„Entscheidungen über das Lebensende bei Amyotrophe Lateralsklerose. Empirische Untersuchungen, ethische Analysen und ein methodologischer Tugendansatz“

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*„Kommen Sie mal mit. Ich möchte Ihnen etwas zeigen.“**

*Diese Einladung eines an Amyotrophe Lateralsklerose (ALS) erkrankten Menschen, ausgesprochen in seinem Zuhause, gerichtet an denjenigen, dem er die vergangenen rund 60 Minuten Fragen zu Themen wie Lebensqualität, lebensverlängernde Massnahmen und dem Wunsch nach Todesbeschleunigung sehr sachlich und engagiert beantwortet hatte, ist aus Sicht des „Eingeladenen“ die trefflichste Zusammenfassung des hier nun vorgelegten vierjährigen Forschungsprojekts.

1. Zusammenfassung

In der Schweiz erhalten jährlich 150 bis 200 Menschen die verheerende Diagnose *Amyotrophe Lateralsklerose*. Diese tödliche, progressive Erkrankung des motorischen Nervensystems mit unsicherer Pathogenese gilt derzeit als unheilbar[1]. Die Lebenserwartung eines an ALS erkrankten Menschen liegt zum Zeitpunkt der Diagnosestellung statistisch bei drei bis fünf Jahren. Im Verlauf der Erkrankung leiden die Betroffenen häufig an Hoffnungslosigkeit, Depression und Angst vor Kontrollverlust[2;3]. Auch wenn der Tod in der Regel friedlich durch Kohlendioxidnarkose[4;5] eintritt, birgt der Sterbeprozess zahlreiche mögliche Komplikationen wie Atemnot, Angst- und Panikzustände sowie psychologische, spirituelle und weitere beschwerliche Symptome. Amyotrophe Lateralsklerose (ALS) ist daher eine Erkrankung, die bei den Betroffenen den Wunsch nach Todesbeschleunigung (WTB) hervorrufen kann[6;7]. Weitestgehend unerforscht waren bislang die Fragen, ob und ggfs. wann der WTB bei ALS-PatientInnen zutage tritt, wie sich der Krankheitsverlauf hierauf auswirkt und welche Haltung die unmittelbaren Angehörigen hierzu einnehmen.

In einer ersten empirischen Longitudinalstudie mit in der Schweiz lebenden ALS PatientInnen und deren Angehörigen konnten wir zeigen, dass der Wunsch nach Todesbeschleunigung unmittelbar nach der Diagnosestellung bei einer deutlichen Mehrheit von 94% der PatientInnen nicht vorhanden war. Trotzdem konnten sich mehr als die Hälfte der Befragten ein Zukunftsszenario im Verlauf der Erkrankung vorstellen, in dem sie für einen assistierten Suizid oder sogar für eine Tötung auf Verlangen („aktive Sterbehilfe“) optieren würden. Während ein Drittel der PatientInnen Themen wie (assistierten) Suizid und aktive Sterbehilfe mit einem Arzt erörtern möchte, wünscht sich sogar mehr als die Hälfte für den Fall des tatsächlich eintretenden WTB

eine aktive Rolle des Arztes. Ein Drittel der Angehörigen kann sich vorstellen, ihrem erkrankten Partner bei der Umsetzung des WTB zu helfen.
Die Frage, ob und ggf. inwiefern die Patienten- und Angehörigeneinstellungen in Bezug auf den WTB im weiteren Verlauf der ALS Erkrankung ändern oder aber stabil bleiben, sollte anschliessend durch eine prospektive Längsschnittstudie beantwortet werden. Hierzu interviewten wir in einem Follow-up erneut PatientInnen und Angehörige, die an unserer Erstbefragung teilgenommen hatten. Um die Aussagekraft dieser Studie zu erhöhen, wurden die Daten einer Vergleichsstudie aus München in die Auswertung integriert. Wir konnten zeigen, dass die Einstellungen der Befragungsgruppen zum WTB in der Schweiz und Süddeutschland weitgehend übereinstimmen, über den Befragungszeitraum stabil bleiben und somit bereits in einem frühen Stadium der Erkrankung – und zwar im Anschluss an die Diagnosestellung - geformt werden. Zudem konnte nachgewiesen werden, dass der WTB als Handlungsoption für den weiteren Krankheitsverlauf bei ALS-PatientInnen und Angehörigen stärker ausgeprägt ist als in einigen US-amerikanischen Studien beschrieben[8].

Der ethischen Bewertung empirischer Forschung an und mit Menschen liegen weitreichende und bisweilen schwerwiegende Problemstellungen zugrunde, die eingehende empirische Studien rechtfertigen[9] (Reiter-Theil 2011) und denen sich ganze Dissertationsprojekte exklusiv widmen könnten, ohne Aussicht, alle diesbezüglich im Raum stehenden Fragen ausreichend zu beantworten. Bereits in der Planungsphase unserer Interviewstudie mit ALS-Betroffenen zeigte sich, dass die Erforschung existentieller Entscheidungen wie jener in Bezug auf das Lebensende nicht nur zu einer tiefgreifenden Analyse der Antwortenden, sondern unweigerlich auch der Fragenden führen müsse, wohl wissend, dass die Qualität des gewählten Studiendesigns und der Methodik gänzlich ausser Frage standen. Auch wenn ein empirisches Forschungsprojekt unter Einbeziehung von Menschen nach Daten und Erkenntnissen sucht und dieser Findungsprozess gemäss bestehender Regularien vorab forschungsethisch abgeklärt und legitimiert wurde, bleibt doch eine bedeutende Unsicherheit bestehen: nämlich ob wir das, was wir (erkennen) *wollen* und ethisch begründet tun *sollen*, auch tatsächlich *gut* ist. Diese erkenntnistheoretische Frage führte uns zeitgleich zu der Entwicklung eines forschungsmethodologischen Ansatzes, den wir den „aidōs-approach“ nennen. Der „aidōs-approach“ ist ein tugendethisches Konzept, dessen Wurzeln zurück in die Antike reichen[10;11]; er soll den bewährten, auf dem Vier-Prinzipien-Ansatz[12] basierten Umgang mit vulnerablen Gruppen unterstützen und erweitern. Dies schliesst die alltägliche Begegnung mit den sog. Schwachen und Bedürftigen in unserer Gesellschaft ebenso ein wie die auf sie ausgerichtete, wohl intendierte medizinische und medizinethische Forschung. Der „aidōs-approach“ kommt dann zum Tragen, wenn Wissen und Erkenntnis in solchen Bereichen generiert werden sollen, die nur durch Grenzüberschreitungen erreichbar sind. Er soll den Forschenden zu einem verantwortungsvollen, ganzheitlichen Umgang mit dem „Forschungsobjekt“ - in unserem Fall der lebensbedrohlich erkrankte Mensch – anleiten und somit den Prozess der Erkenntnisgenerierung gleichberechtigt und auf Augenhöhe mit dem Gegenüber ansiedeln. Mittels der hierdurch stattfindenden Entkategorisierung und Entstigmatisierung soll anstatt des „Studienteilnehmers“ oder „Patienten“ – wieder – der Mensch in den Vordergrund rücken, der in seiner nun erstarkten Position auch auf den eigentlichen Forschungsprozess Einfluss nehmen kann und soll. (Dieser Einfluss findet in der sozialwissenschaftlichen Forschung ohnehin statt; er sollte daher nicht als „Störfaktor“ betrachtet, sondern systematisch reflektiert und ausgewertet werden, wie es schon der Pionier Devereux gefordert hatte[13].) Durch den „aidōs-approach“ können neben den zuvor festgelegten nunmehr zusätzliche, nicht minder wichtige Studienziele definiert werden, da Erkenntnisgewinn auf breiterer Ebene möglich ist.

Beide PatientInnenstudien bearbeiten mit dem Schwerpunkt *Entscheidungen am Lebensende* zwei parallel laufende Schienen, die also auf den Schwellen unseres tugendethischen Forschungsansatzes „aidōs-approach“ sozusagen befestigt wurden und gesamthaft das eine Gleis des Dissertationsprojekts darstellen.

[*]Der „Eingeladene“ folgte dem an ALS erkrankten Menschen in einen Raum, in dem etwa zehn E-Gitarren ordentlich aufgereiht nebeneinander auf dem Boden standen. Zwei Wandregale waren mit Hunderten CDs, Langspielplatten sowie Biographien und Bildbändern über Jimmy Hendrix, The Who, The Rolling Stones und The Beatles gefüllt. Aufgrund einer durch die fortgeschrittene ALS hervor gerufenen Lähmung von Händen und Armen konnte der Einladende seine Gitarren nicht mehr spielen. Aber gemeinsam mit einem Freund hatte er sich eine „Fussgitarre“ gebaut, die er mit seinen Zehen bedienen konnte. Er setzte sich hin und begann zu spielen.

2. Einführung in die Thematik

Amyotrophe Lateralsklerose ist nicht nur eine niederschmetternde Diagnose, die Zukunftsträumen, Hoffnungen und Lebensplanungen der Betroffenen von einem Moment auf den anderen ein abruptes Ende bereitet. Diese progressiv verlaufende Erkrankung, deren minimale Therapiemöglichkeiten sich von Beginn an auf palliative Massnahmen[14] und die Erhaltung von Lebensqualität beschränken, führt im nahen zeitlichen Umfeld der Mitteilung der Diagnoseergebnisse bei den Betroffenen zwingend zu einer Auseinandersetzung mit dem eigenen, nun absehbaren Sterben und Tod. Dieser Situation muss sich in der Regel nicht nur der (auch im eigenen Selbstverständnis) plötzlich als „todkrank" geltende Mensch stellen, sondern ebenso dessen unmittelbare Bezugspersonen wie Partner und Familie[15].

Auch wenn die in dieser Situation verbleibenden Handlungsoptionen noch Ausdruck der bestehenden Autonomie des Patienten sind, so stellt doch die restriktive Auswahl der Entscheidungsmöglichkeiten eine an sich unakzeptable, jedoch unabänderliche Einschränkung seines Handlungsspielraums dar: Patientenverfügung (PV) und Vorsorgevollmacht (VV), Einstellung zu lebensverlängernden Massnahmen (LVM) wie die Perkutane endoskopische Gastrostomie (PEG), die nichtinvasive Beatmung (NIV) und Tracheotomie sowie das aktive Herbeiführen des Todes durch Suizid, assistierten Suizid oder „aktive Sterbehilfe" (legalisiert nur in den Benelux-Staaten) bilden derzeit das Gros der – bisweilen sprachlich grotesk technisierten – Entscheidungsoptionen eines ALS Patienten in Bezug auf seine Erkrankung[16;17]. Wie genau der Prozess der Meinungsbildung hierzu abläuft, ob getroffene Entscheidungen im weiteren Verlauf der Erkrankung stabil bleiben, inwieweit Angehörige und auch Ärzte in dem Entscheidungsprozess involviert sind und unter Umständen auch aktiv werden – diese Fragen sind Gegenstand dringend notwendiger Untersuchungen, denn: die Komplexität dieses Entscheidungsfindungsprozesses ist für alle mittelbar und unmittelbar Betroffenen von medizinischer, ethischer, existenzieller und rechtlicher Relevanz.

Zunächst einmal soll geklärt werden, ob ALS Patienten a) einem WTB zugeneigt sind, b) wann sich dieser Wunsch ggf. formiert und c) ob dieser im Verlauf der Erkrankung stabil bleibt. Die aktuelle Datenlage deutet darauf hin, dass der WTB bei ALS Patienten nicht nur häufig vorhanden ist, sondern bereits zu einem frühen Zeitpunkt entssteht und festgelegt wird[18;19]. Patienten mit anderen lebensbedrohlichen Leiden (z.B. Krebs und Herzkreislauferkrankungen) dagegen wechseln ihre Einstellungen zu WTB im Verlauf der Erkrankung[20] – möglicherweise deshalb, weil der Krankheitsverlauf weniger vorhersehbar und zu Recht mit einem grösseren Mass an Hoffnung auf Heilung verbunden ist.

Überdies ist vor dem Hintergrund der liberalen Schweizer Praxis bzw. Gesetzeslage in Bezug auf den assistierten Suizid eine Untersuchung der Einstellungen von ALS-Betroffenen in diesem Kontext erstrebenswert; diese könnte auch zu der kontrovers geführten Diskussion anderer Länder mit restriktiverer Gesetzgebung bzw. Handhabung einen konstruktiven Beitrag leisten: So gilt es u.a. zu klären, ob die Bedenken von Gegnern der Therapiebegrenzung auf Patientenwunsch (passive / aktive Sterbehilfe) stichhaltig sind, wenn sie geltend machen, dass eine Liberalisierung der Gesetzgebung dem Wunsch nach Tötung auf Verlangen zwingend Tür und Tor („slippery slope") öffnen würde[21;22].

Die Rolle der Angehörigen darf sowohl im Findungsprozess von Entscheidungen am Lebensende, als auch im gesamten Verlauf der Erkrankung Amyotrophe Lateralsklerose nicht unbeachtet bleiben. Mit der Erkrankung des Partners geraten auch ihre Lebensplanungen komplett aus den Fugen[23;24;25]; Gewohnheiten und Sicherheiten, die jedem Lebensalltag die notwendige Stabilität verleihen, werden ohne Ankündigung niedergerissen. Es gilt daher auch zu erforschen, wie sich die tödliche Erkrankung des Partners auf die Lebensumstände und Lebensqualität der Angehörigen auswirkt und ob das gemeinsame Schicksal ALS auch in einer gemeinsam getragenen Haltung bezüglich bevorstehender Entscheidungen am Lebensende mündet.

Dass sich dieses Dissertationsprojekt empirisch validierter und weithin angewandter Methoden bedienen muss, soll angesichts der Gesamtkonzeption des Unterfangens erörtert werden: Diese Forschungsunternehmung begann mit der Annahme, dass empirische Studien zum Lebensende zwar zweifellos in der Lage sind, die vorhandene Datenlage insgesamt zu bereichern und hierdurch die Lebensumstände der Betroffenen u.U. zu verbessern, dabei aber im Umgang mit den im Forschungsfokus Stehenden möglicherweise zu kurz greifen. Erkenntnisvermehrung und Wissensgenerierung betreffen gerade in Lebensendestudien besonders sensible Bereiche, bei denen das szientifische Streben nach Wahrheit mit dem Schutz der Betroffenen in Einklang zu bringen ist – und zwar auch dann, wenn schriftliche Einwilligungen und ‚informed consent' vorliegen. Diese Aufgabe obliegt insbesondere den Forschungsverantwortlichen. Es stellt sich daher die Frage, ob die vorhandenen methodologischen Werkzeuge der empirischen Forschung an und mit Menschen eine Erweiterung und Ergänzung erfahren sollen, die Respekt und Schutz der vulnerablen Betroffenen verstärken, ohne dass die anvisierten Ergebnisse minimiert, sondern viel eher vermehrt werden.

3. Forschungsziel

Diese Arbeit hat ein empirisches, ein ethisch-analytisches und ein methodologisches Forschungsziel.

1. Die empirischen Untersuchung fragt,
   a. ob sich der WTB zeitnah zur Diagnosestellung bei Patienten entwickelt
   b. ob Einstellungen zu LVM bereits zu diesem Zeitpunkt geformt werden
   c. von welchen Faktoren diese Einstellungen, ggfs. auch der WTB, abhängen
   d. inwieweit Angehörige diese Einstellungen von Patienten teilen
   e. ob Angehörige unter Umständen bereit wären, den WTB aktiv zu unterstützen
   f. ob sich die in 1.a. bis 1.e. aufgeführten Haltungen im Verlauf der Erkrankung verändern

2. In der ethischen Untersuchung werden die Einstellungen von Patienten und Angehörigen zu LVM und dem WTB empirisch-deskriptiv ermittelt und analysiert. Besonderes Augenmerk wird hierbei gelegt auf a) den Zeitpunkt der Einstellungs- bzw. Entscheidungsformung; b) etwaige diesbezügliche Parallelitäten zwischen Patienten und Angehörigen; c) die Stabilität dieser Angaben im Verlauf der Erkrankung. Zudem sollen diese Angaben mittels einer Korrelationsanalyse beleuchtet werden, deren Erkenntnisse den Umgang zwischen medizinischem Care Team (Ärzte/Pfleger) und ALS Betroffenen positiv beeinflussen sollen.

3. In der methodologische Untersuchung entwickeln wir eine innovative Ergänzung zu den derzeit im Bereich der empirischen Forschung am und mit Menschen gängigen Methoden: den „aidōs-approach", welcher anhand eines Medienprojektes exemplarisch vorgestellt wird. Ziel dieses Zugangs ist das konstruktive, supplementär ausgerichtete Hinterfragen von Interview-Methodik und Studiendesign in Bezug auf Fragestellungen zum Lebensende. Der „aidōs-approach" soll dabei helfen, vulnerablen, an betreffenden Studien teilnehmenden

Menschen auf Augenhöhe zu begegnen. Kategorien (z.B. ‚Patient') und Stigmatisierung (z.B. ‚Behinderter') sollen hier aufgelöst werden.

4. Veröffentlichte bzw. eingereichte Arbeiten in ihrem thematischen Kontext

4.1 „Attitudes towards assisted suicide and life-prolonging measures in Swiss ALS patients and their caregivers"

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Wir untersuchten Einstellungen und den Meinungsbildungsprozess von Schweizer ALS-PatientInnen und deren Angehörigen in Bezug auf lebensverlängernde Massnahmen sowie den Wunsch zur Todesbeschleunigung zum Zeitpunkt unmittelbar nach Erhalt der Diagnose.

a) Methode

Für unsere Erhebung setzten wir ein semi-strukturiertes Interview mit validierten Fragebögen und persönlichen Interviewfragen ein, das folgende Themen fokussiert: körperliche Beeinträchtigung und Krankheitsschwere gemessen anhand der ALSFRS-R (revised ALS functional rating scale), demographische Daten, Lebensqualität (QoL), Angst, Depression und Einsamkeit, soziales Umfeld, Spiritualität, Leiden und Last der Krankheit sowie lebensverlängernde als auch lebensverkürzende Massnahmen. Die Diagnosestellung der Patienten musste nach den international standardisierten revidierten „El-Escorial-Kriterien[26]" erfolgt sein. Patienten und Angehörige wurden zudem erst dann in die Befragung aufgenommen, nachdem sie über die ALS-Diagnose, Krankheitsverlauf, Prognose und therapeutische Optionen einschliesslich PEG, NIV und Tracheotomie informiert worden waren. Die Interviews mit allen insgesamt 33 teilnehmenden Patienten und 32 Angehörigen fanden auf Wunsch der Befragten bei ihnen zu Hause statt. Patienten und Angehörige füllten die Fragebögen zeitgleich in separaten Räumen aus. Die Durchschnittsdauer der Interviews betrug 60 Minuten, während denen der Fragesteller bei dem Patienten blieb, um ihm/ihr – je nach körperlicher Beeinträchtigung – beim Ausfüllen der Fragebögen zu assistieren. Alle Patienten und Angehörigen wurden von einem tertiären Referenzzentrum (Muskelzentrum / ALS clinic) des Kantonsspitals St. Gallen rekrutiert.

b) Ergebnisse

Obwohl 13 (39%) PatientInnen im Verlauf ihrer Erkrankung schon an Suizid gedacht hatten, verspürten 31 (94%) zum Zeitpunkt der Befragung keinen Wunsch nach Todesbeschleunigung. Ein Drittel der Patienten gab an, das Thema Suizid mit einem Arzt besprechen zu wollen. Mehr als die Hälfte (57%) aller Patienten konnte sich eine Situation im Krankheitsverlauf vorstellen, in dem sie einen Arzt bitten würden, ihnen ein tödliches Medikament zu verabreichen. Suizidalgedanken und der Wunsch, mit einem Arzt über Suizid zu reden, korrelierten dabei in erster Linie mit dem Faktor Lebensqualität. Elf Angehörige (34%) konnten sich vorstellen, dem Patienten bei der Umsetzung seines WTB zu helfen. Zudem schätzten Angehörige auf der Neurological Rating Scale (NRS), einer 11 Punkte Selbsteinschätzungsskala, ihr eigenes durch die Krankheit des Partners hervorgerufenes Leiden, Belastung und Einsamkeit signifikant höher ein als die Patienten selbst.

c) Diskussion

Die Ergebnisse dieser Studie zeigen eindrücklich, dass die liberale Schweizer Gesetzgebung in Bezug auf assistierten Suizid nicht zu einem vermehrten WTB bei Menschen mit einer infausten Prognose wie Amyotrophe Lateralsklerose führt. Dennoch bleibt der assistierte Suizid für eine bemerkenswerte Mehrheit der befragten Patienten eine wichtige zukünftige Handlungsoption, bei der die Rolle des Arztes nicht nur als Gesprächspartner, sondern auch als aktiv Handelnder ausdrücklich gewünscht wird, und zwar in einem Masse, welches das derzeit gesetzlich Mögliche und Erlaubte deutlich übersteigt. Dies ist auch und insbesondere als ein Vertrauensbeweis gegenüber dem Arzt zu deuten, gerade vor dem Hintergrund, dass bei der unheilbaren ALS nur minime Therapiemöglichkeiten zur Verfügung stehen. Gleichzeitig, so folgern wir aus den Ergebnissen dieser Studie, müssen Ärzte bereit sein, sich mit den anstehenden Fragen und Wünschen zum Thema Lebensende offensiv auseinander zu setzen. Diese Bereitschaft wird auch durch die diesbezügliche Haltung der Angehörigen eingefordert. Dass ihr Leiden, Belastung und Einsamkeit deutlich höher als bei Patienten liegen, zeigt zudem, dass gerade die Angehörigen stärker in den Fokus einer ganzheitlichen Behandlung rücken und ihre Bedürfnisse gezielter als bisher berücksichtigt werden müssen.

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Attitudes toward assisted suicide and life-prolonging measures in Swiss ALS patients and their caregivers

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Objectives: In Switzerland, assisted suicide (AS) is legal, provided that the person seeking assistance has decisional capacity and the person assisting is not motivated by reasons of self-interest. However, in this particular setting nothing is known about patients' and their caregivers' attitudes toward AS and life-prolonging measures. **Methods:** Data was retrieved through validated questionnaires and personal interviews in 33 patients and their caregivers covering the following domains: physical function according to the revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R), demographic data, quality of life, anxiety, depression, social situation, spirituality, burden of disease, life-prolonging, and life-shortening acts. **Results:** In patients the median time after diagnosis was 9 months (2–90) and the median Amyotrophic Lateral Sclerosis (ALS) FRS-R score was 37 (22–48). The majority of patients (94%; $n = 31$) had no desire to hasten death. Patients' and caregivers' attitudes toward Percutaneous Endoscopic Gastrostomy (PEG) and Non-Invasive Ventilation (NIV) differed. Significantly more patients than caregivers (21.2 versus 3.1%) stated that they were against NIV ($p = 0.049$) and against PEG (27.3 versus 3.1%; $p = 0.031$). Answers regarding tracheotomy were not significantly different ($p = 0.139$). Caregivers scored significantly higher levels of "suffering" ($p = 0.007$), "loneliness" ($p = 0.006$), and "emotional distress" answering the questionnaires ($p < 0.001$). Suffering ($p < 0.026$) and loneliness ($p < 0.016$) were related to the score of the Hospital Anxiety and Depression Scale (HADS) in patients. **Conclusion:** A liberal legal setting does not necessarily promote the wish for AS. However, the desire to discuss AS is prevalent in ALS patients. There is a higher level of suffering and loneliness on the caregivers' side. A longitudinal study is warranted.

Keywords: ALS, motor neuron disease, quality of life, depression, end of life

INTRODUCTION

During the course of the disease, Amyotrophic Lateral Sclerosis (ALS) patients may suffer from depression, hopelessness, the feeling of loneliness, and loss of control (Rabkin et al., 2000, 2005; Albert et al., 2005; Olney and Lomen-Hoerth, 2005). In the terminal phase respiratory distress, anxiety, and other distressing symptoms may occur (Mandler et al., 2001). Given the suffering associated with the disease, some patients choose to decline life-prolonging measures such as Percutaneous Endoscopic Gastrostomy (PEG) and Non-Invasive Ventilation (NIV) and/or wish to hasten death (Ganzini et al., 1998; Veldink et al., 2002; Fang et al., 2008; Maessen et al., 2009). In an early study from Oregon, about 56% of all ALS patients considered physician-assisted suicide (PAS; legalized after 1997) during the terminal phase and 73% of caregivers and patients had similar attitudes toward PAS (Ganzini et al., 1998). In the Netherlands, during the 2000–2005 period 16.8% of ALS patients decided for euthanasia or PAS (Maessen et al., 2009), while in Sweden (where PAS is not legalized), ALS patients have a sixfold increased risk of committing suicide (Fang et al., 2008). Factors such as depression, hopelessness, loss of meaning, and purpose in life have been discussed to be associated with the wish to hasten death, whereas the contrary applies to religious faith and spiritual beliefs (Rabkin et al., 2000, 2005; Albert et al., 2005; Olney and Lomen-Hoerth, 2005). These findings are not consistent between different countries (Maessen et al., 2009). Moreover, there is a lack of longitudinal studies analyzing changes of these factors over time. It is also unclear whether the legal background in different countries influences patients' attitudes toward assisted suicide (AS) as comparative studies are lacking.

In Switzerland, however, assistance in committing suicide by a physician or a lay person is not explicitly regulated by law, but article 115 of the Swiss Penal Code allows assistance in suicide provided that the person seeking assistance has decisional capacity and the person assisting – physician or lay person – is not motivated by reasons of self-interest. Based on this article, Swiss "right to die" organizations offer assistance to commit suicide (Fischer et al., 2008). A recent study from the City of Zurich revealed that between 2001 and 2004 "Dignitas or Exit Deutsche Schweiz" had facilitated a total of 421 cases of AS (Fischer et al., 2008). Amongst the patients, 60% had been non-residents in Switzerland emphasizing the problem of "suicide tourism." Twenty-four percent of ASs were patients with "neurological disorders" including

ALS. However, no information is available about the total number of ALS patients, their motivation and associated factors that had made them choose this exit strategy.

The objective of this study is to analyze patients' and caregivers' attitudes toward AS, life-prolonging measures as well as associated factors (e.g., depression, quality of life (QoL), loneliness, suffering, education, profession, family status, living situation, Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS, and time after diagnosis) in a country with a comparatively easy access to AS.

METHODS AND PARTICIPANTS

PARTICIPANTS

Swiss patients and their primary caregivers were recruited from a tertiary referral center (Muskelzentrum/ALS clinic) at the Kantonsspital St. Gallen. Patients and caregivers attended the ALS outpatient clinic on a regular basis (usually every 3 months). Patients and caregivers had to be at least 18 years old. Further inclusion criteria for patients were a diagnosis of definitive, probable, or probable laboratory supported ALS according to the revised El Escorial Criteria (Brooks et al., 2000). Patients were only eligible if they had been informed about their ALS diagnosis, disease progression, prognosis, and therapeutic options including PEG insertion and different forms of ventilation (e.g., NIV, tracheotomy). The discussion about PEG and ventilation was usually triggered by clinical decline that resulted in use of PEG or NIV. Both issues are part of ALS – specific advanced directives which are routinely applied during this discussion (Benditt et al., 2001). Patients who inquired about these interventions shortly after diagnosis were also eligible. The study was approved by the local ethics committee and all patients and caregivers gave written informed consent.

For this study inclusion criteria, exclusion criteria, variables, and statistical analysis were pre-specified. Data were retrieved through questionnaires and personal interviews during home visits. The data collection took place as soon as patients had been informed about life-prolonging measures. Interviews were carried out by a researcher trained in interview technique, experienced in pastoral care, and medical ethics, not involved in clinical care of the patients and their primary caregivers. Patients and caregivers filled in the questionnaires simultaneously. In case the patient was unable to complete the questionnaire by his/her own hand due to weakness, the interviewer completed the questionnaire according to the patient's statements. The mean duration of the interview was approximately 60 min. After the interview, the primary caregiver/relative had the opportunity to clarify any issues that may have arisen during completion of the questionnaire. Specifically the following data and questionnaires were retrieved/applied:

Demographic data

The collection of data included age, sex, living situation, education, profession, and religious confession.

Numerical rating scale

(Eleven-point format; 0–10) asking the following questions: (1) What is your current QoL?; (2) How much are you suffering from your disease/from the disease of your partner?; (3) How lonely do you feel?; (4) How strong is your current desire to ask others for help to end your life prematurely?; (5) How distressing or how helpful was it for you to speak about such issues?

Hospital anxiety and depression scale (HADS)

A self-assessment scale to quantify patients' anxiety and depression by choosing one response from four given. The range is from 0 to 42 with the maximum score indicating a high level of depression and anxiety (Bjelland et al., 2002).

Questions regarding life-prolonging measures and hastening death

Patients' and caregivers' opinions were assessed with regards to tracheotomy, NIV, and PEG within a four-point response format. The following questions were asked: What is your attitude toward the following life-prolonging measures: (a) Tracheotomy; (b) NIV; (c) PEG? Possible answers to each item were: (a) I am not sure; (b) I am absolutely in favor of it; (c) I am in favor of it under certain circumstances; (d) I am against it.

Questions in yes/no format included: (1) Have you ever thought about committing suicide after receiving your diagnosis?; (2) Can you imagine a future scenario in which a physician prescribes a fatal drug which you administer yourself?; (3) Can you imagine a future scenario in which a physician prescribes and administers to you a fatal drug?; (4) Have you ever discussed suicide with others?; (5) Would you like to discuss suicide with a physician?

Idler index of religiosity (IRR)

The IRR assesses both public and private religiosity: (1) summing up attendance at religious meetings and services and the number of church members known to the patient; (2) self-assessment of personal religiosity as well as the amount of strength and comfort provided by personal faith (Robbins et al., 2001).

STATISTICAL ANALYSIS

For continuous variables (e.g., age) the mean of the differences between "patient" and "caregiver" was calculated by the t-test. Variables applying scores were compared by the Wilcoxon signed rank tests providing the median difference and its 95% confidence limits. Differences of ordered categorical variables (four-point response format) were tested by the Fishers exact test and the McNemar's Chi-squared test. For analyzing possible associations between the paired samples ("patient," "caregiver") the Spearman's rho correlation coefficient was applied. The level of significance was $p < 0.05$.

In order to predict score ratios between patients and caregiver, generalized linear mixed-effects models with group ("patient" and "caregiver") and given variables as fixed factors (sex, age, education, profession, family status, living situation, children, ALSFRS, time after diagnosis, and QoL) and subject ("patient") as random factor were performed either as multivariate or univariate model (for each parameter as a separate model). In order to predict dichotomous variables (yes versus no) concerning suicidal ideation for patients, logistic regression models were performed providing odds ratios (OR) and 95% confidence intervals (CI) with corresponding p-values.

All analyses were performed using R version 2.12.2 (R Development Core Team, 2011).

RESULTS

DEMOGRAPHIC DATA

During the recruitment period from 2008 to 2010 a total of 59 patients and caregivers were asked whether they would participate in this study. Twenty-six patients declined, 33 patients and their caregivers agreed to participate. The most frequent reason for declining participation was "no interest" and reluctance toward the themes of religiosity and spirituality. **Table 1** summarizes the epidemiological data, social status, and religious denominations of patients and their caregivers. Mean age of patients was 59.6 and mean age of caregivers was 56.9 (paired *t*-test; $p = 0{,}065$). The median time after diagnosis at which the first interview took place was 9 months (2–90) and the median ALSFRS-R was 37 (22–48).

ASSISTED SUICIDE/HASTENING DEATH

Thirteen patients (39%) answered that during the course of the disease they had thought about the possibility of committing suicide (**Table 2**). However, at the time of the interview, 31 of the patients (94%) expressed no wish to hasten death by AS. Thirty-three percent of the patients would like to discuss the issue "suicide" with a physician. Fifty-four percent of the patients could imagine asking a physician in the future to prescribe a fatal drug that they could take themselves; 57% could imagine a physician administer such a drug to them in the future. Logistic regression revealed that for patients QoL was the major predictor toward suicidal ideation (OR: 0.58, CI: 0.35–0.99) and the wish to discuss suicide with a physician (OR: 0.32, CI: 0.13–0.81, **Table 2**). The number of children (OR: 0.54, CI: 0.28–1.04) and HADS score (OR: 1.2, CI: 0.99–1.45) was also predictive of the wish to discuss suicide with a physician. Other analyzed factors (education, profession, family status, living situation, ALSFRS, and time after diagnosis) were not associated.

LIFE-PROLONGING MEASURES

The majority of patients (57.6%) and caregivers (50.0%) were against tracheotomy (**Table 3**). As verified by the McNemar test no significant difference was detected between the coincident answers of the two study groups ($p = 0.37$). No patient and no caregiver were generally in favor of its application, only "under certain circumstances" (27.3 patients versus 25.0% caregivers). The remaining interviewees were "unsure" about tracheotomy. Within the four-point response format attitudes between patients and caregivers regarding NIV and PEG differed (Fishers exact test). Significantly more patients than caregivers (21.2 versus 3.1%) stated that they were against NIV ($p = 0.049$) and against PEG (27.3 versus 3.1%; $p = 0.031$).

Table 1 | Demographic data.

	Patients % (*n*)	Caregivers % (*n*)
Age (mean, range)	59.6 (38–79)	56.9 (31–79)
Sex		
Female	36.4 (12)	62.5 (20)
Male	63.6 (21)	37.5 (12)
Living situation		
Alone	9.1 (3)	3.1 (1)
With spouse	57.6 (19)	59.4 (19)
With spouse and child(ren)	33.3 (11)	37.5 (12)
Religious confession		
Roman-catholic	51.5 (17)	46.9 (15)
Protestant	33.3 (11)	25.0 (8)
No confession	15.2 (5)	28.1 (9)

QUALITY OF LIFE AND BURDEN OF DISEASE

The median of QoL rated on a 11-point scale was six for patients and caregivers ($p = 0.68$). "Suffering," "loneliness," and "emotional distress answering the questionnaire" were significantly higher on the caregivers' than on the patients' side (**Table 4**). The mean HADS score of patients was 10.6 ± 5.1. Univariate analysis by a general linear mixed-effects model revealed a significant influence of the HADS on "suffering" (OR: 1.04 (95% CI: 1.01–1.07, $p = 0.027$) and "loneliness" (OR: 1.17 (95% CI: 1.04–1.33, $p = 0.017$) for coincident answers of patients and caregivers. Other analyzed factors (sex, age, education, profession, family status, living situation, children, ALSFRS-R, time after diagnosis, and QoL) did not show a significant effect, both in univariate and multivariate analysis (data not shown).

RELIGIOSITY

With regard to publicly practiced or private religiosity patients considered themselves to be more religious than their caregivers ($p < 0.001$) and derived more strength and comfort from their faith ($p < 0.01$).

DISCUSSION

The most important finding of the study is that at the time of the interview 94% of the patients had no intention to hasten death. This seems notable as the Swiss legal situation is liberal regarding assistance to commit suicide and the society is tolerating the practice of lay organizations offering the assistance through the collaboration of physicians and lay persons (van der Heide et al., 2003; Reiter-Theil, 2006). In contrast, a comparable study from Germany on ALS patients revealed that 37% of patients wished to hasten death (Jox et al., 2007). Germany is characterized by a liberal regulation of AS in penal law, but at the same time by a restrictive regulation and prohibition of PAS in the medical law (Reiter-Theil, 2006). The only difference between the Swiss and the German study methodology was that our patients were interviewed at home, whereas in the German study the interviews took place in the outpatient clinical. This difference, however, is unlikely to account for the imbalance and suggests that not the legal background as such (e.g., a more liberal legal situation promotes AS), but other factors must be responsible for the wish to hasten death. Previous studies from Oregon and the Netherlands where PAS is also legal, revealed a high prevalence of AS and euthanasia among ALS patients (Ganzini et al., 1998, 2002; Veldink et al., 2002; Albert et al., 2005; Maessen et al., 2009). This contrasts with our findings where only a minority of patients expressed a wish to hasten death. However, a comparison of our results with the Oregonian and Dutch studies is difficult as they were either retrospective (Veldink et al., 2002; Maessen et al., 2009) or interviews took place at a late to terminal stage (Ganzini et al., 2002; Albert et al., 2005). Longitudinal studies analyzing attitudes toward AS

Table 2 | Patient suicidality; n.s., no significant effect.

	Yes % (*n*)	No % (*n*)	No answer % (*n*)	Associated factors (adjusted for gender and age)
Thought about suicide after receiving diagnosis	39.4 (13)	60.6 (20)	0	n.s.
Can imagine future scenario: committing suicide by means of a prescribed drug	54.5 (18)	45.5 (15)	0	Quality of life ($p = 0.026$)
Can imagine future scenario: suicide with the help of physician administering fatal drug	57.6 (19)	42.4 (14)	0	n.s.
Have already discussed suicide with others	33.3 (11)	66.7 (22)	0	n.s.
Would like to discuss suicide with a physician	33.3 (11)	60.6 (20)	6.1 (2)	Number of children ($p = 0.048$), quality of life ($p < 0.001$), HADS ($p = 0.037$)

Table 3 | Live-prolonging measures: "what is your attitude toward the following life-prolonging measures?" *p*-values derived from McNemar test.

	Not sure% (*n*)	Absolutely yes % (*n*)	Yes under certain circumstances % (*n*)	Against % (*n*)	*p*
Tracheotomy					0.37
Patients	15.2 (5)	0	27.3 (9)	57.6 (19)	
Caregivers	25.0 (8)	0	25 (8)	50.0 (16)	
NIV					0.17
Patients	3.0 (1)	42.4 (14)	33.3 (11)	21.2 (7)	
Caregivers	18.8 (6)	43.8 (14)	34.4 (11)	3.1 (1)	
PEG					0.75
Patients	12.1 (4)	24.2 (8)	36.4 (12)	27.3 (9)	
Caregivers	25.0 (8)	18.8 (6)	53.1 (17)	3.1 (1)	

Table 4 | Quality of life and burden of disease variables rated on self-rating scales (0–10).

Parameters	Patients (median, IQR)	Caregivers (median, IQR)	Difference of medians	Lower 95% CI	Upper % 95 CI	*p*-value
Quality of life	6 (5–8)	6 (5–7)	0.25	−1.0	1.5	0.68
Loneliness	0 (0–1)	2 (0–6)	−3.25	−5.5	−1.5	0.003
Emotional distress	0 (0–1)	3 (0.8–5)	−4.25	−5.5	−3.0	<0.001
Suffering	5 (3–6)	6.5 (5–8)	−2.25	−3.5	−0.5	0.006

Differences determined by Wilcoxon signed rank test. IQR, inter quartile range.

have not been published yet, but are important to understand whether these attitudes depend on the degree of disability.

With respect to preferences for life-prolonging and ameliorative technologies it seems that ALS patients make choices consistent with preferences expressed shortly after diagnosis (Albert et al., 1999). It is unclear whether this also applies to attitudes toward AS. Nevertheless, more than one-third (39%) of our patients had thought about the possibility of committing suicide after being diagnosed with ALS and 33% of the patients expressed the wish to discuss suicide with their physician. Even 58% said they could imagine a future scenario in which a physician would not only prescribe, but also administer a fatal drug (i.e., euthanasia which is prohibited in Switzerland) to them. This mirrors other studies which have shown that the themes of assisted dying and suicide are prevalent in ALS patients (Ganzini et al., 1998, 2002; Albert et al., 2005; Palmieri et al., 2010). The wish of patients to discuss suicide with a physician was associated with poorer QoL and a higher HADS score. It can be concluded that medical caregivers need to develop an openness and willingness to discuss with and inform patients about suicide and to deal with the fact that a considerable number of patients facing end of life may ask for their physician's active involvement in hastening death (Bascom and Tolle, 2002; Jox et al., 2007; Moore et al., 2007; Oliver et al., 2007). The prevalence for a physician's active involvement in hastening death in the future corresponds with a retrospective study (Lofmark et al., 2008) which reports that 37% of the Swiss physicians ($n = 1397$) had received a patient request to hasten death.

Patients' and caregivers' attitudes regarding life-prolonging measures were largely concordant. Fifty-eight percent of patients and 50% of caregivers were against tracheotomy. However, caregivers (mean: 22.2%) in general were considerably more unsure about NIV, PEG, and tracheotomy than patients (mean: 9.8%). Furthermore significantly more patients than caregivers were strictly against PEG and NIV. This confirms a fundamental need for more information and discussion about life-prolonging measures as has also been shown by other studies (Albert et al., 1999; Trail et al., 2003).

Another important finding of this study is that caregivers scored significantly higher in the domains of suffering, loneliness, and distress filling out the questionnaires compared to patients, despite overall QoL being not different between patients and their caregivers. The only associated factor was patients' depression and anxiety as measured by HADS. Sex, age, education, profession, family status, living situation, children, ALSFRS, time after diagnosis, and QoL were not related. Previous studies also revealed that depression in patients is associated with caregiver burden (Chio et al., 2005) and that patients' and caregivers' well-being are interrelated (Pagnini et al., 2011). Other examined factors such as time since diagnosis and degree of disability were not related in our as in previous studies (Rabkin et al., 2000; Chio et al., 2005). This is in contrast with studies that have shown that caregiver burden and distress are associated with the degree of disability (Hecht et al., 2003; Chio et al., 2005; Lo Coco et al., 2005). However, it needs to be taken into account that the patients in our study had only mild to moderate handicap as compared to other studies. A prospective longitudinal study may help to resolve this discrepancy and would also reveal dynamic changes as disease and disability progress.

This study has several limitations. Patients were recruited from a single center and may therefore not be representative for all Swiss ALS patients. At our ALS Clinic patient care is strictly adhering to international guidelines (Miller et al., 2009; Andersen et al., 2012) which may not be the case in all Swiss centers. Each follow-up consultation lasts 2 h allowing ample time to discuss end of life decisions and related issues that may have influenced the results. Second, since spirituality and religiosity were part of the study, this may have introduced a self-selection bias toward couples that tend to be more religious which is known to be inversely related to the wish to hasten death (Albert et al., 2005). The themes of religiosity/spirituality may also contribute for the relatively high non-participate rate of 44%. However, these problems are inherent in almost all of the published interview studies.

CONCLUSION

In summary the "liberal" Swiss legal setting does not promote the wish for AS, but the wish to discuss AS is prevalent amongst ALS patients even in moderately advanced stages of the disease. This wish is associated with poorer QoL and degree of depression.

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AUTHOR NOTE

This study was approved by the ethics committee of St. Gallen.

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4.2 **„Attitudes towards hastened death in ALS: a prospective study of patients and family caregivers“** (2013) eingereicht in *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* **Stutzki R, Weber M, Reiter-Theil S, Simmen U, Borasio GD , Jox R**

Unsere erste Studie versuchte zu erforschen, wie sich Lebensende-Entscheidungen bei ALS Patienten und Angehörigen zeitnah zur Diagnosestellung formieren und inhaltlich ausgestalten. Ob der progressive Verlauf der Erkrankung im Laufe der Zeit zu Veränderungen bei den am Krankheitsbeginn formulierten Einstellungen führt, war Gegenstand dieser anschliessenden Untersuchung.

a) Methode

In einer prospektiven longitudinalen follow-up Studie setzten wir erneut unser in 4.1. beschriebenes semi-strukturierte Interview mit validierten Fragebögen und persönlichen Interviewfragen ein. Befragungen fanden spätestens 15 Monate (Durchschnitt 13.2) nach dem Erstinterview bzw. bei einer Verschlechterung des Patienten-ALSFRS-R Wertes um ≥ 5 Punkte statt. Wir erfassten zusätzlich die Antworten einer Vergleichsstudie der ALS outpatient Klinik des Universitätsspitals München, um die Aussagekraft dieser Studie zu erhöhen, aber auch um die durch frühzeitiges Versterben bedingten Ausfälle von Studienteilnehmern (Patienten) zu kompensieren. An dieser Befragung nahmen insgesamt 38 Patienten und 35 Angehörige teil. Die Auswertung auch der Münchener Daten erfolgte im Rahmen dieses Forschungsprojektes.

b) Ergebnisse

Die Einstellungen in Bezug auf den WTB blieben im Laufe der ALS Erkrankung sowohl bei den Patienten als auch bei ihren Angehörigen stabil und ohne signifikante Veränderung. 84% der Patienten (Erstbefragung 82%, gepoolt) verspürten zum Zeitpunkt des Interviews keinen Wunsch, das Leben vorzeitig zu beenden. Beinahe jeder 2. Patient (45%) konnte sich für die Zukunft eine aktive Rolle des Arztes in Bezug auf Todesbeschleunigung (assistierter Suizid als auch aktive Sterbehilfe) vorstellen. Diese Haltung korreliert mit psychiatrischen Folgeerkrankungen wie Angst und Depression, aber auch mit psychosozialen Faktoren wie Einsamkeit sowie das Gefühl, Anderen zur Last zu fallen. Rund ein Drittel (31%) der Angehörigen wäre bereit, seinem an ALS erkrankten Angehörigen bei der Umsetzung des WTB zu unterstützen. 18 Patienten (47 %) würde das Thema WTB gern mit einem Arzt besprechen. Angehörige schätzten ihr Leiden, Belastung und Einsamkeit erneut höher ein als

Patienten, wobei sich bei Patienten – anders als bei den Angehörigen – im Verlauf der Erkrankung Einsamkeit und das Gefühl, anderen zur Last zu fallen, signifikant erhöhten.

c) Diskussion

Einstellungen zum Lebensende, insbesondere in Bezug auf den WTB, veränderten sich nicht signifikant im Verlauf der durchschnittlich 13-monatigen follow up Periode und werden demzufolge zu einem frühen Zeitpunkt der Erkrankung geformt. Zudem bemerkenswert ist die diesbezügliche weitgehende Übereistimmung zwischen den Patienten beider Länder. Bedingt durch das historische Erbe der Nazizeit gilt gerade Deutschland bei der Diskussion um assistierten Suizid und aktiver Sterbehilfe als gemeinhin zurückhaltend; dies führt offensichtlich aber nicht dazu, dass Patienten in Deutschland diese Themen grundsätzlich unterschiedlich bewerten als Patienten in anderen Ländern. Die soziokulturelle Umgebung spielt bei der Entwicklung von Einstellungen zu Entscheidungen am Lebensende möglicherweise eine – wenn überhaupt – untergeordnete Rolle. Die Prävalenz für den WTB ist in beiden untersuchten Patienengruppen bedeutend und bleibt über den gesamten Befragungszeitrum stabil. Ärzte sollten pro-aktiv und als vorbeugende Massnahmen Patientenwünsche und -optionen in Bezug auf Lebensende mit den Betroffenen ansprechen. Eine frühzeitige Identifizierung und Behandlung psychosozialer Stressfaktoren ist ebenso geboten wie die Abklärung, ob psychiatrische Folgeerkrankungen bei ALS Patienten unterschätzt und nicht ausreichend behandelt werden.

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Title: Attitudes towards hastened death in ALS: a prospective study of patients and family caregivers

Running Title: **End-of-life attitudes in ALS: a prospective study**

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ABSTRACT

Objectives: Amyotrophic lateral sclerosis (ALS) may provoke the wish to hasten death (WTHD). We aimed to determine the prevalence and stability of WTHD and end-of-life attitudes in ALS patients, identify predictive factors, and explore communication about WTHD.

Methods: We conducted a prospective questionnaire study among ALS patients and their primary caregivers attending ALS Clinics in Germany and Switzerland.

Results: We enrolled 66 patients and 62 caregivers. Half of the patients could imagine asking for assisted suicide or euthanasia; 14% expressed a current WTHD at the baseline survey. While 75% were in favour of non-invasive ventilation, only 55% and 27% were in favour of the percutaneous endoscopic gastrostomy and invasive ventilation, respectively. These attitudes were stable over 13 months. The WTHD was predicted by depression, anxiety, loneliness, perceiving to be a burden to others, and a low quality of life (all $p < 0.05$). Lower religiosity predicted whether patients could imagine assisted suicide or euthanasia. Two thirds of patients had communicated their WTHD to relatives; no one talked to the physician about it, yet half of them would like to do so.

Conclusions: Physicians should consider proactively asking for WTHD, and be more sensitive towards neglected psychosocial problems and psychiatric comorbidity.

KEY WORDS:

Ethics, palliative care, wish to hasten death, assisted suicide, depression.

INTRODUCTION

Amyotrophic Lateral Sclerosis (ALS) is a progressive and devastating disease with an uncertain pathogenesis and is likely to remain a fatal disorder for the years to come.[1] Median survival is less than 3 years from diagnosis. Many patients with ALS experience depression, anxiety, loss of control, and other psychosocial complications.[2 3] Although death is usually peaceful,[4 5] the patient's last phase of life may be burdened by respiratory distress, anxiety, psychosocial or spiritual concerns.[3 4 6 7]

Hence, ALS is one of the disease states that may trigger the wish to hasten death (WTHD). In the Netherlands, 16-20 % of ALS patients die by physician-assisted suicide (PAS) or euthanasia, and another 15% after continuous deep sedation.[8 9] An early Oregon study prior to the legalization of PAS showed that 56% of ALS patients would consider PAS, and in fact 7.3% of all Oregon citizens who die by PAS are ALS patients (while ALS prevalence is 0.006%).[1 10 11] In a Swedish study, ALS patients had a 6-fold increased risk of suicide compared to the general population.[12]

In the neighboring countries Germany and Switzerland euthanasia is prohibited, but assisted suicide by any person is not legally punishable, yet there are no legal regulations comparable to those in Oregon.[13] Swiss law allows assisted suicide except if it is done with selfish motivation, and the practice of assisted suicide, mainly implemented by right-to-die organizations, is tolerated by society.[14] In Germany, a liberal law contrasts with a restrictive code of the medical profession, rendering assisted suicide a risky practice for physicians. In both countries, ALS patients are known to be a considerable group among those dying from PAS.[15 16] It is unknown, however, how many ALS patients have the wish to hasten death and would consider PAS or euthanasia in the two countries.

A general wish to die in ALS patients has been associated with depression, hopelessness, lower religiosity scores, and loss of meaning in life.[17 18] Studies from the

Netherlands and Oregon point to hopelessness and fears of suffocation and dependency as predictors of hastening death, but are inconsistent regarding the influence of quality of life and physical symptoms.[10 19-21] Most of the published studies on WTHD in ALS, however, were conducted at a time when efficient, ALS-specific palliative care was not yet available. In addition, many studies were retrospective and often indirect assessments by post-mortem surveys of relatives or physicians.[5 8 21] There is a lack of longitudinal studies analysing the temporal stability of WTHD and end-of-life preferences. Moreover, it is unknown whether patients communicate their WTHD to physicians or family caregivers, and how many of those would be prepared to assist in hastening death.

We therefore conducted a prospective longitudinal study with ALS patients and their family caregivers in Germany and Switzerland. Our aims were (1) to determine the prevalence of WTHD and the attitudes towards life-sustaining treatment among ALS patients, (2) to investigate the stability of these attitudes during the course of the disease, (3) to explore communication about WTHD and the attitudes of family caregivers, and (4) to determine predictive factors for WTHD.

PATIENTS AND METHODS

Design and participants

A prospective longitudinal cohort study was conducted at two tertiary referral centers in Germany and Switzerland between September 2008 and July 2011. German patients and their primary family caregivers were recruited from the ALS Clinic at the XXX (anonymised), Swiss patients and caregivers from the ALS Clinic at the XXX (anonymised). Both centres provide a state-of-the-art multi-professional palliative care to patients and caregivers,[22] who usually attend the clinic every three months.

Participants had to be at least 18 years old, legally competent, and able to communicate in German. Patients were eligible if they had a diagnosis of clinically definite, probable or laboratory-supported ALS according to the revised El Escorial Criteria.[23] All participants were informed about the diagnosis, prognosis, and therapeutic options including percutaneous endoscopic gastrostomy (PEG) and forms of ventilation. The study was approved by the local Research Ethics Committees and all participants gave written informed consent.

Data collection and instrument

Data were gathered through questionnaires that were completed by patients and caregivers simultaneously in separate rooms, either in the clinic or the participant's home. Patients received assistance if they were unable to fill in the forms due to paralysis. Data were collected by a psychologist (Germany) and a theologian (Switzerland), both experienced in empirical social science studies and not involved in patient care.

The baseline survey was performed as soon as the patients had been informed about the option of life-sustaining measures. The follow-up survey was done when the patient's scores on the Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS) had deteriorated by ≥ 5 points (but not later than 15 months after baseline). Completion of the survey lasted up to one hour.

The questionnaire consisted of validated psychometric scales and questions formulated for the purpose of this study. Demographic data contained age, sex, marital status, educational level, and profession. All participants were asked to fill in the Idler Index of Religiosity (IIR), a 4-item scale determining private and public elements of religiosity.[24] Patients completed the Hospital Anxiety and Depression Scale (HADS), a 14-item scale (4 answers per item, range 0-21 per anxiety and depression subscales, respectively, with high scores indicating high levels of depression or anxiety).[25] Numerical Rating Scales (NRS, 0-10) were applied to assess the individual quality of life, the intensity of suffering from the disease, the feeling of loneliness, and the evaluation how distressing or helpful the survey was perceived.

End-of-life attitudes were elicited at the end of the survey, beginning with the attitudes on PEG, non-invasive and invasive ventilation (4-point response: disfavour, favour under certain circumstances, favour generally, uncertain). Patients' actual WTHD was assessed using the question: "How strong is your current wish to ask others for assistance to end your life prematurely" (NRS 0; 1-10). They were also asked about advance care planning, suicidal ideation, treatment for depression, whether they could imagine asking for PAS or euthanasia, and about communicating the WTHD (yes-no format). Caregivers were asked whether they can imagine helping the patient to hasten death (via suicide assistance or euthanasia, yes-no format).

The questionnaire was pilot-validated among ALS experts and a small group of patients and caregivers. Additional clinical data (ALSFRS, time since diagnosis) were extracted from the patients' records.

Statistical analysis

To compare patients from both countries, t-tests and Fisher's exact tests were performed for continuous and categorical variables, respectively. For items with yes-no answers and 4-point response format the McNemar test was used to compare coincident answers either between baseline and follow-up surveys or between patients and caregivers. For HADS and NRS, mixed-effects models (for quality of live and suffering) or generalized linear mixed models (for score values of loneliness) were applied to compare between baseline and follow-up or between caregivers and patients. Differences of mean and the corresponding p-values were calculated. In order to find predictive factors for WTHD generalized linear models were applied providing odds ratios (OR) and 95% confidence intervals (CI) with corresponding p-values. Score values were assumed to be approximately Poisson distributed, however the models allowed for over-dispersion of the Poisson distribution. Because of the descriptive nature of the study, no adjusting for multiple comparisons was performed. The level of significance was $p < 0.05$. All analyses were performed using R version 2.12.2 [26].

RESULTS

A total of 66 ALS patients and 62 primary caregivers were enrolled (4 patients had no caregiver). Among the caregivers, there were 29 female partners, 20 male partners, 6 daughters, 3 sons, 1 mother, 1 sister, and 2 nurses. The participants' demographic and clinical characteristics are listed in table 1. The follow-up survey was conducted on average 13.2 months after the initial survey and comprised 38 patients and 35 caregivers. A total of 28 patients could not be asked a second time because they had either died in the meantime (n=24) or could not be contacted any more (n=4). None of the subjects withdrew from the study. Completing the questionnaire was rated as hardly distressing (NRS 0-10: mean 1.2 for patients and 3.5 for caregivers), but moderately helpful (NRS 0-10: mean 4.8 both for patients and caregivers, baseline data, no change at follow-up). The demographic characteristics were not significantly different for the two recruitment sites (data not shown). The patients recruited in Germany, however, had a lower ALSFRS score at the first survey (mean 28.3 vs. 36.4, $p < 0.001$) and the time since diagnosis tended to be longer (mean 24.8 months vs. 14.6 months, $p = 0.19$).

The wish to hasten death (WTHD): prevalence, stability, and communication

Attitudes towards hastening death remained stable between the two surveys (Table 2). Roughly half the patients stated that they had thought about committing suicide, and every second patient can imagine asking for PAS or euthanasia. At the baseline survey, nine patients (14%) expressed a current WTHD (mean intensity 3.4 on NRS 1-10). At follow-up, four of them had died or couldn't be contacted, one who had expressed the WTHD in a very slight intensity (0.5 on NRS 1-10) did not express it anymore, and the other four reiterated the WTHD in constant intensity (mean 4 and 3.75 on NRS 1-10). Two patients who had initially not expressed the WTHD did so at follow-up. More than half of the patients reported that they had talked with others about the option to hasten death, mostly with family members (Table 2). One third of the caregivers could imagine helping the patient to hasten death (31% at baseline and 29% at follow-up). A majority of them could imagine to supply their partner with a fatal drug (70% and 90% over time, p= 0.37) and even to administer the fatal drug (45% and 67%, p=0.43).

Attitudes towards life-sustaining treatment

Most patients and caregivers had positive attitudes towards non-invasive ventilation, fewer favored PEG and even less invasive ventilation (Table 3). There was a tendency for caregivers to be more often in favour of these treatments than patients. These attitudes did not significantly change over time. However, the number of patients who had written advance directives significantly increased over time.

Quality of life and psychological distress

Patients and caregivers both assessed their own quality of life in the middle range, while the caregivers reported higher levels of loneliness and suffering at both time points (Table 4). During the course of the disease, however, the patients, but not the caregivers, showed a significant increase in reported levels of loneliness and the feeling to be a burden to others, as well as a lower quality of life. When the patients were asked at baseline what they suffered most from, 58% mentioned social problems, 30% physical symptoms, 8% psychological suffering and no one spiritual or religious issues (follow up: 68%, 22%, 8%, and 0%, respectively). About a third of the patients reported clinical or borderline anxiety (HADS-A ≥ 8 points, 31% both at baseline and follow-up). Also, a third (34%) had clinical or borderline depression at baseline, which increased to 50% until follow-up (HADS-D ≥ 8 points). Yet, only 14% of the patients in the baseline and 11% in the follow-up survey reported that they had been treated for depression.

The mean anxiety level was higher among German than Swiss patients (mean HADS-A at baseline 7.4 vs. 5.2, p = 0.028; at follow-up 8.3 vs. 5.3, p = 0.003), as were those for depression (mean HADS-D at baseline 8.4 vs. 5.4, p = 0.009; at follow-up 8.7 vs. 5.8, p = 0.042). Quality of life was lower in the German cohort at both time points (NRS 0-10, mean at baseline 5.2 vs. 6.3, p = 0.013; at follow-up 4.0 vs. 5.8; p = 0.011; data not shown).

Factors predicting WTHD

The WTHD was predicted by high levels of anxiety, depression, loneliness, and the feeling to be a burden to others, as well as by a low quality of life (Table 5), but not by the ALSFRS score or time since diagnosis. This predictability was constant during the follow up for loneliness, burden to others, and quality of life (not shown). Low levels of religiosity at both time points predicted whether or not patients could imagine asking for PAS and euthanasia.

DISCUSSION

This prospective study of ALS patients and their primary caregivers demonstrates that WTHD is more common than often reported: While 14% of patients expressed a current WTHD, half of them could imagine asking for assistance in hastening death someday. These numbers are consistent with studies from New York, Montreal, and Oregon.[10 17 27] A lower prevalence was reported from a previous German interview study with 29 family caregivers of deceased (and formerly non-invasively ventilated) ALS patients according to which only 24% of caregivers thought about PAS and, based on the caregivers' reports, only 10% of patients did so.[5] Yet, this study was qualitative, and may have underestimated the true prevalence of WTHD because of its reliance on post-mortem reports by caregivers and its selection of ventilated patients. Although the public discourse about PAS and euthanasia is still comparatively cautious in Germany due to its historical heritage,[28] this obviously does not preclude patients from thinking about these options. Although euthanasia is legally prohibited in both Germany and Switzerland, in our study the percentage of patients that could imagine euthanasia was the same as for PAS which is lawful. There are no official statistics about PAS prevalence in either country, as physicians are not obliged to report such cases. Yet, a representative poll among German physicians found that 50% of general practitioners have been addressed by patients asking them for PAS.[29] In Switzerland, and to a lesser degree in Germany, there are private, non-medical organizations (e.g. Exit, Dignitas, SterbeHilfe Deutschland e.V.) that offer assistance in suicide. Their statistics, though uncontrolled, show that ALS is a common disease group among the patients dying from PAS.[15 16]

The most important finding of this study is that patients' WTHD and attitudes towards life-sustaining treatment remained stable during the average 13 months follow-up period. An earlier American study with a cohort of terminally ill patients found that half of them changed their minds during 6 months regarding their preferences for PAS and euthanasia.[30] An explanatory hypothesis may be that cancer and cardiovascular diseases usually follow a fluctuating disease trajectory raising hopes for a cure, while ALS follows a predictably declining disease course. Accordingly, the only prospective study with ALS patients reported that the wish to die significantly predicted the same wish several months later.[17]

The observed stability of ALS patients' attitudes towards life-sustaining treatment warrants trust in their advance treatment directives. Indeed, a high percentage of our patient cohort made use of advance directives, comparable to the data from a large American study among elderly patients.[31] It is known that end-of-life preferences show a higher stability in those who issue advance directives.[32] In addition, terminally ill are more concerned about the binding force of their directives than non-terminally ill.[33] While the German and Swiss jurisdictions have long been recognizing the binding nature of advance directives, both countries have recently introduced specific laws to assure this.[34]

Interestingly, the aggravating symptom burden toward the end of life did not increase WTHD among our ALS patients. Conversely, the fact that all of them were enrolled in multidisciplinary, ALS-specific palliative care programs did not allay their WTHD. It may be hypothesized that WTHD depends more on the personality of the patient than the quality of care or the sociocultural environment, reinforcing data from Oregon.[35] [36] In any case, the assertion of some policy-makers and hospice lobbyists that palliative care is able to prevent the insurgence of WTHD is not supported by our data.

Our study shows that psychosocial factors and comorbidities such as anxiety and depression, but also loneliness, the perception to be a burden to others, and a low self-perceived quality of life, predict WTHD. Highly religious patients seem to be less inclined to imagine hastening death. These findings corroborate an emergent set of data from other studies.[2 8 10 17 19 21 27] Although a third to half of ALS patients in our study had borderline or clinical depression in the HADS, only 14% had been treated for depression, raising the question of underestimation and under-treatment of psychiatric comorbidity in ALS.

Other studies also found a correlation between WTHD of ALS patients and the distress of family caregivers.[2 37] Of note, we found that caregivers had higher levels of loneliness and suffering than the patients. It is increasingly acknowledged that ALS care must include offering specific treatment and support for the family caregivers.[22 38] This is all the more relevant because we found that relatives were the only ones with whom ALS patients communicated about WTHD. We also found that 30-47% of patients would have liked to talk to their doctor about it, but almost no one did. Thus, physicians should be prepared to proactively address the question of WTHD, which could ease distress for both the patient and the caregivers and may even prevent some patients from hastening death.[39]

Our study has several limitations. First, we did not assess the frequency of the act of hastening death. Second, the drop-out rate at follow-up was high due to intervening death of patients, because we wanted to study patients in their last phase of life. Third, our results may only be cautiously generalized to other regions or countries because cultural factors, including legal regulations, play a large role in end-of-life attitudes.[40]

In conclusion, our data show a considerable prevalence of WTHD in German and Swiss ALS patients treated at specialized centres that offer high-quality palliative care. The WTHD were remarkably stable during the disease course and correlated with psychosocial factors rather than symptom burden. There is evidence for under-treatment of psychiatric comorbidities. Sustained efforts towards prevention, early identification and treatment of psychosocial distress in ALS patients and their caregivers are clearly warranted.

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DISCLOSURE OF INTEREST

None.

CONTRIBUTORS

RS and MW contributed to the study design, collected and analysed the Swiss data, drafted and revised the paper. SRT contributed to the study design and data analysis and revised the paper. US performed statistical analyses and revised the paper. GDB contributed to the study design and the analysis of the German data and revised the paper. RJJ drafted the study design, collected the German data, analysed all data, drafted and revised the paper.

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LEGENDS OF TABLES

Legend to Table 1:

SD = standard deviation. N = number. Numbers may not add up to 100 due to rounding.

* Level of education according to the UNESCO International Standard Classification of Education: lower secondary education = level 2, upper secondary education = levels 3+4, tertiary education = levels 5-8.

Legend to Table 2:

*P values derived from McNemar tests comparing coincident answers between baseline and follow-up surveys for patients.

† NRS 0-10. The answer 0 signifies no WTHD, while a number between 1 and 10 signifies a WTHD to varying intensities, which are reported in the text.

Numbers of patients giving no answer are not shown. Numbers may not add to 100 due to rounding.

Legend to Table 3:

* In the 4-point response format, the answers “favor generally” and “favor under certain circumstances” were summed up in order to dichotomize the answers.

† McNemar test to compare coincident answers between baseline and follow-up surveys for patients and caregivers.

‡McNemar test to compare coincident answers between patients and caregivers at baseline and follow-up surveys

Legend to Table 4:

NRS = Numerical Rating Scale. SD = Standard Deviation. CI = Confidence Interval. HADS = Hospital Anxiety and Depression Scale (“A” for subset anxiety and “D” for subset depression). * Differences of mean calculated using mixed-effect models (for quality of life and suffering) or generalized linear mixed models (for loneliness). The comparison of the patients’ and the caregivers’ mean is presented vertically; the comparison of the mean at baseline and follow-up (for patients and caregivers) is presented horizontally. † Borderline anxiety: 8-10 out of 21 points in HADS-A; Clinical anxiety 11-21 out of 21 points. Borderline depression 8-10 out of 21 points in HADS-D; Clinical depression 11-21 out of 21 points.

Legend to Table 5:

Generalized linear model testing the predictive value of psychosocial and spiritual factors on the wish to hasten death (only significantly predicting factors are shown). Odds ratio indicate either the regression slope or the ratio yes vs. no for religiosity. HADS = Hospital Anxiety and Depression Scale (“A” for subset anxiety and “D” for subset depression),

IIR = Idler Index of Religiosity, CI = Confidence Interval.

TABLES

Table 1 Demographic and clinical data

	Baseline survey		Follow-up survey	
	Patients (n=66)	Caregivers (n=62)	Patients (n=38)	Caregivers (n=35)
Mean age (SD)	61.9 (10.5)	56.4 (12.7)	59.3 (10.2)	54.2 (12.8)
Sex, n (%)				
Female	27 (41)	38 (61)	14 (37)	24 (69)
Male	39 (59)	24 (39)	24 (63)	11 (31)
Marital status, n (%)				
Married	53 (80)	49 (79)	30 (79)	29 (85)
Single	4 (6)	6 (10)	3 (8)	5 (15)
Divorced	5 (8)	5 (8)	3 (8)	-
Widowed	4 (6)	2 (3)	2 (5)	-
Level of education*, n (%)				
Lower secondary education	39 (70)	42 (75)	20 (67)	22 (71)
Upper secondary education	3 (5)	4 (7)	2 (7)	5 (16)
Tertiary education	14 (25)	10 (18)	8 (27)	4 (13)
Religious affiliation, n (%)				
Roman-Catholic Christian	40 (61)	35 (57)	23 (61)	20 (57)
Protestant Christian	17 (26)	14 (23)	9 (24)	8 (23)
Others	1 (2)	1 (2)	1 (3)	1 (3)
None	8 (12)	12 (19)	5 (13)	6 (17)
Recruitment site, n (%)				
Switzerland	33 (50)	32 (52)	26 (69)	24 (69)
Germany	33 (50)	30 (48)	12 (32)	11 (31)
ALSFRS (mean, SD)	32.4 (8.7)	-	26.3 (9.8)	-
Mean time since diagnosis, months (SD)	19.7 (26.5)	-	32.9 (29.1)	-

Table 2 The wish to hasten death among ALS patients

	Baseline survey	**Follow-up survey**	**p-value***
	n=66	n=38	
Have you ever thought about committing suicide? n (%)			
Yes	28 (42)	22 (58)	0.25
No	35 (53)	16 (42)	
Can you imagine asking a physician for a prescription to commit suicide? n (%)			
Yes	33 (50)	17 (45)	1.0
No	30 (46)	21 (55)	
Can you imagine asking a physician to administer a lethal medication? n (%)			
Yes	33 (50)	17 (45)	0.68
No	30 (46)	21 (55)	
How strong is your current wish to ask others for assistance to end your life prematurely?			
1-10/10[†]	9 (14)	6 (16)	1.0
0/10	54 (82)	32 (84)	
Have you been under treatment for depression since your ALS diagnosis? n (%)			
Yes	9 (14)	4 (11)	1.0
No	54 (82)	34 (90)	
Have you ever talked about someone about the option to hasten death? n (%)			
Yes	44 (67)	21 (55)	
No	19 (29)	16 (42)	0.39
With whom did you talk about the option to hasten death? n (%)			
With a family member	16 (84)	14 (88)	1.0
With a friend	-	1 (6)	
With another ALS patient	1 (5)	-	

With to a chaplain	1 (5)	-	
With a physician	1 (5)	1 (6)	
Would you like to talk with a physician about the option to hasten death? n (%)			
Yes	20 (30)	18 (47)	0.72
No	37 (56)	18 (47)	

Table 3 Attitudes towards life-sustaining treatment			
	Baseline survey	**Follow-up survey**	**p-value**†
	Patients n=66 Caregivers n=62	Patients n=38 Caregivers n=35	
In favor* of PEG tube			
Patients, n (%)	35 (55)	22 (58)	1.0
Caregivers, n (%)	39 (64)	23 (66)	0.55
p-value‡	0.52	0.80	
In favor of non-invasive ventilation			
Patients, n (%)	47 (75)	34 (89)	0.073
Caregivers, n (%)	51 (84)	33 (94)	0.22
p-value‡	0.21	0.18	
In favor of invasive ventilation by tracheotomy			
Patients, n (%)	17 (27)	9 (24)	0.61
Caregivers, n (%)	19 (31)	15 (43)	0.39
p-value‡	0.68	0.61	
Advance treatment directive written			
Patients, n (%)	31 (49)	31 (82)	0.0036
Durable power of attorney issued			
Patients, n (%)	20 (32)	14 (37)	0.45

Table 4 Quality of life and psychological distress

	Baseline survey	**Follow-up survey**	**Difference of mean (95% CI)***	**p-value**
	Patients n=66 Carers n=62	Patients n=38 Carers n=35		
Quality of life, NRS 0-10				
Patients´ mean (SD)	5.7 (1.8)	5.2 (2.0)	-0.63 (-1.24, -0.01)	0.045
Caregivers´ mean (SD)	5.9 (2.1)	5.5 (2.1)	-0.41 (-1.00, 0.17)	0.16
*Difference of mean (95%CI)**	*0.2 (-0.4, 0.8)*	*0.3 (-0.5, 1.2)*		
p-value	*0.55*	*0.45*		
Loneliness, NRS 0-10				
Patients´ mean (SD)	1.6 (2.0)	2.3 (2.3)	0.42 (0.08, 0.75)	0.016
Caregivers´ mean (SD)	2.7 (3.0)	3.3 (2.8)	0.15 (-0.14, 0.43)	0.31
*Difference of mean (95%CI)**	*1.1 (0.3, 1.9)*	*1.0 (0.0-2.1)*		
p-value	*0.010*	*0.053*		
Suffering, NRS 0-10				
Patients´ mean (SD)	5.2 (2.6)	4.6 (2.1)	-0.17 (-0.87, 0.53)	0.62
Caregivers´ mean (SD)	6.6 (2.4)	6.3 (2.4)	-0.16 (-0.88, 0.56)	0.66
*Difference of mean (95%CI)**	*1.4 (0.6, 2.1)*	*1.7 (0.7, 2.7)*		
p-value	*<0.001*	*0.001*		
Feeling to be a burden, NRS 0-10				
Patients´ mean (SD)	3.8 (3.1)	4.7 (2.7)	0.25 (0.02, 0.49)	0.037
Anxiety, HADS-A				
Patients´ mean (SD)	6.3 (4.1)	6.3 (3.0)	0.02 (-0.16, 0.2)	0.85

Borderline anxiety†, n (%)	11 (17)	10 (26)		
Clinical anxiety†, n (%)	9 (14)	2 (5)		
Depression, HADS-D				
Patients´ mean (SD)	6.9 (4.1)	6.7 (4.1)	0.07 (-0.1, 0.24)	0.40
Borderline depression†, n (%)	13 (20)	10 (26)		
Clinical depression†, n (%)	9 (14)	9 (24)		

Table 5 Predictive factors for the wish to hasten death (patients, baseline interview, n=66)

	Odds Ratio	**95% CI**	**p-value**
Current wish to hasten death			
Anxiety (HADS-A)	1.18	1.10, 1.26	<0.001
Depression (HADS-D)	1.10	1.01, 1.20	0.027
Loneliness	1.20	1.02, 1.38	0.021
Burden to others	1.14	1.03, 1.25	0.0076
Quality of life	0.89	0.82, 0.95	0.0013
Could imagine asking for physician-assisted suicide			
Religiosity (IIR)	0.55	0.42, 0.72	<0.001
Could imagine asking for euthanasia			
Religiosity (IIR)	0.53	0.41, 0.69	<0.001

4.3 „Finding their voices again: a media project offers a floor for vulnerable patients, clients and the socially deprived“ (2013) *Medicine, Health Care and Philosophy* (2013) DOI: 10.1007/s11019-013-9468-2

Stutzki R, Weber M, Reiter-Theil S

Die beiden Interviewstudien mit ALS Patienten und deren Angehörigen verfolgten das Ziel, anhand von Fragestellungen insbesondere zum Thema Lebensende die (Über-)Lebenssituation der Betroffenen zu beleuchten, zu hinterfragen und mittels der bestehenden und durch uns neu zu generierenden Daten ggfs. einen Beitrag zur Verbesserung dieser Situation zu leisten - z.B. auch durch Impulsgebung für das Therapieangebot dieser noch immer weitgehend unerforschten Erkrankung. Dennoch zeigten sich bereits zu Beginn dieser Studie auf Seiten des Dissertierenden eine gewisse Unsicherheit und Unbehagen über das Projektverfahren als solches, dessen Design zweifellos dem state of the art gängiger Forschungsmethodik entsprach und zudem – natürlich – auch durch informed consent validiert worden war. Im Raum standen insbesondere zwei Fragen: 1. Ob die avisierte Erkenntnisgenerierung in Bereiche menschlichen Lebens vorstossen würde, deren Betreten eine unerlaubte bzw. nicht tolerierbare Grenzüberschreitung darstellt, welche selbst durch die schriftliche Einwilligung der Studienteilnehmer nicht egalisiert werden kann.
2. Ob sich diese (und ggfs. auch andere) Studie neben empirischer Forschungsmethoden noch weiterer Ansätze bedienen kann, mittels derer Erkenntnisgewinn und Wahrheitsfindung voranschreiten können.

a) Methode

Wir entwickelten eine Methode, deren Ziel es ist, den wissenschaftlichen aber auch alltäglichen Umgang mit vulnerablen Gruppen in der Art neu zu strukturieren, dass der Anteil an Verantwortung, Einfluss und Kompetenz grundsätzlich auf alle Beteiligten gerecht verteilt wird. Hierzu untersuchten wir den Tugendbegriff „aidōs", der bereits in den frühen Schriften der Griechischen Mythologie als unabdingbarer Wegweiser für das menschliche Streben nach Erkenntnis und Wahrheit beschrieben wurde. So liegt beispielsweise Platon's anthropologische Deklaration, dass alle Menschen zu gleichen Teilen talentiert und qualifiziert sind, über Gerechtigkeitsfragen in der Gesellschaft ('polis') zu urteilen[27], der aidōs-Begriff zugrunde. Wir nannten den erkenntnistheoretischen Ansatz den "aidōs-approach" und wendeten ihn in einem in 2009 eigens hierfür entwickelten Medienprojekt, welches sich gezielt Patienten und anderen vulnerablen Gruppen unserer Gesellschaft widmete, erstmalig an. Hierbei erhalten die Gruppen in Fokus die Möglichkeit, insgesamt 120 Minuten Radio-Sendezeit – frei von jeglicher journalistischer oder anderer Einflussnahme – inhaltlich eigenverantwortlich zu gestalten und zu produzieren.

b) Ergebnisse

In den zurückliegenden vier Jahren haben sich rund 300 Menschen an dem aidōs-Medienprojekt mit dem Namen "DU bist Radio" aktiv beteiligt. Die Produktionen haben gezeigt, dass unser forschungsmethodologischer Ansatz, freie und ungefilterte Partizipation zu ermöglichen nicht nur neue, sondern teilweise auch unvorhersehbare und bedeutende Inhalte bzw. Erkenntnisse generiert. Mittels des "aidōs-approach" kann es gelingen, Erkenntnisse freizulegen, die bisweilen über jene Datenstrukturen hinausreichen, die rigorose empirische Forschung in der Lage ist ans Licht zu befördern. Indem die Teilnehmenden eigenverantwortlich und selbstentscheidend Inhalte festlegen und gestalten können, erhalten sie nicht nur die uneingeschränkte Suveränität über die Produktion; sie erfahren zudem eine (auch auf anderen gesellschaftlichen Gebieten) längst überfällige Entkategorisierung und Entstigmatisierung, indem sie nicht mehr von Aussenstehenden als "vulnerable Menschen, "Patienten, "Behinderte", "Klienten", o.ä. zu Themen gezielt befragt werden, sondern eigenständig die Richtung der Inhalte bestimmen können.

c) Diskussion

Die Erfahrungen aus dem aidōs-Medienprojekt können einen konstruktiven Beitrag zu der gegenwärtigen medizinethischen Diskussion über die Rolle der sog. "Schwachen" und "Vulnerablen" leisten. Der unzweifelhaft wertvolle vier-Prinzipien-Ansatz in der Medizinethik kann von dem "aidōs-approach" insofern profitieren, als er durch das Aufbrechen (allein schon sprachlich-) klassifizierender und teilweise diskriminierender Strukturen den Menschen wieder zuförderst in seiner Gesamtheit betrachtet. Dieser Prozess kann allerdings in seiner Konsequenz nur radikal, sprich: auf Augenhöhe, vonstatten gehen , was die Auflösung der herkömmlichen Rollenverteilung beispielsweise zwischen Patient/Behdandelndem zur Folge haben muss. Durch den "aidōs-approach" werden Verantwortung, Einflussnahme und Kompetenz unter allen Beteiligten neu und zu gleichen Teilen aufgeteilt.

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SCIENTIFIC CONTRIBUTION

Finding their voices again: a media project offers a floor for vulnerable patients, clients and the socially deprived

Ralf Stutzki · Markus Weber · Stella Reiter-Theil

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Abstract 'DU bist Radio' (DBR) is an award winning [DBR has been awarded with the "Catholic Media Award of the German Bishops Conference, Prädikat WERTvoll" (2011), the Suisse "Media Prize Aargau/Solothurn" (2010), the German "Alternative Media Award" (2009) and was nominated for the "Prix Europa" (2009)] monthly radio format that goes on air on three Swiss radio stations. The purpose of this program which was first broadcast in 2009 is the development of a new media format which—without applying any journalistic (or other) filter and influence—conveys authenticity of expression amongst society's most vulnerable fellow citizens such as patients, clients and the socially deprived. So-called *marginal groups* are encouraged to speak for themselves, as a possible paradigm case for encouraging the inclusion of patients' and relatives' "unfiltered" voices in general and in clinical ethics as well. Before handing over the microphone to the groups in focus, a team of journalists, educated in medical ethics, over a period of 4 days, teaches them on-site radio skills and craft. Once this task is completed and the actual production of the broadcast begins, the media crew does not exert any influence whatsoever on the content of the 1-h program. Thus, the final product is solely created and accounted for by the media-inexperienced participants, leading to unforeseen and often surprising results. It is discussed that the DBR approach of fostering authenticity of expression can serve as an enhancement to today's respect and autonomy oriented field of medical ethics.

Keywords Medical ethics · Media ethics · DU bist Radio · DBR · Patient participation · Vulnerable groups · Aidōs · Patient rights · Patient discrimination

Introduction

There are many groups in our society, of which we know merely that they exist. Not only our lack of in-depth interest in them, but also their exclusion from societal resources which can be easily accessed by us at any time, deprive them of their right to fully live out their humanity. They have become stereotyped, categorized and even stigmatized minorities: "handicapped persons", "patients", "clients", "detainees" etc. The media project "DU bist Radio" (*YOU are Radio*) aims at retrieving those groups out of their artificial social distance by providing them with a tool that allows them to articulate themselves freely, i.e. without applying any journalistic, methodological or ethical filter and influence thereby conveying authenticity of expression. These oftentimes so-called marginal groups[1] are encouraged to speak for themselves as a possible paradigm case for stimulating the inclusion of patients' and relatives' "unfiltered" voices in the field of medical ethics as well. We claim a significance of this project for clinical ethics in the sense that it serves as an encouragement to dare involving patients

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[1] DBR has produced programs with groups of people suffering from e.g. amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), eating disorders; children in a hospice; people with psychiatric disorders, clients in rehab centers for addiction treatment, people in facilities for the handicapped, inmates in maximum security prisons.

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and relatives more directly in ethical discussions; pioneer projects doing this have been reported rarely (Reiter-Theil 1998a), despite an overall societal trend to favor participation (Schicktanz 2009), which has become a prominent principle in the bioethics discourse (Reiter-Theil 2003; Borders et al. 2005; Weingart et al. 2011; Harun et al. 2012; Schicktanz et al. 2012). In clinical ethics support (CES) there is an ongoing discussion as to whether and how patients and relatives should and could have access to CES or be involved to speak for themselves; the topic developed from a completely neglected issue to an attractive debate (Reiter-Theil 2003; Newson et al. 2009). Besides the principled matter of unquestioned patient rights to access and transparency, there is also concern that not all experiences around ethical case discussion or consultation might be beneficial to those affected and destabilized by illness and suffering. Routine healthcare professional-patient conversation also deserves to be looked at in terms of roles and reciprocity, and even closely following the doctrine of informed consent in its predominantly intellectual meaning has been identified as being insufficient, e.g. in end-of-life situations (Reiter-Theil 1998b). However, in practical life, there are many areas where participation is less visible than discrimination or segregation; thus, we are more likely to err by offering too little rather than too much participation. One such area of neglect has certainly been the involvement of patients in the discussion of ethical issues in health care (Reiter-Theil 1998a; Frojd et al. 2011). And the question whether patients' rights and participation ought to be extended to other fields of social life as well has yet to be raised. As far as active media involvement of patients is concerned, recent scientific discussion has focused primarily on the pros and cons of social media (Thielst 2011; Yamout et al. 2011; Glick and Yamout 2012; Sweet 2012), the role of the media in end-of-life decisions (Drake and Cox 2012) or the disclosure of celebrity patient information in the traditional media like newspaper, radio and television (Burkle and Cascino 2011). The issue of free media access for those who due to illness or other circumstances, which make them vulnerable in our society, are unable to participate so far has—to say the least—not been at the core of recent research.

Our paper will start with a detailed description of the ideas and the procedures behind DBR. This will be followed by a discussion of the theory this media project is built on, namely the assumption that the encounter with the "other" on an eye-to-eye level—with the forces being equally distributed—can only be achieved if those who are involved are guided by a concept that we want to call *aidōs.* Aidōs, according to Greek mythology a virtue required for men's peaceful co-existence, is the road man must walk in order to approach the other in a manner that exceeds mere respect. This encounter, it will be argued, can only take place in an un-conditioned manner, i.e. without conditions (German: *un-bedingt*); meeting the other in this sense is a premise for all human self-understanding and self-realization.[2]

The experience and insights gained in the DBR media project so far will be analyzed along the following research questions: (1) To what extent does the application of the virtue of aidōs support our relation to as well as the condition of the vulnerable? (2) Can the DBR approach, which defines human encounter particularly as a transfer of competence and responsibility to the side of the vulnerable, encourage efforts to amplify the four principle based (Beauchamp and Childress 2001) medical ethics of our time?

Background, concept and goals

Starting point

The idea of developing this broadcasting format grew out of a longitudinal study that we conducted with Swiss amyotrophic lateral sclerosis (ALS) patients and their caregivers. ALS is an incurable progressive motor neuron disease, which in the later stage can lead to total paralysis. The average life expectancy of patients suffering from ALS ranges between 3 and 5 years from time of diagnosis. This study was authored by the Muskelzentrum/ALS clinic at the Kantonsspital St. Gallen and the Department of Medical and Health Ethics, Medical Faculty of the University of Basel[3] and focused on end of life issues, suicidality, spirituality and quality of life of ALS-patients and their caregivers at an early and later stage of this fatal disease (Stutzki et al. 2012). In the process of conducting interviews[4] that took place at the patients' homes, a question arose for the responsible interviewer, who is also an experienced journalist,[5] about the nature of the data being collected. On the one hand, it was clear that this research was based on current methodological standards of research and should provide valuable data for the ongoing ALS-research. On the other hand, the most private and intimate interview setting—i.e. patient homes—stimulated two unexpected insights and experiences which later on would provide the grounds for the theoretical foundation of the DBR media project:

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[2] This approach rests on the dialogical school of philosophical thought developed by thinkers such as Martin Buber: "I become through my relation to the Thou" (Buber 2005).

[3] See: http://klinische-ethik.unispital-basel.ch.

[4] The questioning consisted of validated questionnaires, rating scales and semi-structured open and tape recorded interviews.

[5] First author.

(a) The interviewer specifically sensed a peculiar uncomfortableness due to the in-house setting. Asking the participants about most personal and existential matters (such as their attitude towards life prolonging measures, suicidality and the quality of the relationship between the patient and caregivers—usually wife or husband) in their private rooms to him felt like an almost forbidden and unacceptable intrusion into the lives of the participants, who undoubtedly had invited him to this proceeding. The interviewer decided to follow up on this experience, the results of which will be shown later in this article.

(b) The setting stimulated reactions and further statements of the participants, which the methodologies as such used in this research did not trigger.[6] Upon completion of the study questionnaires and semi-structured interviews, when the recording device had been switched off and no further questions were directed at them, a majority of both patients and caregivers began to open up to the interviewer, thereby providing another quality of insights into their overall condition. This experience is not strange to social scientists (Devereux 1973) and we argue that this information, given upon completion of the interviews, provides a fruitful and valuable input for the on-going ALS-research as well as for medical ethics at large. In addition to the empirical research tools used in this study, patients and caregivers in a sense developed their own "methodology" that led to further insights into their coping strategies with regard to their disease. An example:

Upon completion of the interview, when the casual part of the meeting began, a male patient asked the interviewer to no longer address him as such: "Don't call me 'patient'. I have a name. I am a human being." The interviewer immediately felt caught red-handed while a sentiment of shame (German: Scham, see Chap. 'A methodology stimulated by mythology: the aidōs-approach') arose within him. The study participant—most likely unintentionally—had unmasked the interviewer by mirroring an attitude that interpreted this relation as one where the powers had been distributed unequally—obviously to the disadvantage of the patient. A situation where the 'I' is the interviewer while the 'You' is the 'patient' serves as a convenient resort for the one who is asking the questions. It provides a distance between the two and categorizes those who are involved—possibly caused by the wish (or even need) for self-protection. Once, as happened in this case, these categories have been identified and resolved, the former I/You relationship turns into a common "We." After all, the interviewer—just like the interviewee—has a first name and is a human being. The focus of this relation then switched towards that which was commonly shared. It unified and no longer separated.

The interviewee then invited the interviewer into another room in his house and began to share with him one of his life long passions: music. This room was filled with guitars, countless CDs and LPs. Due to the advanced stage of the ALS disease, the interviewee's hands and arms were completely paralyzed. But he could still play music. With the help of a friend he had constructed a foot-guitar, which can be operated with toes. Without saying a word the "former patient" sat down and began to play.[7]

Experiences as this one were the starting point for developing DBR as a tool of expression for vulnerable groups. DBR calls them "Menschen mit einer besonderen Lebensgeschichte" ('people with a remarkable story in life').

Background

"DU bist Radio" (DBR) is a public platform for those who are hardly recognized or even excluded by society. At the core of this media concept is free broadcasting time (120 min) which is being offered unconditionally and without any obligation whatsoever to the people in focus. The explorative and live character of this project—visiting and working with vulnerable groups on site (e.g. on the ward) makes DBR unique. These face-to-face encounters activate an interpersonal process that is an important feature of the concept. The DBR producers consist of a team of four professional journalists also educated in medical ethics, as well as a group of long-term unemployed persons striving for an occupational redeployment in the media field. Thus, not only a professional, but also a frail group of journalists works face-to-face with others who have to deal with severe life crisis or real life threats. Quarreling with these circumstances—as has been our experience so far and will be discussed—may also lead to a reassessment and even repositioning of one's own allegedly difficult situation. Since DBR focuses particularly on people with a 'special life-story', i.e. vulnerable groups or individuals at risk, the approach towards them by all means must not be artificially created. The encounter has to take place at eye

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[6] Especially in empirical research settings with patients, questions and questionnaires oftentimes emphasize the interviewer's quest for knowledge (which includes his/her attitude, presuppositions and prejudices) rather than encouraging the intervierwee's spontaneous expression (Reiter-Theil 2012). Systematic methodologies like the Grounded Theory (Glaser and Strauss 2005) acknowledged this dilemma and made a great contribution to bridging this gap between theory and empirical research; nevertheless, the problem of an artificial setting where the interviewer faces the interviewee has not been eliminated.

[7] Video: http://www.youtube.com/watch?v=U7XkpHaTwps.

level, meaning that the other—despite his situation—is foremost seen in his humaneness and not in categories like e.g. ‘patient’, ‘addict’ or ‘disabled’. This can only be achieved if every member of the professional team involved in the DBR production knows about and accepts his own abysses: “If thou gaze for long into an abyss, the abyss gazes also into thee” (Nietzsche 1984, p. 82).[8] In a certain sense this media concept requires a position of equality between the participants and the producers. This condition undoubtedly cannot be reached completely; nevertheless there exists no reason why a group of people—both ways—should not attempt to de-categorize[9] each participant, emphasizing his humaneness only and aim at experiencing an “original position” behind a “veil of ignorance”, thereby assuming “that the parties do not know their conceptions of the good or their special psychological propensities. […] This assures that no one is advantaged or disadvantaged” (Rawls 1999, p. 11).

DBR is produced and has been broadcast since 2009 by the regional radio channel Kanal K in Aarau, Switzerland. Kanal K was founded in 1987 and is a non-commercial 24-h program with a keen focus on cultural contents. While a certain segment of broadcasting time is open to the public (“public radio”), the majority of the program is produced by two in-house editorial departments, which are directed by professional journalists. The first department is composed of up to 10 journalism-students who spend a 3 months traineeship (compulsory) as part of their academic program at the station. The second department “stage on air”, which produces DBR, consists of up to eight long-time unemployed persons who qualify for an occupational redeployment in the media field. They usually receive 6–9 months media training at the station. The Swiss Federal Office of Communication (OFCOM) and the federal unemployment insurance fund this training commitment of Kanal K. Kanal K and the co-broadcasting radio stations of DBR, Radio X in Basel and Radio RaBe in Bern, are members of UNIKOM, the Swiss organization of non-commercial radio broadcasters.

Approach

For a period of 4 days a team of journalists visits the DBR groups on site (wards, therapeutic living communities, prisons etc.) and works with them towards preparing the upcoming production. A DBR group[10] on average consists of 10–20 people. After a comprehensive introduction into the 4-day program the DBR participants split up into small working groups. It is important to point out that the DBR group members have been informed that they are not expected to define themselves in categories such as “handicapped” or “patients” during the course of the program. They are free to broach the issue of their suffering; they’re also free to choose a completely different horizon of content. Under the supportive yet non-directive guidance of the journalists these groups develop ideas and contents for their broadcast, which at the end of each day are put to discussion amongst all. As in good brainstorming, every idea is welcome and considered worth to be discussed. There is room for sharing dreams, talking about the present or past, about hopes and fears, and, of course, about what it means to live a categorized existence at the edge of society. Everything can, while nothing must be discussed. During the day each and every suggestion is put up to discussion amongst the whole DBR group which, as the production team takes on a role of non-intervention in this process as well, decides completely on its own about the themes that shall be presented in the program. The primary task of the production team during the 3 days of preparation for the recording is to assure that every participant has a chance to speak up and to put his/her ideas to discussion with the underlying rule that the input of each person is equally important and worth to be considered as everybody else’s. As soon as the ideas take shape and the group at large decides to include them in the program, the production team if necessary assists in the process of writing the script, particularly in light of the fact that “radio language” is a language of its own. Once the scripts are finalized, the DBR participants practice presenting them under the guidance of the journalists in front of a microphone. At the end of day 3, when all ideas and stories have been written down and presentation has been finalized, the DBR group—not the journalist—by majority vote decides on issues such as sequence or music selection and picks out those participants who will present the radio broadcast. Day 4 is the recording day. Depending on the size of the group and the number of inputs, the recording time for the final 2-h program is between six and 8 h.

At the end of each production day the DBR journalists post a personal report about what happened during the day as well as photos and videos on social media such as the

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[8] In 1984 the first author met Pastor Dr. Werner Koch at his home in The Netherlands who shared with him a remarkable encounter. Koch had been a student and member of the Confessing Church in Nazi-Germany, which led to his confinement in the concentration camp Sachsenhausen. After the end of WW II, Koch picked up his theological studies, enrolling in a lecture given by Protestant theologian Karl Barth whom Koch greatly admired. At the end of class Koch approached Barth who—still in the lecture hall—had lit his pipe and was getting ready to leave. Upon introducing himself, Koch extensively confessed his adoration for the renowned dogmatist Karl Barth who, puffing on his pipe, answered with but one sentence: “I know my abysses, Mr. Koch.”

[9] This approach of overturning hierarchies has been advocated by the semiotic analysis of “deconstruction” (Derrida et al. 1981).

[10] Groups may apply for participation in this project.

Fig. 1 Gathering thoughts and typing the scripts: group work with people suffering from ALS

DBR Facebook page and the DBR YouTube channel,[11] inviting the DBR participants (if they have access) as well as everyone interested in the production to comment and join the discussion online (Fig. 1).

Project goals and their societal context

DBR aims at breaking down taboos and categories that deprive vulnerable groups of the chance to participation. The on-site approach enables the group in focus to take part in a media setting which up to then had been out of their reach. Free access to the media is a fundamental democratic right that the vast majority of society is able to execute. This right, however, for the most part cannot be practiced by severely ill patients, clients, inmates etc. provoking a question of uttermost importance: who decides about the allocation of rights in a democratic society—and on what grounds? As far as free access to the media is concerned, DBR assumes that there exists no justification for excluding others from their rights to participation. Furthermore, a society that withholds in particular its most vulnerable members the opportunity of free speech and independent presentation in the media adds to their deprivation of rights in general.

If for example people who are mentally challenged reclaim the medium for themselves, they send out a strong signal that in this area of social life there can exists equity between them and the supposedly "normal" and not disabled. A paradigm change becomes possible: the de-categorization signals the possibility to (re-) conquer areas of community life that until then had been inaccessible. And, of course, also the "other side"—media and society at large—can benefit since the democratization of the (here:) microphone can lead to new insights and contents. All of a sudden and to the advantage of all a discriminatory term and concept become unmasked and demystified: "handicap" (German: *Behinderung*[12]) stands for obstacle (German: *Hindernis*). Unfiltered media access is a key to tear down those obstacles, which provide a fertile soil for socially convenient prejudices, fears and ignorance. Further, the transfer of journalistic expertise to these vulnerable groups is a strong sign that they—like everyone else—are both authorized *and* able to take on an equitable position among media professionals and to present their authentic issues and concerns to the public. This can serve as a model for other areas of life, in which equality, participation and integration of e.g. patients and disabled people have not yet been reached. An example:

Barbara, a 34 year old woman with trisomy 21, wanted to participate in a DBR production. When it was her turn to record, she sat down in front of the microphone and for 45 s merely moved her lips. Her caregiver explained that Barbara never speaks when she feels completely at ease. In such a situation she only moves her lips, articulating herself visually.

Forty-five seconds of silence are considered a "transmission hole" in daily radio business and must be—as is common broadcasting practice—avoided by all means. We decided, however, to broadcast Barbara's contribution, since it was obvious that she had communicated with the listeners. As a matter of fact, Barbara's contribution served as an advancement of the DBR concept: the problem of "not understanding" is—thanks to Barbara—now considered to be a problem on the side of the listeners. If they don't understand, they will have to search for the cause.

Stories told on DBR

The variety as well as concentration of contents, stories and thoughts expressed in the DBR productions so far is remarkable, as the following four examples shall show.

Children—setting their own agenda

The first DBR-production took place at "Kispex" in Zurich. "Kispex" is an institution offering palliative care for seriously ill or dying children. The production crew had prepared for a strenuous and intense time to be spent with a group of up to 14-year-old children suffering from a variety of (fatal) diseases. Before the production started it was clear to the journalists that the children would want to talk

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[11] http://www.facebook.com/dubistradio, http://www.youtube.com/user/dubistradio, http://www.dubistradio.ch.

[12] This word in the German language still is also used for describing obstacles that prevent the "normal" to move on: e.g. *Verkehrsbehinderung* (obstruction of traffic).

about issues related to their illnesses: e.g. about pain and fears; not being like other (healthy) children; the struggles of each day; the short lifetime left; the tense situation in their families etc. The production team had erred. The children did not spend a single word on issues related to their ill health. Instead, all of them talked about their future: Mario (11) brought along his keyboards, played some tunes and talked about his goal to become a professional musician. Marco (13) talked about his favorite subject at school ("vacation") and presented the history of his favorite football team FC Zurich. His career goal was to become a sports reporter. Lara (14) discussed her plans to go on a safari 1 day. She liked predators and at night she dreamt about having a tiger baby on her lap. The children talked about the future—not about our expectations.[13]

How a fatal disease triggered a "wonderful" family experience

In another DBR-production André wanted to talk about his illness. André, 43, was suffering from devastating ALS. At the time we met him, he was sitting in a wheelchair and was unable to move his arms and hands. In our program he shared two most personal aspects of his life with the disease. One was about his 8 year old daughter and how she struggled to accept her father who had turned from a healthy man to a seriously ill person in a very short time. André from his childhood on had a great affection for handicrafts and had always hoped to pass this talent on to his child. Being together in the hobby room, unable to point towards anything, he now had to tell his daughter: "Watch where I am looking." But whenever the point is reached where words do not suffice (e.g. when the daughter is not strong enough to saw a piece of wood) "all we can do is stop and do something else."

André describes his disease as "sent by the devil"—and at the same time as the reason for a dream come true. For a long time his father had dreamt about a fishing trip to Norway—together with his children André, his twin-sister and younger brother. Father and siblings lived abroad. Despite André's physical limitations they all got together and realized this long-cherished wish: "This was a wonderful vacation and we all got along great. I believe that without my illness this trip would never have been realized. All of a sudden everyone could spare the time and shared the desire to realize this dream."[14]

Fig. 2 Recording a Djembe-Song: "Lilith"-women in Oberbuchsiten

I am Lilly—YOU are Lilly

We also produced in "Lilith" in Oberbuchsiten—a rehab center for addiction treatment for women and their children. Some of the participants chose to talk about their roads of the past, which led them into hard drug addiction. Almost all life stories were characterized by the experience of severe violence like rape in their childhood and youth. Even for experienced DBR-journalists it was difficult to listen to some of the stories told. And some of the women struggled as well when talking about their past.[15] The "Lilith" women developed a remarkable acoustic tool, which made it at least a bit easier to tell their stories: together they created a kind of alter ego who they called "Lilly" and hence wrote their manuscripts in the third person, each and every one beginning her story with: "Lilly is …"

At the end of these roundabout 1-min spots each story ended with: "YOU are Lilly", echoed by the whispering choir of all the other participants: "I am Lilly, I am Lilly, I am Lilly …" This translation of transferring the own story into a third person, echoed by a whispering choir, undoubtedly has been one of the most magic moments in the DBR broadcast history so far (Fig. 2).[16]

I got myself a second face

Tobias lives and works in the "Stiftung für Behinderte" in Lenzburg along with 280 people with a variety of mental disorders. During 3 days of our production he was absolutely quiet and showed no sign of wanting to actively

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[13] Names used with permission.

[14] André's stories can be listened to online: http://youtu.be/mdv_PiKT9B0.

[15] In order to avoid e.g. re-traumatisation and to assure the wellbeing of the DBR participants at all times, DBR works closely together with the institutions' therapeutic and medical staff during the production.

[16] Three Lilly-Spots can be listened to online: Spot 1 http://www.youtube.com/watch?v=heUi2f6xHjU&feature=plcp, Spot 2 http://www.youtube.com/watch?v=M5stOj3fojM&feature=plcp, Spot 3 http://www.youtube.com/watch?v=GaWpFOH0uDQ&feature=plcp.

participate in the broadcast. During breaks we asked him how he was doing and if he wanted to contribute a story, a song or whatever to our production. He answered: "I'll write something." When we recorded DBR on day 4, Tobias came up to us during a break and pulled out a typed manuscript that he apparently had prepared on a computer. "I would like to record 2 pieces", he said, and this is what he did. In piece 1 he described himself as a person with "Asperger's Syndrome" (autism spectrum disorder) and presented a most detailed and profound analysis of this condition. Tobias' second contribution was a summary of his childhood and youth, emphasizing the discrimination he experienced in school as well as during his apprenticeship: "I was always alone. I was never accepted in school—no matter what happened. And I was someone who did not defend himself. They said: 'No, not him again. We don't want him.' And I started to change. I got myself a second face."[17]

Tobias—along with other DBR participants in Lenzburg—taught us one important lesson: people with special mental conditions (whatever they may be) know when and how we discriminate them.

A methodology stimulated by mythology: the aidōs-approach

DBR is an attempt to transfer an equal share of responsibility and power to the side of the vulnerable "other". For a methodological orientation we adopted the aidōs-approach, which is a highly complex term found in ancient Greek mythology, particularly in the writings of Plato who even considered it an imperative for mankind's survival. As it is the case with other concepts carrying emotional as well as moral connotations (Hollwich and Reiter-Theil 2012), aidōs has been characterized as both an "emotion-word" (Cairns 1993, pp. 7–13) and as a virtue (Kullmann 1998; Hogrebe 2004), the latter of which we choose to use in our analysis, leaning on Erffa that aidōs is "eine eigene Kraft, für die uns das Wort fehlt"—a power in itself for which we lack the terminology (Erffa 1937). Before we will sketch the mythological background of aidōs, we will describe the "methodological" aspects of the approach.

Since its beginnings in 2009 DBR has been—and will continue to be—an evolving project. Both the varieties of the hundreds of people involved so far as well as their individual and unique inputs into each program have challenged the producers to continually react and adjust a concept that had started out as a 'simple' broadcast idea. Accordingly, it would be presumptuous on the authors' side to claim that "DBR" rests on a clear cut methodology carved in stone. It simply cannot. Nevertheless, as this media concept continually advances, so does its theoretical framework: this 'methodology in progress' serves as a bridge connecting and interpreting our work with the vulnerable on the one side with the aidōs-approach on the other side. Aidōs, as will be shown, is a virtuous tool provided to all men particularly to guide them in their quest for knowledge. Respect, curiosity and tolerance, attitudes as important they may be, do not suffice in this endeavor if our *quest to find out* touches or even digs into those spheres that solely belong to our counterpart. Serving as a moral and emotional compass, aidōs requires the strict abidance to rules and principles: (1) The DBR-encounter has to take place within a framework where all parties involved hold a position of equality.[18] (2) Structures of authority must be minimized to the smallest degree possible, the organization and responsibility of which lies in the hand of the majority (i.e. *participants* of the DBR-project). (3) Since in this media project the vulnerability of the participants not only becomes apparent physically (wards; cells; condition of patients), but oftentimes also through the most intimate stories shared during the production days, the members of the professional crew must for the sake of reciprocity be willing—whenever asked by the participants—to allow insight into their own vulnerability as well (cf. discussion on "abyss", Chap. 'Background'). Abiding by these three principles allows an atmosphere of trust and security to unfold. It is this approach that creates a unique setting where the story of the "other" all of a sudden can become "my" story (Fig. 3).

Terminological clarification in the mythological context

Since the scientific discussion of the Greek term aidōs so far has not reached a widespread scholarly attention—let aside in particular Douglas L. Cairns' remarkable work (Cairns 1993)—we will now have to analyze the terminology of adiōs-translations in order to grasp the rich meaning of the concept behind the word. The standard Greek-English lexicon (Liddell et al. 1996) translates aidōs as "reverence", "shame", "awe" and "respect". The Greek-German lexicon (Pape 2005) translates aidōs as "Ehrfurcht", "sittliche

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[17] Tobias' contribution: http://www.youtube.com/watch?v=rrNydAiNhwo&feature=plcp.

[18] To underline this, on day 1—after an introduction into the project—the DBR producer officially opens the "editorial meeting" and henceforth addresses the participants as "colleagues." DBR has received numerous feedbacks documenting that this position of equality can be realized: "You made an editorial meeting out of the '*Harmonie*' [institution for long-term drug addicts in Langenbruck]. There was no difference between the residents and the radio producers. Very impressive and sensitive. It is a privilege to be working with you." (Jürg Lützelschwab, director *Haus Harmonie*, January 15, 2013. http://www.facebook.com/dubistradio).

Scheu", "Hochachtung" and "Scham, Unrecht zu tun". Particularly the latter term (*Scham*) is of interest here, since it describes an emotion that has no equivalent expression in English. The German language distinguishes between "Scham" and "Schande" (engl.: "shame"). "Scham"[19] desribes an emotion that keeps a person from performing an (immoral or forbidden) act, whereas "Schande" is an externally as well as internally imposed feeling following the act. The English term "shame" refers to both: a desire to "disappear from view" or to the "comportment that would avoid the emotion (the obverse of shamelessness)" (Lansky 1996, p. 769). Riezler bridges this linguistic gap between "Scham" and "shame" by concluding: "Aidōs is the shame that derives from reverence" (Riezler 1943, p. 463). Thus aidōs exceeds the level of reverence and mere respect. It is a state of "being awestruck" (German: "Ergriffensein") while at the same time "experiencing reticent awe in light of the revered object" (Fahlbusch 2003, p. 2500) thereby representing a quality of emotional behavior that ought to be—and can be—achieved. In this sense, aidōs is a call for moral action. It approaches the "other" in adoration and herein recognizes his divine attributes: encounter guided by aidōs implies a "receding awe and shame, which prohibit hurting the dignified or even to approach it in an untactful manner" (Bollnow 1988, p. 99). There is both silence and amazement in the presence of a divine that is not only concealed above us but also *vis-à-vis* and revealed within the human "other."[20] To Protestant theological ethicist H. R. Niebuhr aidōs

> keeps its distance even as it draws near; it does not seek to absorb the other in the self or wants to be absorbed by it; it rejoices in the otherness of the other; it desires the beloved to be what he is and does not seek to refashion him into a replica of the self […]. In all such love there is an element of that "holy fear" which is […] deep respect for the otherness of the beloved and the profound unwillingness to violate his integrity (Niebuhr 1956, p. 56).

In this holy fear man is "not allowed to touch everything" for there are "holy experiences before which they must take off their shoes and keep away the unclean hand" (Nietzsche 1984, p. 189). Nietzsche laments—interestingly enough—the cultured classes' "lack of shame, the easy insolence of eye and hand with which they touch, taste, and finger everything."

It has been discussed that encounter guided by aidōs must take on a reticent approach, accepting the boundaries set by the otherness of the counterpart. Aidōs enables man to abstain from crossing those "red lines", which only on the surface appear to be manifold and different in origin. They all share—as the following discussion of two ancient Greek myths will show—one common ground: the human quest for (forbidden) knowledge.

In Plato's "Myth of Protagoras" (Plato 1960) things on earth got out of control due to a well intentioned mind which pursued an honorable goal by taking the wrong turn. The virtue of aidōs in the end prevented mankind's impending destruction and led Plato to develop his widely acclaimed anthropological declaration that all men are equally talented and qualified to decide on issues of justice in the polis (Kirste 2002):

After having created the earth the gods ordered Prometheus and Epimetheus to equip all mortal creatures with skills. Epimetheus was so eager to do the job that he asked Prometheus to step aside and merely serve as an inspector as soon as the distribution was completed. This was agreed, and so Epimetheus gave strength to the weak, armed some while he left others unarmed; he granted size to some in order to be able to protect themselves by their mere statue while he made others small and gave them wings in order to be able to escape. He shared all skills in such a manner that each mortal creature had the means to avoid extinction and to defend itself against all other races. Epimetheus even bestowed skills that protected all against the seasons: he clothed some with warming hair and others with thick skins that defended them against the summer heat and cold winters. He also provided a diverse food chain, including herbs of the soil for some, fruits of the trees for others, and to some he gave other animals as food. Epimetheus beyond a doubt meant well and would have completed the divine assignment to the gods' absolute satisfaction, had he not in the process of bestowing skills lost oversight and forgotten one species. This is where the problems began. When Prometheus inspected the distribution, he found man to be completely unprovided. While all other animals and creatures were well furnished, man was naked, even without shoes. Man had no bed and no arms of defence. The hour in which the gods would examine the work of Epimetheus and Prometheus drew near, prompting Prometheus to take a wrong turn: he stole fire and the mechanical arts (required for its handling)—knowledge the human kind was not supposed to have—from the gods and gave them to man. The gods, of course, found out that man now had a share of the divine attributes. But without the art of government, these divine attributes would inevitably lead to man's dispersion and destruction:

> Zeus feared that the entire race would be exterminated, and so he sent Hermes to them, bearing justice (diké) and reverence (adiōs) to be the ordering principles of cities and the bonds of friendship and conciliation. Hermes asked Zeus how he should impart

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[19] *Scham* covers manifold emotional aspects: it also refers to the malaise of a person with his/her nakedness. To 'cover your private parts' in German translates as "die Scham bedecken." The feeling of *Scham* causes a person to blush. See also FN 22.

[20] Albert Schweitzer even urges the extension of aidōs to *all* life (Schweitzer 2003).

Fig. 3 A talk about what it means to live with multiple sclerosis. Swiss Multiple Sclerosis Society, Zurich

> justice and reverence among men: Should he distribute them as the arts are distributed, that is to say, to a favoured few only, one skilled individual having enough of medicine or of any other art for many unskilled ones? “Shall this be the manner in which I am to distribute justice and reverence among men, or shall I give them to all?” “To all,” said Zeus; “I should like them all to have a share; for cities cannot exist, if a few only share in the virtues, as in the arts. And further, make a law by my order, that he who has no part in reverence and justice shall be put to death, for he is a plague (Plato 1960, 320d–322d).

In Plato’s myth man shares in forbidden aspects of the Divine (here: knowledge and crafts) and, in consequence, needs the virtue of aidōs in order to secure his survival. And he is free to decide whether or not he wants his life to be guided by it: Zeus’ answer to Hermes implies the possibility that man might not want to have a share in it. It is a decision in favor or against a moral law man is able to give himself.”[21]

What happens when the balancing tool of aidōs is purposely neglected is shown in Sophocles’ play *Philoctetes*. Even though there is no mentioning of the word aidōs in the play, the text “none the less provides us with a perceptive and convincing representation of the emotion in circumstances in which the ethical suppositions on which it rests are put to the test. The question of aidōs is raised by the issue of deceit” (Cairns 1993, p. 250). This ancient myth illuminates particularly the aspect of *Scham* involved in the aidōs-concept.

A snake in the Trojan War had bitten the warrior Philoctetes. Because of his terrible agony and foul smelling wound Odysseus banned him along with his magic bow to the desert island Lemnos where he was left to live all by himself. Ten years later the seer Helenus foretells that the Greeks can only conquer Troja if they possess Philoctetes’ magic bow. So Odysseus sails back to Lemnos where he asks his servant Neoptolemos to trick Philoctetes into handing out the bow (which in this story stands for knowledge the Greek were prohibited to gain): “I know, son, that by nature you are unsuited to tell such lies and work such evil. But the prize of victory is a sweet thing to have. Go through with it. The end justifies the means, they’ll say. For a few short, shameless hours, yield to me. From then on you’ll be hailed as the most virtuous of men” (Sophocles 1986). Neoptolemos was torn between right and wrong: “I do not want to make things hard for you. But I far prefer failure, if it is honest, to victory earned by treachery.” Odysseus stuck to his guns, trying to “forestall [Neoptolemos’] aidōs” (Cairns 1993, p. 251) by conjuring him that this one lie would lead to salvation. Neoptolemos gave in, not without asking his master a most crucial question, foreseeing, that by tricking Philoctetes something essential inside of him would have to fall out of equilibrium: “How could one say such things and keep a straight face? […] Then let it be so. I will do what you order, putting aside my sense of shame.” Later on, when Philoctetes finds out about the deceit, he charges Neoptolemos for having given up a part of his essential human nature: “How you have betrayed me! Are you not ashamed to look at me, who have kneeled to you, the suppliant, you bitter ones?” […] This is atrocious! He’s not speaking to me. He won’t even look me in the eye, as if he’ll never give me back my bow.” A straight face and the ability to look someone in the eye is the highest expression of a humanity guided by aidōs. It is an unspoken yet universally understood language which guards the rules required for living together in peace and freedom. To abandon this “virtue mechanism”—like Neoptolemos did—means to abandon a fundamental anthropological standpoint by treating man merely as a means, not as an end (Kant 1978). By putting aside the sense of shame (“Scham” as a self-inflicted emotion which prohibits man to commit the immoral act) a person needs to give up a share of his humaneness: “A man has to knock down (“niederknüppeln”) something inside of him in order to be able to look someone straight in the eye while lying to him. […] For Neoptolemos, to abdicate shame is equal to abdicate one’s own nature” (Spaemann 2011, p. 217).[22]

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[21] Was kann denn wohl die Freiheit des Willens sonst sein, als Autonomie, […] sich selbst ein Gesetz zu sein?” (Kant 1978).

[22] The emotion of shame in conjunction with the human strives for forbidden knowledge also plays a significant role in religious writings, particularly in the scriptures of the monotheistic religions. In the history of creation the Judaic-Christian and Muslim texts report on how man—despite the divine orders—ate the fruit from the forbidden tree of knowledge. Prior to this act man was not aware nor ashamed of his nakedness (Genesis 2:25). When they had tasted of the tree, their shame became manifest to them (Quraan, Surah 7:22 and Genesis 3:7).

Results

Since 2009, close to 300 people have produced nearly 40 DBR broadcasts (Fig. 4). The productions have shown that the concept and approach work in the sense that collaboration and participation was obtained in all cases leading to significant results. The core of the DBR experience has been the oftentimes unforeseen and thus surprising content of each broadcast that could not have surfaced, had the state of the art journalistic tools and procedures been applied alone. Having been inspired by people participating in a "patient" study, DBR has shown that there exists another layer of truth[23] behind the data structure that rigorous empirical research is incapable of finding. Rather, the aidōs-approach is capable to uncover this layer; it is possible that these truths belong to a sphere that should not be entered.[24] The mythological and religious texts cited in this article, however, have shown that man in his eternal strive for knowledge is notoriously crossing those borders he is not supposed to pass—and therefore needs guidance by virtue.

By handing over its most important tool—the microphone—and by taking a backseat during the production process, the DBR producers also transfer the substantive sovereignty to the vulnerable groups at stake, thereby contributing to the disaggregation of the original role distribution (e.g. 'journalist' and 'patient'). Numerous feedbacks and responses[25] written to the DBR team at the end of the production show that the aidōs-approach indeed launches a process of development for each participating individual and the group as well: the "self-confidence of the participants has increased"; groups "have been blessed", are "thrilled" and the "the community feeling has improved"; DBR is a "unique experience for the community" etc.

Even the production team benefits from this broadcast approach. Particularly members of the professional team have entered into a process of shifting the focus of their self understanding from *being* to *becoming*; other members of the DBR team, who have been long time unemployed and participate in the production as journalistic trainees, talk about their need to reassess their own situation: encountering vulnerability apparently has taken place on both "sides", offering the chance for re-evaluation and repositioning of one's own situation of life.

Fig. 4 DBR group and production team celebrating at the end of the recording day. Stiftung für Behinderte in Lenzburg

Furthermore, the DBR broadcasts create new listening habits and at times challenge the audience: Barbara's contribution of 45 s of silence[26] for example scrutinizes our commonly shared idea of what "good" radio should sound like and questions the status quo. A transmission hole, instead of leading to irritation alone, can turn into a silence that is worth to be borne. DBR participants reinvent the sound, content and format of broadcasting over and over again—without any input given by journalists and not a single question asked.

Discussion

"DBR" started out as a project aiming at giving those, who oftentimes are considered to live at the edge of society, their *voices* back, thereby also reinstalling fundamental democratic rights they have been deprived of. It has been and still is the position of the DBR authors that granting a right not always comes along with the actual possibility to exercise it. With this position in mind the DBR experience would like to stimulate a discussion about the role and position of the vulnerable in the current medical ethics debate and about the conclusions we might draw from there for health professional-patient conversation. We hold that principle-based medical ethics, unquestionably important as it is, will not reach the fullness of its potential if it is applied only to those realms of life, which define the vulnerability (e.g. illness) of a person. Even the most well intended concept of (e.g. patient) rights may unintentionally run danger of discriminating instead of supporting the group at focus if the rights offered also promote the group's categorization. Autonomy, justice, beneficence and non-maleficence, for example, must—as guaranteed rights and

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[23] For an in-depth discussion of definitions, criteria and theories of truths see also Kirkham (Kirkham 1995).

[24] cf. e.g. "Lilly"-stories, Chap. 'I am Lilly - YOU are Lilly'; also: "(forbidden) knowledge", Chap. 'A methodology stimulated by mythology: the aidōs-approach'.

[25] Feedback to the DBR productions has been published online: http://www.du-bist-radio.de/html/dbr_feedback.html.

[26] See Chap. 'Project goals and their societal context'.

principles—also reach all other areas of man's existence; areas such as passions, hopes, dreams, and individual circumstances which all add to the fullness of his humaneness. We believe that addressing the wholeness of the individual can also be a fruitful approach in the patient/physician setting: if, e.g. a physician invites a seriously ill patient to participate in the process of choosing one of the available treatment options, the outcome generated should also be evaluated in light of the question whether or not the role distribution of the two involved has been upheld or whether sovereignty in all its radicalness has been shared into equal parts. Furthermore, patient rights exercised in the sense that a certain decision has been made upon having given informed consent are at least questionable if the person finds himself thereafter alone and again in the 'patient's corner'. While the development of patient rights with its keen focus on autonomy and respect over the past decades beyond a doubt has led to an eminent improvement of the overall situation of society's most vulnerable groups, we believe it is indispensable to take one further step: the *non*-vulnerable side (which includes the majority of us and comes down to e.g. caregivers and alike) must get even more actively involved into the process of dealing with those who are in need. The aidōs approach can be a fruitful tool in helping us not only to grant and maintain respect, but also to share and transfer responsibility.

While in the beginning days of the production the theoretical framework had by all means not clearly been developed, it soon became clear to the members of the journalist team that an attitude of mere respect towards the target group would not suffice and that they had entered a sphere in which they were *not allowed to touch everything* and where they had *to take off their shoes*.[27] Studying the philosophical aidōs-literature on human encounter was the key to understanding the DBR experience. Man can only fully experience his own humaneness and grasp his identity with the help of the other. Becoming is only possible by entering into a relation that accepts the boundaries set by the other. And it is aidōs, this almost forgotten virtue, freely distributed by the ancient gods to all men, that enables man to enter into this relationship.

The DBR experience so far has shown that the aidōs-approach once applied can enhance the overall situation of those who due to their weakness have been categorized and thereby experience discrimination. By 'acoustically stepping out' of their wards and institutions, the DBR participants also step out of an identity that has never been their own in the first place: it had been imposed from the outside. This courageous move into the public view may lead to a as we believe long overdue and desperately needed discussion, at the core of which lies the question whether society needs to re-asses the role, value and potential of its most vulnerable groups.

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[27] cf. Nietzsche citation, Chap. 'A methodology stimulated by mythology: the aidōs-approach'.

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5. Diskussion, Schlussfolgerung und Anschlussprojekte

Die Arbeiten über Einstellungen von ALS Patienten und ihren Angehörigen zum Thema Lebensende zeigen deutlich, dass der betreffende Entscheidungsfindungsprozess bereits in einer sehr frühen Phase der Erkrankung stattfindet. Patienten und Angehörige treffen demzufolge aufgrund der zur Verfügung stehenden Informationslage bereits im zeitlichen Umfeld der Diagnosestellung autonom und eigenverantwortlich Entscheidungen, die sowohl für den weiteren Therapieverlauf als auch für die Endphase der Erkrankung, welche als solche in erster Linie vom Patienten definiert wird, von erheblicher Bedeutung sind.

Unbeeindruckt von der juristischen Sachlage reklamieren Patienten und Angehörige das Recht auf Selbstbestimmung auch für das Herbeiführen des eigenen Lebensendes und beanspruchen die ausschliessliche Planungshoheit hierüber. Bemerkenswert an dieser Haltung ist insbesondere die bedeutende Rolle, die ALS-Betroffene hierbei dem Arzt zuerkennen. Der Arzt bleibt auch nach infauster Prognosestellung wie Amyotrophe Lateralsklerose und angesichts lediglich palliativer Therapiemöglichkeiten eine prominente Vertrauensperson. Mit ihm/ihr möchte der ALS Patient das Thema WTB und assistierter Suizid erörtern. Sogar eine aktive Rolle des Arztes, die über den Rahmen des derzeit juristisch Erlaubten deutlich hinausreicht, kann sich der Patient für den weiteren Verlauf der Erkrankung vorstellen. Die Ergebnisse unserer Studie zeigen eindeutig, dass sich die Ärzteschaft in Zukunft mit diesen deutlichen Wünschen und Signalen stärker auseinandersetzen wird müssen. Auseinandersetzen bedeutet hier allerdings nicht automatisch umsetzen; vielmehr soll argumentativ abgewogen und vermittelt werden, wie der Arzt zukünftig mit dem in ihn hier konkret gesetztes Vertrauen des Patienten umgehen kann, darf und will. Diesem nicht einfachen Diskurs allerdings müssen sich die Ärzteschaft und der Ärztestand insgesamt stellen.

Auch der Tatsache, dass Patienten Themen wie Lebensende und Suizid insbesondere mit ihm besprechen möchten, darf sich der Arzt nicht verschliessen. Der Patient hat einen Anspruch auf ausreichende Aufklärung über jene Massnahmen, die ihm am Lebensende eine Handlungsoption darstellen. Ein derlei gewichtiges Thema von gesamtgesellschaftlicher Relevanz darf nicht den "dunklen Ecken" der Meinungsbildung überlassen werden. Meinungsführerschaft muss sich auch hier anhand von Ausgewogenheit und Kompetenz herauskristallisieren, Eigenschaften, welche Patienten ganz offensichtlich den Ärzten zuschreiben und diese somit in die Verantwortung nehmen.

Unsere Arbeiten haben zudem gezeigt, dass Angehörige der ALS Erkrankten besonders stark unter der Krankheit leiden und Gefahr laufen, zu vereinsamen. Auch wenn das Problem des Angehörigen-Leidens kein unbekanntes ist, stellt es doch nach wie vor offensichtlich ein ungelöstes dar. ALS Therapiemassnahmen müssen daher in Zukunft verstärkt auch auf die Bedürfnisse von Angehörigen ausgerichtet werden die, den Ergebnissen unserer Studie folgend, im Rahmen der Behandlung noch immer den "vergessenen Patienten" darstellen.

ALS – wie alle anderen heimtückischen Krankheiten mit infauster Prognose trägt auch dazu bei, dass der Betroffene mit dem Zeitpunkt der Diagnosestellung in eine Art kategorisiertes, stigmatisiertes Dasein hineintransformiert wird. War er/sie gerade eben noch vom eigenen Selbstverständnis und vom Verständnis der Aussenwelt her zunächst einmal Mensch in all seinen Facetten, so ist er durch die Diagnosemitteilung – quasi innert der Länge eines Augenzwinkerns – zum Patienten erklärt worden. Aus dieser Schublade lässt es sich schwerlich herauskommen, und diese Kategorisierung, häufig auch mit Entrechtung einhergehend, führt zu zusätzlichem – vermeidbaren – Leiden. Eine Rückbesinnung auf die zutiefst menschliche tugendhafte Umgangsform aidōs kann dabei helfen, dass sowohl der Behandlung eines kranken Mitmenschen und dem Wissensdrang der Forschenden genüge getan wird, ohne dass dabei der vemeintlich Schwächere diskiminiert und zusätzlich verletzt wird. Auch als Patient will und muss der Mensch (als) Mensch unter Menschen bleiben.

FRAGEBOGEN FÜR PATIENTEN

1. Demographische Daten:

Geschlecht: ☐ w ☐ m
Alter: ______________
Familienstand: ☐ ledig ☐ verheiratet ☐ geschieden ☐ verwitwet
Wohnsituation: ☐ lebe alleine ☐ lebe mit Partner ☐ lebe mit Kindern
Wie viele Kinder? ________________________

Höchster Schulabschluss? ☐ Realschule ☐ Sekundarschule ☐ Matura
☐ Hochschule ☐ Sonstiges: ____________________
Beruf: ________________________
☐ selbstständig ☐ angestellt

Religionszugehörigkeit: ☐ katholisch ☐ evangelisch ☐ muslimisch
☐ andere: ___________________________ ☐ keine

2. Lebensqualität

2.1 Wie ist Ihre derzeitige Lebensqualität?

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

könnte nicht schlechter sein könnte nicht besser sein

2.2 Wie stark leiden Sie unter Ihrer Krankheitssituation?

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

leide überhaupt nicht leide extrem

2.3 Worunter leiden Sie am meisten?

☐ körperliche Beschwerden (z.B. Schmerzen, Muskelkrämpfe)
☐ seelische Beschwerden (z.B. Angst, Depression)
☐ soziale Probleme (z.B. Sprechstörung, Abhängigkeit von Anderen)
☐ spirituell-religiöse Probleme (z.B. Glaubenszweifel, Suche nach Sinn)

2.4 Fragen zum Lebenssinn

2.5 **HADS-D:** Die folgenden Fragen beziehen sich auf Ihre allgemeine und seelische Verfassung. Wir bitten Sie die Fragen so zu beantworten, wie es für Sie persönlich **in der letzten Woche** am ehesten zutraf. Machen Sie bitte nur ein Kreuz pro Frage und lassen Sie keine Frage aus. Überlegen Sie bitte nicht lange, sondern wählen Sie die Antwort aus, die Ihnen auf Anhieb am zutreffendsten erscheint.

1.Ich fühle mich angespannt oder überreizt.
- ☐ meistens
- ☐ oft
- ☐ von Zeit zu Zeit/gelegentlich
- ☐ überhaupt nicht

2.Ich kann mich heute noch so freuen wie früher.
- ☐ ganz genau so
- ☐ nicht ganz so sehr
- ☐ nur noch ein wenig
- ☐ kaum oder gar nicht

3.Mich überkommt eine ängstliche Vorahnung, dass etwas Schreckliches passieren könnte.
- ☐ ja, sehr stark
- ☐ ja, aber nicht allzu stark
- ☐ etwas, aber es macht mir keine Sorgen
- ☐ überhaupt nicht

4.Ich kann lachen und die lustige Seite der Dinge sehen.
- ☐ ja, so viel wie immer
- ☐ nicht mehr ganz so viel
- ☐ inzwischen viel weniger
- ☐ überhaupt nicht

5.Mir gehen beunruhigende Gedanken durch den Kopf.
- ☐ einen Großteil der Zeit
- ☐ verhältnismäßig oft
- ☐ von Zeit zu Zeit, aber nicht allzu oft
- ☐ nur gelegentlich/nie

6.Ich fühle mich glücklich.
- ☐ überhaupt nicht
- ☐ selten
- ☐ manchmal
- ☐ meistens

7.Ich kann behaglich dasitzen und mich entspannen.
- ☐ ja, natürlich
- ☐ gewöhnlich schon
- ☐ nicht oft
- ☐ überhaupt nicht

8. Ich fühle mich in meinen Aktivitäten gebremst.
- ☐ fast immer
- ☐ sehr oft
- ☐ manchmal
- ☐ überhaupt nicht

9. Ich habe manchmal ein ängstliches Gefühl in der Magengegend.
    - ☐ überhaupt nicht
    - ☐ gelegentlich
    - ☐ ziemlich oft
    - ☐ sehr oft

10. Ich habe das Interesse an meiner äußeren Erscheinung verloren
    - ☐ ja, stimmt genau
    - ☐ ich kümmere mich nicht so sehr darum, wie ich sollte
    - ☐ möglicherweise kümmere ich mich zu wenig darum
    - ☐ ich kümmere mich so viel darum wie immer

11. Ich fühle mich rastlos, muss immer in Bewegung sein.
    - ☐ ja, tatsächlich sehr
    - ☐ ziemlich
    - ☐ nicht sehr
    - ☐ überhaupt nicht

12. Ich blicke mit Freude in die Zukunft.
    - ☐ ja, sehr
    - ☐ eher weniger als früher
    - ☐ viel weniger als früher
    - ☐ kaum bis gar nicht

13. Mich überkommt plötzlich ein panikartiger Zustand
    - ☐ ja, tatsächlich sehr oft
    - ☐ ziemlich oft
    - ☐ nicht sehr oft
    - ☐ überhaupt nicht

14. Ich kann mich an einem guten Buch, einer Radio- oder Fernsehsendung freuen
    - ☐ oft
    - ☐ manchmal
    - ☐ eher selten
    - ☐ sehr selten

3. Soziale Beziehungen:

3.1 Wer versorgt Sie überwiegend (Hauptbezugsperson)? ______________________

3.2 Wie oft haben Sie Kontakt zu Menschen außer der Hauptbezugsperson (Verwandte, Freunde, Bekannte)?

- ☐ mehrmals täglich
- ☐ einmal täglich
- ☐ alle paar Tage
- ☐ einmal pro Woche oder seltener

3.3 Haben sich durch Ihre Erkrankung Beziehungen zu Freunden verändert?

(Mehrfachnennung möglich)

☐ Ja, ich habe Freunde verloren.
☐ Ja, ich habe Freunde gewonnen.
☐ Nein, nichts hat sich verändert.

3.4 Hat sich Ihre Partnerschaft durch die Erkrankung verändert?

(Mehrfachnennung möglich)

☐ Ja, die Partnerschaft ist auseinander gebrochen.
☐ Ja, die Partnerschaft ist schwieriger geworden.
☐ Ja, die Partnerschaft ist enger geworden.
☐ Nein, nichts hat sich verändert.

3.5 Wie einsam fühlen Sie sich?

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

überhaupt nicht einsam — könnte nicht einsamer sein

3.6 Wie sehr fühlen Sie sich als Belastung für Ihr soziales Umfeld (Verwandte, Freunde)?

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

überhaupt nicht als Belastung — als extreme Belastung

3.7 Waren Sie vor der Diagnose ALS jemals wegen einer Depression in medizinischer oder psychotherapeutischer Behandlung?

☐ Ja
☐ Nein

3.8 Sind Sie nach der Diagnose ALS wegen einer Depression in medizinischer oder psychotherapeutischer Behandlung gewesen?

☐ Ja

☐ Nein

4. Religiosität: Idler Index of Religiosity (IIR)

4.1 Wie oft gehen Sie zu religiösen Treffen oder Gottesdiensten?

☐ nie
☐ 1–2x/Jahr
☐ alle paar Monate
☐ 1-2x/Monat
☐ 1x/Woche
☐ mehrmals pro Woche

4.2 Wie viele Menschen aus Ihrer religiösen Gemeinschaft (z.B. Kirche, Moschee, Synagoge, Bibelgruppe) kennen Sie?

☐ niemand
☐ wenige
☐ mehr als die Hälfte
☐ alle oder fast alle

4.3 Wie würden Sie sich selbst einschätzen?

☐ tief religiös
☐ ziemlich religiös
☐ nur leicht religiös
☐ nicht religiös

4.4 Wie viel Kraft und Trost beziehen Sie aus Ihrer Religion?

☐ keine Stärke und Trost
☐ etwas Stärke und Trost
☐ viel Stärke und Trost

5. Entscheidungen zum Lebensende:

5.1 Haben Sie (a) eine Patientenverfügung? (b) eine Vorsorgevollmacht?

	(a) eine Patientenverfügung?	(b) eine Vorsorgevollmacht?
	☐ Ja	☐ Ja
	☐ Nein	☐ Nein

5.2 Wie stehen Sie zu folgenden Formen lebensverlängernder medizinischer Maßnahmen bei der ALS?

(a) Ernährung über eine PEG-Sonde (= Sonde durch die Bauchdecke in den Magen)

☐ Ich bin dagegen.
☐ Ich befürworte sie unter bestimmten Umständen.
☐ Ich befürworte sie grundsätzlich.
☐ Ich bin mir unsicher.

(b) Zeitweise Heimbeatmung über eine Maske (z.B. einige Stunden nachts)

☐ Ich bin dagegen.
☐ Ich befürworte sie unter bestimmten Umständen.
☐ Ich befürworte sie grundsätzlich.
☐ Ich bin mir unsicher.

(c) Dauerbeatmung durch einen Luftröhrenschnitt („Tracheostomie“)

☐ Ich bin dagegen.
☐ Ich befürworte sie unter bestimmten Umständen.
☐ Ich befürworte sie grundsätzlich.
☐ Ich bin mir unsicher.

Manche Patienten berichten uns, dass sie wegen ihrer Erkrankung schon einmal daran gedacht haben, sich das Leben zu nehmen.

5.3 Haben Sie im Zusammenhang mit ihrer Erkrankung <u>jemals</u> daran gedacht, sich das Leben zu nehmen?

☐ Ja
☐ Nein

*<u>Falls **ja**:</u>*

a) Haben Sie jemals konkrete <u>Pläne</u> hierzu entworfen?

☐ Ja
☐ Nein

b) Haben Sie irgendwann <u>Versuche</u> unternommen, sich das Leben zu nehmen?

☐ Ja
☐ Nein

c) Was half Ihnen in so einer Situation dabei, sich nicht das Leben zu nehmen?

____

Manche Patienten, die den Wunsch nach vorzeitiger Lebensbeendigung haben, wenden sich damit an andere Menschen und bitten diese um Mithilfe.

5.4 Wie stark ist derzeit Ihr Wunsch, andere Menschen um Mithilfe zu bitten, das eigene Leben vorzeitig zu beenden?

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

überhaupt nicht vorhanden extrem stark

5.5 Können Sie sich vorstellen, einen Arzt zu bitten, Ihnen ein tödliches Mittel zu verschreiben, damit sie es selbst einnehmen können?

☐ Ja
☐ Nein

5.6 Können Sie sich vorstellen, einen Arzt zu bitten, dass er Ihnen ein tödliches Mittel verabreicht?

☐ Ja
☐ Nein

*Falls **ja** in 5.5 oder 5.6:*

5.7 Was für eine Situation im Verlauf Ihrer Erkrankung müsste eintreten, damit sie diese Bitte äußern würden?

____

5.8 Haben Sie schon einmal mit jemandem über die Möglichkeit, das Leben vorzeitig zu beenden, gesprochen?

☐ Ja
☐ Nein

*Falls **ja** in 5.8:*

5.9 Mit wem haben Sie darüber gesprochen?

☐ einem Angehörigen
☐ einem Freund
☐ einem Geistlichen
☐ einem Betroffenen
☐ einem Arzt
☐ Anderen: ____________________

5.10 Würden Sie gerne mit einem Arzt darüber sprechen?

☐ Ja
☐ Nein

5.11 Wie belastend fanden Sie es, in diesem Gespräch über solche Themen zu sprechen?

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

überhaupt nicht belastend extrem belastend

5.12 Wie hilfreich fanden Sie es, in diesem Gespräch über solche Themen zu sprechen?

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

überhaupt nicht hilfreich extrem hilfreich

FRAGEBOGEN FÜR ANGEHÖRIGEN

1. Demographische Daten:

Geschlecht: ☐ w ☐ m
Alter: ________________
Familienstand: ☐ ledig ☐ verheiratet ☐ geschieden ☐ verwitwet
Wohnsituation: ☐ lebe alleine ☐ lebe mit Partner ☐ lebe mit Kinder
Wie viele Kinder? __________________________

Höchster Schulabschluss? ☐ Realschule ☐ Sekundarschule ☐ Matura
☐ Hochschule ☐ Sonstiges: ______________________
Beruf: _________________________
☐ selbstständig ☐ angestellt

Religionszugehörigkeit: ☐ katholisch ☐ evangelisch ☐ muslimisch
☐ andere: _____________________________ ☐ keine

2. Lebensqualität:

2.4 Wie ist Ihre derzeitige Lebensqualität?

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

könnte nicht schlechter sein — könnte nicht besser sein

2.5 Wie stark leiden Sie unter der Krankheit Ihres Angehörigen?

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

überhaupt kein Leiden — größtes vorstellbares Leiden

2.3 Fragen zum Lebenssinn

2.4 ***HPS – Häusliche Pflege***

Zu den nachfolgenden Aussagen bitten wir Sie um Angaben, die in Zusammenhang mit Ihrer *gegenwärtigen* Situation stehen. In den Aussagen wird nicht zwischen Betreuung und Pflege unterschieden. Mit dem Wort „Pflege“ ist beides gemeint.

Kreuzen Sie zu jeder Aussage die Zeile an, die für Sie am ehesten zutrifft.
Beantworten Sie bitte jede Frage!

1. Ich fühle mich morgens ausgeschlafen.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

2. Durch die Pflege hat die Zufriedenheit mit meinem Leben gelitten.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

3. Ich fühle mich oft körperlich erschöpft.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

4. Ich habe hin und wieder den Wunsch, aus meiner Situation „auszubrechen“.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

5. Ich vermisse es, über die Pflege mit anderen sprechen zu können.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

6. Mir bleibt genügend Zeit für meine eigenen Interessen und Bedürfnisse.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

7. Ich fühle mich von dem/der Pflegebedürftigen manchmal ausgenützt.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig

8. Ich kann außerhalb der Pflegesituation abschalten.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

9. Es fällt mir leicht, dem/der Pflegebedürftigen bei den notwendigen Dingen zu helfen (z. B. beim Waschen und Essen).

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

10. Ich empfinde mich manchmal nicht mehr richtig als „ich selbst“.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

11. Die von mir geleistete Pflege wird von anderen entsprechend anerkannt.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

12. Mein Lebensstandard hat sich durch die Pflege verringert.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

13. Ich habe das Gefühl, dass mir die Pflege aufgedrängt wurde.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

14. Die Wünsche des/der Pflegebedürftigen sind meiner Meinung nach angemessen.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig

☐ stimmt nicht

15. Ich habe das Gefühl, die Pflege „im Griff“ zu haben.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

16. Durch die Pflege wird meine Gesundheit angegriffen.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

17. Ich kann mich noch von Herzen freuen.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

18. Wegen der Pflege musste ich Pläne für meine Zukunft aufgeben.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

19. Es macht mir nichts aus, wenn Außenstehende die Situation des/der Pflegebedürftigen mitbekommen.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

20. Die Pflege kostet viel von meiner eigenen Kraft.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

☐ stimmt nicht

22. Ich empfinde den Kontakt zu dem/der Pflegebedürftigen als gut.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

23. Wegen der Pflege gibt es Probleme mit anderen Familienangehörigen.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

24. Ich habe das Gefühl, ich sollte mal wieder ausspannen.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

25. Ich sorge mich aufgrund der Pflege um meine Zukunft.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

26. Wegen der Pflege leidet meine Beziehung zu Familienangehörigen, Verwandten, Freunden und Bekannten.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

27. Das Schicksal des/der Pflegebedürftigen macht mich traurig.

☐ stimmt genau
☐ stimmt überwiegend
☐ stimmt ein wenig
☐ stimmt nicht

3. Soziale Beziehungen:

3.1 Haben sich durch die Erkrankung Ihres Angehörigen Beziehungen zu Freunden verändert?

(Mehrfachnennung möglich)

☐ Ja, ich habe Freunde verloren.
☐ Ja, ich habe Freunde gewonnen.
☐ Nein, nichts hat sich verändert.

3.2 Wie einsam fühlen Sie sich?

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

überhaupt nicht einsam — könnte nicht einsamer sein

4. Religiosität: Idler Index of Religiosity (IIR)

4.1 Wie oft gehen Sie zu religiösen Treffen oder Gottesdiensten?

☐ nie
☐ 1–2x/Jahr
☐ alle paar Monate
☐ 1-2x/Monat
☐ 1x/Woche
☐ mehrmals pro Woche

4.2 Wie viele Menschen aus Ihrer religiösen Gemeinschaft (z.B. Kirche, Moschee, Synagoge, Bibelgruppe) kennen Sie?

☐ niemand
☐ wenige
☐ mehr als die Hälfte
☐ alle oder fast alle

4.3 Wie würden Sie sich selbst einschätzen?

☐ tief religiös
☐ ziemlich religiös
☐ nur leicht religiös
☐ nicht religiös

4.4 Wie viel Kraft und Trost beziehen Sie aus Ihrer Religion?

☐ keine Stärke und Trost
☐ etwas Stärke und Trost
☐ viel Stärke und Trost

5. Entscheidungen zum Lebensende:

5.1 Wie stehen Sie zu folgenden Formen lebensverlängernder medizinischer Maßnahmen bei der ALS?

(d) Ernährung über eine PEG-Sonde (= Ernährungssonde durch die Bauchdecke in den Magen)

☐ Ich bin dagegen.
☐ Ich befürworte sie unter bestimmten Umständen.
☐ Ich befürworte sie grundsätzlich.
☐ Ich bin mir unsicher.

(e) Zeitweise Heimbeatmung über eine Maske (z.B. für einige Stunden nachts)

☐ Ich bin dagegen.
☐ Ich befürworte sie unter bestimmten Umständen.
☐ Ich befürworte sie grundsätzlich.
☐ Ich bin mir unsicher.

(f) Dauerbeatmung durch einen Luftröhrenschnitt („Tracheostoma")

☐ Ich bin dagegen.
☐ Ich befürworte sie unter bestimmten Umständen.
☐ Ich befürworte sie grundsätzlich.
☐ Ich bin mir unsicher.

5.2 Haben Sie mit Ihrem kranken Angehörigen schon einmal über die Möglichkeit einer Ernährung mittels PEG-Sonde gesprochen?

☐ Ja
☐ Nein

5.3 Haben Sie mit Ihrem kranken Angehörigen schon einmal über die Heimbeatmung mittels Maske (ohne Luftröhrenschnitt) gesprochen?

☐ Ja
☐ Nein

5.4 Haben Sie mit Ihrem kranken Angehörigen schon einmal über die Dauerbeatmung durch einen Luftröhrenschnitt („Tracheostoma") gesprochen?

☐ Ja
☐ Nein

Manche Patienten haben den Wunsch, ihr Leben vorzeitig zu beenden, und bitten andere Menschen dabei um Mithilfe.

5.5 Hat Ihr Angehöriger Ihnen gegenüber den Wunsch geäußert, sein Leben vorzeitig zu beenden?

☐ Ja
☐ Nein

5.6 Hat Ihr Angehöriger mit Ihnen darüber gesprochen, einen Arzt um Mithilfe zu bitten, sein Leben vorzeitig zu beenden?

☐ Ja
☐ Nein

5.7 Hat Ihr Angehöriger Sie persönlich jemals um Mithilfe gebeten, sein Leben vorzeitig zu beenden?

☐ Ja
☐ Nein

5.8 Können Sie sich für sich vorstellen, Ihrem Angehörigen dabei zu helfen, sein Leben vorzeitig zu beenden?

☐ Ja
☐ Nein

*Falls **ja** in 5.8*

5.9 Können Sie sich vorstellen, Ihrem Angehörigen auf die Weise zu helfen, dass Sie ihm ein tödliches Mittel beschaffen, welches er selbst einnehmen kann?

☐ Ja
☐ Nein

5.10 Können Sie sich vorstellen, Ihrem Angehörigen auf die Weise zu helfen, dass Sie ihm ein tödliches Mittel verabreichen?

☐ Ja
☐ Nein

5.11 Wie belastend fanden Sie es, die vorhergehenden Fragen zum Thema „Sterbehilfe“ zu beantworten?

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

überhauptnicht belastend extrem belastend

5.12 Wie hilfreich fanden Sie es, die vorhergehenden Fragen zum Thema „Sterbehilfe“ zu beantworten?

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

überhauptnicht hilfreich extrem hilfreich

Fragebogen nach dem Sinn des Lebens

Alter ________ Jahre **Geschlecht** ☐ männlich ☐ weiblich

Familienstand ☐ Ledig/Single ☐ Verheiratet/Partnerschaft ☐ Geschieden/Getrennt ☐ Verwitwet

---

Die Frage nach dem **Sinn des Lebens** bewegt viele Menschen. In den verschiedensten Lebenssituationen stellen sich Menschen diese Frage. Dies können besondere Glücksmomente sein, aber auch leidvolle Erfahrungen.

Im folgenden interessiert uns, **was Ihrem Leben Sinn gibt**. Darunter verstehen wir Bereiche, die einem wichtig

______ sind, Halt geben und dem Leben Bedeutung verleihen. Kurz gesagt: für was es sich zu leben lohnt.

Diese **Bereiche** sind für jede Person unterschiedlich, es gibt daher keine „richtigen“ oder „falschen“ Antworten. Bitte beantworten Sie die Fragen einfach so offen und ehrlich wie möglich.

Bitte nennen Sie die aktuell 3 bis 7 wichtigsten Bereiche, die ihrem Leben Sinn geben, unabhängig davon wie zufrieden oder unzufrieden Sie momentan mit diesen Bereichen sind. Die Reihenfolge der Nennung spielt keine Rolle.

Bereich 1: ____

Bereich 2: ____

Bereich 3: ____

Bereich 4: ____

Bereich 5: ____

Bereich 6: ____

Bereich 7: ____

Bevor Sie mit der Bearbeitung beginnen, lesen Sie sich bitte noch einmal Ihre Antworten durch. Bitte achten Sie darauf, dass die Nummerierung der Bereiche mit der auf der vorhergehenden Seite übereinstimmt. Bitte bewerten Sie jeden der von Ihnen genannte Bereiche! Beziehen Sie sich in Ihrer Einschätzung auf Ihre aktuelle Lebenssituation.

Bitte kreuzen Sie an, wie **wichtig** jeder einzelne Bereich für Ihren Lebenssinn insgesamt ist.

Wie wichtig ist für Sie ...	Etwas wichtig				Äußerst wichtig
Bereich 1	①	②	③	④	⑤
Bereich 2	①	②	③	④	⑤
Bereich 3	①	②	③	④	⑤
Bereich 4	①	②	③	④	⑤
Bereich 5	①	②	③	④	⑤
Bereich 6	①	②	③	④	⑤
Bereich 7	①	②	③	④	⑤

Bitte kreuzen Sie an, wie **zufrieden bzw. unzufrieden** Sie in den einzelnen Bereichen sind, d.h. wie sehr sich der jeweilige Bereich positiv oder negativ auf Ihren Lebenssinn auswirkt.

Wie zufrieden sind Sie mit ...	Sehr unzufrieden			Weder noch			Sehr zufrieden
Bereich 1	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)
Bereich 2	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)
Bereich 3	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)
Bereich 4	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)
Bereich 5	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)
Bereich 6	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)
Bereich 7	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)

	Sehr unzufrieden			Weder noch			Sehr zufrieden
Wie zufrieden sind Sie mit dem Sinn in Ihrem Leben insgesamt?	(-3)	(-2)	(-1)	(0)	(+1)	(+2)	(+3)

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Leitfaden zur telefonischen Befragung post mortem

Einstellungen und Wünsche von Patienten mit Amyotropher Lateralsklerose und ihrer Angehörigen zu lebensverlängernden Maßnahmen, zur Problematik des ärztlich unterstützten Suizids und zum Verbot der aktiven Sterbehilfe

Formales:

- Zeitpunkt der Befragung? **1-6 Monate nach dem Tod**
- Teilnehmer? **Bisheriger Studienteilnehmer**
  (falls nötig, zusätzlich anderen Angehörigen befragen)
- Art der Befragung: **halbstrukturiertes Telefoninterview oder persönlich**

Inhalt (Fragen):

Datum: _____________ **Uhrzeit:** _____________ **Fragestellerin**: _______________

ID: __________________

Zunächst Begrüßung, Kondolenz, Erinnerung an die Befragung...

Todestag: ___________________

1. Waren Sie in den **letzten Tagen** ihres/seines Lebens dabei? ☐ ja ☐ nein
2. Wie verlief der **Sterbeprozesses** in den letzten 24-48 Stunden? Ist sie/er friedlich gestorben? ☐ ja ☐ nein
3. Falls „nein“: Unter welchen **Beschwerden/Symptomen** hatte sie/er zu leiden?
   ____
   ____
   ____

4. **Sterbewunsch**: Hat Ihr verstorbener Angehöriger seit der letzten Befragung am [Datum] in irgendeiner Form den Wunsch geäußert, dass sie/er nicht mehr leben möchte? ☐ ja ☐ nein

   Falls „ja”: Was hat sie/er genau geäußert?

Gedanke/Wunsch der Selbsttötung geäußert? ☐ ja ☐ nein

Konkrete Pläne hierzu? ☐ ja ☐ nein

Versuche unternommen? ☐ ja ☐ nein

4. **Wunsch nach Assistenz beim Suizid**: Hat die/der Verstorbene einen Angehörigen, einen Arzt oder irgendjemanden anderen darum gebeten, ihr/ihm dabei zu helfen, sein Leben vorzeitig zu beenden?

   (hier anmerken, dass die befragte Person denjenigen nicht namentlich nennen soll)

   ☐ nein, niemanden ☐ ja, einen Angehörigen ☐ ja, einen Arzt

5. **Euthanasiewunsch**: Hat die/der Verstorbene einen Angehörigen, einen Arzt oder irgendjemanden anderen darum gebeten, ihr/ihm ein tödliches Mittel zu verabreichen?
   ☐ nein, niemanden ☐ ja, einen Angehörigen ☐ ja, einen Arzt

6. **Einstellungsänderung der Hauptbezugsperson:** Bei der letzten Befragung am [Datum] wurde u.a. gefragt: „Können Sie sich vorstellen, Ihrem Angehörigen dabei zu helfen, sein Leben vorzeitig zu beenden?“

   Hat sich seither Ihre Einstellung hierzu verändert? (in Anbetracht der letzten Lebensphase Ihres Angehörigen)

   ☐ ja ☐ nein

   Falls „ja“:

   Können Sie sich heute vorstellen, einem Angehörigen so zu helfen, dass Sie ihm ein tödliches Mittel **beschaffen**, das er dann selbst einnimmt?

   ☐ ja ☐ nein

   Können Sie sich heute vorstellen, einem Angehörigen so zu helfen, dass Sie ihm ein tödliches Mittel direkt **verabreichen**?

   ☐ ja ☐ nein

Dank für die Teilnahme.

7. Curriculum Vitae

7.1 Persönlicher Hintergrund in Ethik

Dieses Dissertationsprojekt hat mein Interesse an der Ethik intensiviert und mich in der Annahme bestärkt, dass die ethische Auseinandersetzung eine für die verantwortliche Gestaltung unserer Gegenwart und Zukunft unverzichtbare, lösungsorientierte Argumentationskunst ist. In unserer hochentwickelten zivilisierten Welt, deren insbesondere technischer Fortschritt scheinbar unaufhaltsam voranschreitet, bleibt der hierfür Verantwortliche und nicht selten als Empfänger dieses Fortschritts vorab Definierte – der Mensch – häufig auf der Strecke. Er steht einem Entwicklungsprozess gegenüber, dessen stetige Herausforderungen ihn angesichts bestehender, erlernter und scheinbar unverrückbarer Grenzen durchaus überfordern können. Dieser Problematik gilt es, sich zu stellen. Der verantwortungsvolle, fundierte ethische Diskurs allein ist in der Lage, über den bestehenden Horizont hinauszuweisen.

Mein Interesse für Ethik entstammt einer langjährigen und stets wechselhaften Verbundenheit mit dem christlichen Glauben. Deshalb bedeutete die Teilnahme am Studiengang des *European Master in Bioethics* für mich nicht nur eine Anknüpfung an mein zuvor absolviertes Theologiestudium, sondern insbesondere auch eine Erweiterung. Der in diesem Bioethikprogramm vermittelte kulturelle Zugang zur Beleuchtung und Analyse ethischer Fragestellungen war für mich ein ausserordentlich lehrreiches und lohnendes Erlebnis. Dass im Anschluss an diesen European Master an der Universität Basel der PhD-Studiengang in Medizin- und Gesundheitsethik etabliert und ich zur Teilnahme daran zugelassen wurde, stellte für mich einen weiteren Glücksfall dar. Zudem hat mich die enge Kooperation mit Frau Professor Reiter-Theil auch in Bereichen der Ethik, die über mein Dissertationsprojekt hinausreichen, in den vergangenen Jahren nicht nur geprägt, sondern auch beflügelt, meine berufliche Zukunft Forschungsprojekten insbesondere aus den Bereichen der Medizinethik zu widmen.

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