul Case Studies in Bioethics & Society. Department of Global Health and Social Medicine, King’s College London.

26.01.2017 Gudat H. Individualisierte Palliative Medizin. Was schwer kranke Menschen brauchen. Fachtagung Psychosomatik und Palliative Care, Klinik Schützen, Rheinfelden

23.11.2016 Gudat H. Suizidales Begehren im Alter und in schwerer Krankheit. Fachtagung Katholische Akademie, Berlin.

04.11.2016 Gudat H. Was Betroffene meinen, wenn sie sagen, dass sie sterben wollen. Hauptvortrag, ALS-Tag. Organisator: Gesellschaft für ALS Schweiz.

30.09.2016 Streeck N. Gut sterben: Die Sicht der Betroffenen, Tagung „Sterbewünsche bei Menschen in schwerer Krankheit“ im Rahmen des NFP 67 „Lebensende“, 29.-30. September 2016, REHAB Basel.

13.04. und 27.09.2016 Gudat H. Sterbewünsche bei Menschen in schwerer Krankheit. Vortrag und Workshop, Jahresfortbildung Bistum Basel.

17.09.2016 Streeck N. Das Ideal vom guten Sterben. Gesellschaftliche Perspektiven. 7. Diözesaner Ärztetag zum Thema „Ars Moriendi. Haltungen und Herausforderungen in der Begleitung sterbender Menschen. Medizin, Psychologie und Seelsorge im interdisziplinären Dialog, Erzdiözese München und Freising.

08.09.2016 Ohnsorge K, Sterbewünsche in der Palliative Care – ein komplexes, multi-dimensionales Phänomen (Poster); 11. Kongress der Deutschen Gesellschaft für Palliativmedizin, 07. - 10. September 2016, Leipzig

6.9.2016. Rehmann-Sutter C. Ethische Probleme der organisierten Suizidhilfe in der Schweiz. Vortrag am Workshop I, Arbeitsgruppe Sterbehilfe, Verein Ethik und Medizin Schweiz VEMS, Olten.

09.06.2016 Gudat H. Zur Last fallen. Workshop für Psychosomatiker. HOSPIZ IM PARK, ARLESHEIM.

18.6.2016. Rehmann-Sutter C. Self-perceived burdens to others. Towards and ethics of dependency in end-of-life care relationships. Talk at the Institute of Medical Ethics Conference in Edinburgh, The Royal Scots Club.

10.6.2016 Ohnsorge K. Feeling to be a burden to others and wishes to die in palliative care. 9th World Research Congress of the European Association for Palliative Care, Dublin.

4.6.2016. Rehmann-Sutter C. Sterbe- und Lebenswünsche in schwerer Krankheit aus der Sicht der Betroffenen. Warum qualitative Forschung wichtig ist. Vortrag an der Fachtagung zum 20. Jubiläumsjahr „Vom Hospiz zum Palliativzentrum, Hospiz im Park, Arlesheim.

30. Mai 2016. Rehmann-Sutter C. Zur Last fallen. Vortrag, zusammen mit Heike Gudat, im Rahmen der Wanderausstellung Palliative Care. Kulturhotel Guggenheim, Liestal,

9. 5.2016, Rehmann-Sutter C. Wenn Menschen sterben möchten. Zu einer patientenzentrierten Ethik des Wünschens am Lebensende. Tagung deutsche Krebsregister Lübeck,.

10.04.2016 Streeck N. *Sterben gestalten – wie?*, Jahresretraite des Pfarrkapitels Stadt Zürich, Reformierte Kirche, „Das schwierige Sterben. Die Debatte um Suizidhilfe und Palliative Care“, 10.-12.04.2016, Magliaso.

1.4.2016 Rehmann-Sutter C. Ethik der Sterbehilfe und der Suizidbeihilfe. LAP-Kurs im 1. Jahreskurs Medizin der Universität Basel (zusammen mit Dr. Marion Schafroth, Exit). Im Hospiz im Park, Arlesheim,.

1.3.2016 Rehmann-Sutter C. Ethics at the end of life – biopolitics of dying. Lecture and Seminar in the Masters Programme „Bioethics & Society“, Department of Social Science, Health and Medicine, King’s College London,.

31.01.2016 Gudat H. Trauer und Abschied. Was schwerkranke Menschen erzählen. Öffentlicher Vortrag, HOSPIZ IM PARK. Im Rahmen der Wanderausstellung Palliative Care, Basel. Organisatoren: römisch-katholische und reformierte Kirchen Baselland.

30.01.2016 Matinée mit Christoph Rehmann-Sutter und Heike Gudat. Was schwer kranke Menschen über das Lebensende sagen. Im Rahmen der Wanderausstellung Palliative Care, Basel. Organisatoren: römisch-katholische und reformierte Kirchen Baselland.

22.01.2016 Streeck N. *Ende gut, alles gut? Sterbeerzählungen und Entscheidungen am Lebensende*, Interdisziplinäre Forschungstagung „Sterbenarrative. Hermeneutische Erkundungen des Erzählens am/vom Lebensende“, Universität Zürich

21.01.2016 Gudat H. **Erzählen am Lebensende im Kontext von Palliative Care**. Interdisziplinäre Forschungstagung Sterbenarrative – Hermeneutische Erkundungen des Erzählens am/vom Lebensende. Organisator: Peng S., theologische Fakultät, Zürich.

16.12.2015 Streeck N. *Sterbeideale oder: Gibt es den guten Tod?*, Öffentliche Ringvorlesung „Altern, Sterben und Tod“, Universität Zürich

26.11.2015 Streeck N. *Selbstbestimmt sterben: geht das?*, Medizinische Fortbildung, Pfizer Schweiz, Zürich

- 13.11.2015 Streeck N. *Ethics in Everyday Palliative Care*, Zurich Intensive Bioethics Course, 13.-15.11.2015, Universität Zürich
29. 10.2015 Rehmann-Sutter C. Einführung in die ethischen Aspekte der Sterbehilfe. Vortrag und Moderation des Workshops "Ärztliche Sterbehilfe oder assistierter Suizid?" Auditorium Kantonsspital Olten, (veranstaltet vom Verein Ethik und Medizin Schweiz VEMS, published as film on Youtube: <https://www.youtube.com/watch?v=5YzgDKCr72k>).
9. 10.2015 Rehmann-Sutter C. Was bedeutet es, Wünsche zum Lebensende Ernst zu nehmen? Vortrag an der Diskussionsveranstaltung "Selbstbestimmung? Sozialphilosophische Perspektiven auf Alter und Behinderung", IMEW Berlin,.
- 05.09.2015 Streeck N. *Spotlight Ethik: Sterbehilfe – geraten wir auf die schiefe Bahn?*, Scientifica – Zürcher Wissenschaftstage, 5./6.09.2015, Universität Zürich
- 04.09.2015 Streeck N. *Feeling like a burden to others: a good reason for assisted suicide?*, Workshop „Palliative Care Patients’ Wish to Die. Feeling like a Burden“, 03./04.09.2015, Basel
29. 8.2015 Rehmann-Sutter C. Ethik überhaupt und speziell am Lebensende. Nachmittag am Studientag "Ethik" im Fernstudium Feministische Theologie, Biel.
- 27.08.2015 Streeck N. *Grenzen der Professionalisierung in der Palliative Care*, Fachsymposium „Palliative Care – Zusammenspiel von Profis, Angehörigen und Gemeinden?“ der Forschungsplattform Palliative Care Deutschschweiz in Zusammenarbeit mit dem NFP 67 und dem Universitären Zentrum für Palliative Care am Inselspital, Bern
- 19-22 August 2015. Rehmann-Sutter C. Between Medicalization and De-Medicalization of Wishing to Die. Talk at ESPMH Conference "Medicalization", Ghent.
- 22.08.2015 Streeck N. *The Medicalised Good Death*, European Conference on Philosophy of Medicine and Healthcare, 19.-22.08.2015, Gent, Belgien
- 30.05.2015 Streeck N. *Wann ist es Zeit zu sterben?*, Impulstagung „Wann ist es Zeit zu sterben? Entscheidungen am Lebensende“, Romero-Haus Luzern
- 23.3.2015 Rehmann-Sutter C. Ethische Überlegungen zum assistierten Suizid. Vortrag im Bürgersaal Bad Segeberg, organisiert vom Hospizverein Segeberg e.V.
- 17.3.2015 Rehmann-Sutter C. Ethics at the end of life. Biopolitics of dying. Master Program „Bioethics & Society“, Department of Social Science, Health and Medicine, King’s College London,
26. 2. 2015 Rehmann-Sutter C. Qualitative Forschung und die Intimsphäre. Vortrag im Seminar Forschungsethik, Gerhard Domagk Nachwuchsförderprogramm, Universitätsmedizin Greifswald.
4. 2. 2015 Rehmann-Sutter C. Medizin, Sterbewünsche und Sterbehilfe. Vortrag in der katholischen Studentengemeinde Lübeck.
- 31.01.2015 Streeck N. *Palliative Care als totalisierende Fürsorge: eine Kritik*, Workshop des Arbeitskreises „Medizin und Theologie“, 30./31.01.2015, Universität Wien
- 14.11.2014 Rehmann-Sutter C. Sterbewünsche und familiäre Interaktion. Ethische Überlegungen im Anschluss an die Arbeiten von Claudia Gamondi. (Vortrag an der Fortbildungsveranstaltung am Kantonsspital Bruderholz)
- 25.08.2014 Gudat H. Sterbewünsche bei Menschen in schwerer Krankheit. Darf man darüber forschen? Oncolunch. Organisator: Onkologie Universitätsspital Basel.

02.-05.04.2014 Streeck N. *Authentisch sterben? Authentizität als ethisches Ideal am Lebensende* (Poster-Präsentation), Symposium „Randzonen des Willens. Entscheidung und Einwilligung in Grenzsituationen der Medizin: Anthropologie, Psychologie, Recht und Ethik, Hannover

27.3.2014 Rehmann-Sutter C. Hauptergebnisse der Studie 'Terminally ill patients' wish to die'. Der Handlungsraum von Patientinnen und Patienten am Lebensende. Vortrag am Workshop für Ärztinnen und Ärzte "Wenn Menschen sterben möchten". Hospiz im Park, Klinik für Palliative Care, Arlesheim.

06.03.2014 Streeck N. *On Authenticity of Wishes to Die*, Forschungskolloquium, Institut für Biomedizinische Ethik, Universität Zürich.

25.2.14 Rehmann-Sutter C. Towards a New Biopolitics of Dying: Empirical, Social and Ethical Perspectives. Workshop at the Department of Social Science, Health and Medicine, King's College London, 25 February 2014.

05.02.2014 Streeck N. *Human Dignity and Assisted Suicide*, Kommentar zu Luke Gormally, Workshop „The Role of Human Dignity in Assisted Suicide“, Ethik-Zentrum, Universität Zürich

21.01.2014 Gudat H. Terminally ill patients' wish to die. Diagnostisches/therapeutisches Seminar. Fortbildungsreihe für Ärztinnen und Ärzte, Kantonsspital Baselland, Bruderholz.

21.11.2013 Ohnsorge K. Was meinen Patienten, wenn sie Sterbewünsche äussern? Krankenhaus Reinbeck, Hamburg

12.11.2013 Gudat H. Palliative Care oder Exit? Vortrag und Podiumsdiskussion. Organisator: Seniorenverein Nordwestschweiz

25.10.2013 Ohnsorge K, L'accompagnamento del morente: aspetti bioetici. Hospital of Vicenza, Italy.

25.9.2013 Rehmann-Sutter C. Ethische Fragen der (aktiven) Sterbehilfe. Vortrag am 3. Palliativmedizinischen Symposium Lübeck, veranstaltet vom Universitätsklinikum Schleswig-Holstein.

6. Publications (listed until Summer 2017)

Peer-reviewed

Christoph Rehmann-Sutter, Kathrin Ohnsorge, Bregje Onwuteaka-Philipsen, Guy Widdershoven (Guest Editors): **'Being a burden to others' and wishes to die: An ethically complicated relation.** Bioethics. Special Issue (Call for papers published, publication planned in 2018)

Rehmann-Sutter C: **Moral implications of self-perceived burden to others and wishes to die. A conceptual analysis** (submitted to Bioethics call for special issue on 'Being a burden to others').

Gudat H, Rehmann-Sutter C, Streeck N, Ohnsorge K. **Sense of burden and wishes to die in patients facing end of life** (to be submitted to Bioethics call for special issue on 'Being a burden to others').

Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H. **It is not only about hastening, consider the complexity of wishes to die.** British Medical Journal (submitted)

Ohnsorge K, Gudat H, Streeck N, Widdershoven G, Rehmann-Sutter C. **Was bedeutet es, das eigene Sterben zu „akzeptieren“? Ergebnisse aus einer qualitativen Studie mit 62 Palliativpatientinnen und -patienten.** Zeitschrift für Palliativmedizin 18(2017): 144-151.

Streeck, N. (2017). **Das Lebensende gestalten. Soziale Anforderungen und individuelle Umgangsformen mit dem Sterben.** Psychosozial 40 (1), 2017, 93-104.

Rehmann-Sutter C, Gudat H, Ohnsorge K. **Wishing to die and the concept of ‚hastening death‘**. PLOS ONE. 2016 (Dec). Comment on: Balaguer A et al. An International Consensus Definition of the Wish to Hasten Death and Its Related Factors. <http://journals.plos.org/plosone/article/comments?id=10.1371/journal.pone.0146184>.

Streeck, N. „**Leben machen, sterben lassen**“: **Palliative Care und Biomacht**. Ethik in der Medizin 28(2), 2016,135-148.

Christoph Rehmann-Sutter, Heike Gudat, und Kathrin Ohnsorge (Hrsg.): **The Patient’s Wish to Die. Research, Ethics, and Palliative Care**. Oxford: Oxford University Press, 2015

Ohnsorge K, Gudat H and Rehmann-Sutter C. **Intentions in wishes to die: analysis and a typology – A report of 30 qualitative case studies of terminally ill cancer patients in palliative care**. Psycho-Oncology. 2014. DOI: 10.1002/pon.3524

Ohnsorge K, Gudat H and Rehmann-Sutter C. **What a wish to die can mean: Reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care**. BMC Palliative Care. 2014;13:38. DOI: 10.1186/1472-684X-13-38

Ohnsorge K, Gudat H, Widdershoven G, Rehmann-Sutter C: **‘Ambivalence’ at the end of life: How to understand patients’ wishes ethically**. Nursing Ethics. 2012. 19(5):629-641.

Pereira J, Pautex S, Cantin B, Gudat H, Zaugg K, Eychmuller S, Zulian G. Palliative care education in Swiss undergraduate medical curricula: a case of too little, too early. Palliat Med. 2008 Sep;22(6):730-375.

Not peer-reviewed

Rehmann-Sutter C. **Der Wunsch zu sterben**. Bundes-Hospiz-Anzeiger, Heft 2/2017, Schwerpunkt "Suizidalität" (in press).

Rehmann-Sutter, Christoph; Ohnsorge, Kathrin and Gudat, Heike: **Understanding terminally ill patients’ wishes to die. Significant narratives and a typology**. In: Herrmann, Beate et al. (eds.) New Issues in Ethics and Oncology. München: Alber (in press, 2017), 103-120.

Rehmann-Sutter, C.: **Annas Wunsch-Geschichte. Deutungsweisen, um das Beste für die betroffenen herauszufinden**. Praxis Palliative Care 34, 2017, S. 14-16.

Rehmann-Sutter, C.: **Menschen sind sterblich und die letzte Phase des Lebens, die wir sterben nennen, gehört auch zum Leben. Ethische Probleme palliativer Versorgung aus einer care-ethischen Perspektive**. Praxis Palliative Care 34, 2017, S. 27-29.

Rehmann-Sutter, Christoph; Gudat, Heike and Ohnsorge, Kathrin (2016) **Wishing to die and the concept of ‚hastening death‘**. Online Comment on: Balaguer A, Monforte-Royo C, Porta-Sales J, Alonso-Babarro A, Altisent R, Aradilla-Herrero A, et al. (2016) An internal consensus definition of the wish to hasten death and its related factors. PLoS ONE 11(1): e0146184.

URL: <http://journals.plos.org/plosone/article/comments?id=10.1371/journal.pone.0146184>

Rehmann-Sutter, C.: **Wünsche am Lebensende wahrnehmen – Ethische Impulse palliativer Versorgung**. In: Conradi, Elisabeth und Vosman, Frans (Hrsg.) Praxis der Achtsamkeit. Schlüsselbegriffe der Care-Ethik. Frankfurt a. M.: Campus 2016, S. 167-187.

Rehmann-Sutter, Christoph und Lehnert, Hendrick: **Ethische Aspekte der Palliativmedizin**. Der Internist 57 (2016), S. 946-952.

Rehmann-Sutter, Christoph: „**Ich möchte jetzt sterben.**“ **Über Sterbewünsche am Lebensende.** In: Moos, Thorsten; Schües, Christina; Rehmann-Sutter, Christoph (Hrsg.) *Randzonen des Willens. Entscheidung und Einwilligung in Grenzsituationen der Medizin.* Frankfurt a.M.: Peter Lang 2016, S. 91-112.

Rehmann-Sutter C. **Transnational Issues of Assisted Dying.** EACME Newsletter 36 – May 2014, Special Issue: Perspectives on Assisted Dying in Europe, pp. 14-15.

Gudat H, Rehmann-Sutter Ch, Ohnsorge K. **Sterbewünsche – weit mehr als ein Hilferuf.** Schweiz Krebsbulletin. 2013, No. 1: pp 33-35.

Gudat H. **Palliative Care oder Exit?** PrimaryCare. 2012;12(19):372-374.

Streeck N. **Nicht für immer. Ars moriendi nova – Sterbekunst ohne Jenseitsperspektive.** Hermeneutische Blätter, Themenheft „Für immer“, 2016,150-160.

Streeck N. **Selbstbestimmung als Element der Vorstellung vom guten Tod.** *Bioethica Forum* 7, 2014, 136-138.

Bücher und Buchkapitel

Rehmann-Sutter C (Hrsg.): **Was uns der Tod bedeutet.** Berlin: Kadmos (Buchprojekt, geplantes Erscheinungsdatum 2018), darin:

- Rehmann-Sutter C. **Einleitung. Lebendiger Umgang mit Sterben und Tod**
- Streeck N. **"Die Frage ist, ob der Tod etwas ist, was man selber gestaltet." - Das anforderungsreiche Sterbeideal der Palliative Care**
- Gudat H. **Was Sterbende sich vom Tod wünschen**
- Rehmann-Sutter C. **Entscheiden und sterben können**
- Ohnsorge K. **Den Tod akzeptieren - was heißt das eigentlich?**

Gudat H. **Erzählen am Lebensende im Kontext von Palliative Care.** In: Peng S. *Sterbenarrative – Hermeneutische Erkundungen des Erzählens am / vom Lebensende (in Vorbereitung).*

Streeck, N. **Ende gut, alles gut? Sterbeerzählungen und Entscheidungen am Lebensende.** In: Simon Peng-Keller (Hrsg.), *Sterbenarrative. Hermeneutische Erkundungen des Erzählens am/vom Lebensende.* Berlin: DeGruyter (im Erscheinen).

Streeck, N. **Sterben, wie man gelebt hat. Die Optimierung des Lebensendes.** In: Nina Jakoby & Michaela Thönnies (Hrsg.), *Zur Soziologie des Sterbens. Aktuelle theoretische und empirische Beiträge.* Wiesbaden: Springer 2016, S. 29-48.

Streeck, N. **Sterbewünsche – medizinethisch-empirische Zugänge.** In: Konrad Hilpert & Jochen Sautermeister (Hrsg.), *Selbstbestimmung – auch am Lebensende? Streit um den assistierten Suizid.* Freiburg: Herder 2015, 17-29.

Rehmann-Sutter C, Gudat H, Ohnsorge Kathrin (Editors). **The Patient's Wish to Die.** Oxford University Press. 2015. We wrote the following chapters:

- Rehmann-Sutter C, Gudat H, Ohnsorge K. Introduction
- Ohnsorge K. Intentions, motivations, and social interactions regarding a wish to die
- Rehmann-Sutter C. End-of-life ethics from the perspective of patients' wishes
- Gudat H, Rehmann-Sutter C, Ohnsorge K. Communication of wishes to die
- Gudat H. From understanding to patient-centred management: clinical pictures of a wish to die.

Rehmann-Sutter, Christoph: **Sterbeprozess**. In: Gröschner, Rolf; Kapust, Antje und Lembke, Oliver W. (Hrsg.) Wörterbuch der Würde. München: Fink 2013, S. 270-271.

Rehmann-Sutter, Christoph: **Arzt-Patienten-Verhältnis**. In: Gröschner, Rolf; Kapust, Antje und Lembke, Oliver W. (Hrsg.) Wörterbuch der Würde. München: Fink 2013, S. 253-254.

Hagger, Lynn and Rehmann-Sutter, Christoph: **Suicide Centres: A Reasonable Requirement or a Step Too Far?** In: Hagger, Lynn and Woods, Simon (eds.) A Good Death? Law and Ethics in Practice. Farnham: Ashgate 2013, pp. 55-81.