Aus der Klinik und Poliklinik für Palliativmedizin
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3 aspects in the handling of patients severely affected by neurodegenerative diseases:

Medical care

Nursing care

And precaution (Advance-Care-Planning).

Dissertation zum Erwerb des Doktorgrades der Humanbiologie
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vorgelegt von
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aus Goslar

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Mit Genehmigung der Medizinischen Fakultät der
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Lex, Katharina Maria

I hereby declare, that the submitted thesis entitled:

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Medical care

Nursing care

And precaution (Advance-Care-Planning).

is my own work. I have only used the sources indicated and have not made unauthorized use of services of a third party. Where the work of others has been quoted or reproduced, the source is always given.

I further declare that the submitted thesis or parts thereof have not been presented as part of an examination degree to any other university.

Salzburg, 16.02.2022 Katharina Lex
place, date Signature doctoral candidate

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Publication list

Lex K M, Larkin, P, Osterbrink J, Lorenzl S. A Pilgrim`s Journey - When Parkinson´s Disease comes to an End in Nursing Homes, Frontiers in Neurology 2018, 9:1068. doi:10.3389/fneur.2018.01068.

Weck, C E, Lex K M, Lorenzl S. Telemedicine in Palliative Care: Implementation of New Technologies to Overcome Structural Challenges in the Care of Neurological Patients, Frontiers in Neurology 2019, 10:5010. doi:10.3389/fneur.2019.00510. eCollection 2019.

in der Schmitten J, Lex K, Mellert C, Rothärmel S, Wegscheider K, Marckmann G: Implementing an advance care planning program in German nursing homes: results of an inter-regionally controlled intervention trial. Deutsches Ärzteblatt International 2014; 111(4): 50–7. doi: 10.3238/arztebl.2014.0050.

Your contribution to the publications

In this chapter, the author will state her contribution to all three papers that form this thesis, which are:

“A pilgrim`s Journey- When Parkinson’s Disease Comes to an End in Nursing Homes” (Original Paper) (Lex et al., 2018).

“Telemedicine in Palliative Care: Implementation of New Technologies to Overcome Structural Challenges the Care of Neurological Patients” (short report) (Weck et al., 2019).

“Implementing an Advance Care Planning Program in German Nursing Homes” (Original Paper) (in der Schmitten et al., 2014).

1.1 Contribution to paper I

Katharina Lex designed the interview protocol, interviewed the patients, analysed the results and composed the first draft of „A Pilgrim’s Journey—When Parkinson’s Disease Comes to an End in Nursing Homes”. She subsequently incorporated comments by Professor Stefan Lorenzl and some advice on English language usage by Dr. Charlotte Behr.

1.2 Contribution to paper II

Katharina Lex was responsible for the analyses of the qualitative, guided interviews conducted by Christiane Weck with specialist outpatient palliative care team members as part of her research, “Telemedicine in Palliative Care”. Katharina Lex and Christiane Weck contributed equally to the interpretation of analyses and jointly drafted and finalised the manuscript with input from Professor Stefan Lorenzl.

1.3 Contribution to paper III

The author’s contributions to the research “Implementing an Advance Care Planning Program in German Nursing Homes” included major reviewing, commenting on and improving successive drafts of the manuscript.

2. Introductory summary

In this introductory summary the author will show that the three publications forming this thesis all cover the research subject:

"3 aspects in the handling of patients severely affected by neurodegenerative diseases:

Medical care

Nursing care

And precaution (Advance-Care-Planning)".

This broader topic was chosen as it has the power to interlink the 3 different research subjects which are tackled in the publications, forming this thesis. The main point is that all publications tackle the time

- when patients are faced with an advanced phase of a neurodegenerative disease. Parkinson`s Disease (PD) is in this thesis one example for a neurodegenerative disease.
- What kind of medical/nursing care is needed (Weck et al., 2019; Lex et al., 2018)
- How innovative tele medical tools can support in achieving good medical care (Weck et al, 2019) and
- How elderly residents living in nursing homes can take precautions for their end-of-life-phase by a structured Advanced-Care-Planning –process in which nurses have a key role (in der Schmitten et al., 2014).

Neurodegenerative Disease is "an umbrella term for a range of conditions, which primarily affect the neurons in the human brain" (EU Joint Program

me - Neurodegenerative Disease Research (JPND), 2019). The whole human nervous system (including brain and spinal cord) is built by neurons (JPND, 2019). Neurons are not able to copy or substitute themselves, that is why when neurons die or are broken, the body is not able to replace those (JPND, 2019). Neurodegenerative Diseases are not curable, disabling conditions (JPND, 2019).

Examples for neurodegenerative diseases include:

- Dementias
- Prion diseases
- Spinal muscle atrophy
- Huntington`s disease and
- Parkinson`s disease (JPND, 2019).

PD is the second most common neurodegenerative disease globally, also in Austria and Germany and the fastest growing one (Oliver et al., 2016, Dorsey & Bloem 2018). The prevalence increased by 7% from 1990 to 2017 (Deutschl et al., 2020). The Disease is usually only progressing slowly, and it is not curable (Balzer-Geldsetzer et al., 2018). PD is life limiting and disabling (Fox et al., 2016). The disease burden in late stages is as high as in patients with advanced oncological diseases (Myasaki et al., 2012). PD is also an age-related disease. That is why the frequency of diagnoses is increasing with the rising life-expectancy globally, also in Austria and Germany (Dorsey & Bloem, 2018). At present, PD burden shifts globally from wealthier to less wealthier nations (Dorsey & Bloem, 2018). In Europe alone 1.2 million PD-patients are living (Gustavsson, 2011). This number will rise considerably in the future and will lead to increased challenges for patients, family carers and health-professionals alike. Up-to date data state that 420.000 patients live with PD in Germany (Heinzel et al., 2018). That implies that 3% of the population above 65 years have been diagnosed with PD and up to 5% of the population aged 85 and above (Dexter & Jenner, 2013). For Austria, it is estimated that the number of PD-patients lies at around 20 000 (Bundesministerium Soziales, Gesundheit, Pflege und Konsumentenschutz, 2020). For Austria, only this estimation is available. One in ten German nursing-home-residents has been diagnosed with PD (Kutschar et al., 2018). Between 15% and 20% of all PD patients are in a late stage (Enders et al., 2017).

A lot of research has been conducted to gain good knowledge and multiple therapeutic options for patients in early or middle PD stages (Weck, Lorenzl 2018). Although tremendous efforts in the (medical) care of PD-patients can be viewed, which enables a high percentage of these patients to live independently for a long time, patients in late stages are still troubled by huge symptom burdens (Weck, Lorenzl, 2018). Predicting when a patient has reached an advanced stage is not easy (Titova et al., 2017). For stating an advanced PD-stage there are several indicators including:

- „long“ disease duration (Titova et al., 2017)
- Hoehn & Yahr stage IV or V (Hoehn & Yahr, 1967).
- swift from „stable“ to „unstable“ illness condition (Titova et al., 2017)
- swallowing difficulties (Lorenzl et al., 2013)
- Pain (Lorenzl et al., 2013)
- Rigidity/Spasticity (Lorenzl et al., 2013)
- Sleep disturbances (Lorenzl et al., 2013)
- Delirium/epileptic seizures (Lorenzl et al., 2013)
- Shortness of breath (Lorenzl et al., 2013)
- Depression (?) (Lorenzl et al., 2013)
- Anxiety (?) (Lorenzl et al., 2013)

In the publication by Lex et al., 2018, palliative needs of care home residents who live with advanced stages of PD are analyzed. The group of patients that was investigated are cared for in nursing homes in Salzburg and its surrounding areas (Lex et al., 2018). In the second publication by Weck et al., one model of palliative care provision for people with far advanced PD who developed neurological symptoms is demonstrated and explained as this group of patients benefits directly from the use of telemedicine tools for the advice by neurologists (Weck et al., 2019).

In the third publication by in der Schmitten and team, the process of the first implementation of Advanced Care Planning for residents in German nursing homes is examined (in der Schmitten et al., 2014). The authors argue for an alternative perspective on the challenges and opportunities that people who are very old and/or suffering from multimorbidity are facing. They suggest that Advance Care Planning, in a structured process, is a tool, that allows elderly residents to state their wishes for the last phase of their lives in a manner with which families can cope. That a structured Advance Care Planning process is possible in German nursing homes, has been demonstrated in this study (in der Schmitten et al., 2014).

Lex and team performed their study in Austria (Salzburg and surroundings) (Lex et al., 2018). Christiane Weck and her colleagues conducted their pilot telemedicine study in southern Germany (Bavaria) (Weck et al., 2019). The setting in der Schmitten and team used for their prospective trial on Advance Care Planning in German nursing homes was in Western Germany (North Rhine Westphalia) (in der Schmitten et al., 2014).

To determine the stage of PD several well-established scales are used, the classical and most widely used one is the Hoehn & Yahr scale (Hoehn & Yahr, 1967). It uses 5 phases to detect the stage of the illness by assessing motoric symptoms. Phase IV describes the stage when a patient cannot live independently anymore but is still able to walk, usually with some help. Being in phase IV means being in an advanced stage of the disease (Weck & Lorenzl, 2018).

Due to the rising complexity of the illness and the treatment options in every stage specialized PD-care-options, especially for patients who are cared for at home, are urgently needed (Prell et al., 2020). As a PD-diagnosis (like the diagnosis of any neurodegenerative disease) can shock patients profoundly, precautionary measures should be taken, e.g., a sensitive assessment of how much and what kind of information the patient might be able to digest (Paal et al., 2020).

Patients and carers may face a broad range of difficulties when confronted with PD in its later stages:

- PD patients have between 6 and 10 non-motor-symptoms simultaneously (Jenner, 2015).

- Falls occur frequently, even in patients that are already bed-bound (Schrag et al, 2020).
- Many patients are troubled by speech and swallowing problems (Schrag et al., 2020; Strupp et al., 2017).
- Patients may experience a severe “threat to personhood” with high burdens of existential distress caused by loss of autonomy and being confronted with other distressing subjects like death and dying (Gofton et al., 2018).
- Other complications include constipation, bladder problems, fatigue and dementia (Schrag et al., 2020).
- Patients themselves may feel severely affected by PD because of mobility impairments and coordination problems (Strupp et al., 2017).
- Many patients with PD experience pain, even when being cared for professionally in nursing homes (Kutschar et al., 2018).
- The disease trajectories are often difficult to predict and can take longer than in oncological diseases (Gofton et al., 2018).
- For patients being affected by neurological diseases, it is still far more difficult to get access to palliative care than for patients with oncological diseases (Eggers et al., 2018).
- Decisions for the last phase of life are often difficult ones. This applies especially for the question whether, if, and for what purpose, a feeding tube should be inserted when choking is frequent (Lex et al., 2018 b). One purpose for the insertion of a feeding-tube in an advanced stage of PD may be to prolong life; another to enable PD-patients to receive levodopa-alike medications, which is often still beneficial in the end-of-life-phase (Lex et al., 2018 b).
- The foundation of palliative care, which is verbal communication, either being able to express oneself or being able to understand spoken language, is often limited in PD-patients in late stages of the illness (Weck & Lorenzl, 2018).
- The most suitable point in time when to talk with the patient and her/his carers about integrating palliative care is often difficult to predict. There are so far no evidence-based guidelines on this subject (Weck & Lorenzl, 2018).

Currently, 3.4 million people are dependent on some care provisions in Germany (Destatis, 2018). In this figure, only those care-dependent people are counted who are entitled to government benefits (SGB XI, Sozialgesetzbuch (German Social Security Code)). Of these 0.81 million people are cared for in one of the 14 500 German nursing homes (Destatis, 2018).

After a challenging recruitment process the team was able to evaluate 23 residents, living in five different nursing homes in the City and the surrounding area of Salzburg. At first and to clarify that the residents were in stage ≥ 4 according to Hoehn & Yahr the researchers (Lex and Lorenzl) examined the residents with standard assessment instruments. In a second phase, the scientists interviewed the residents and their families using a guided interview that they had designed themselves specifically for this purpose. From the 23 residents that had been originally recruited only nine fulfilled the pre-defined inclusion criteria, which were:

- To be able to give written consent to study participation (or to be able to instruct the attorney to consent to study participation on one's behalf)
- To be assessed as Hoehn & Yahr stages 4 or 5.
- To live in a nursing home, either in the city of Salzburg or in Salzburg country.

The most interesting results was that the nine residents who participated in this study were not as depressed as the researchers had expected, despite them being very disabled and needing help for nearly every activity of daily life. None of the residents had a feeding tube and all only received minimal specific anti-Parkinson-medication. The most surprising result of the qualitative interviews was that the families had the impression that the closeness within the family was even larger after the resident had moved into the nursing home.

The second publication "Telemedicine in Palliative Care. Implementation of New Technologies to Overcome Structural Challenges in the Care of Neurological Patients" analyzed an explorative pilot study which links traditional hospital bound neuropalliative expertise with specialized outpatient palliative care (SPC) teams (SAPV-teams: Teams der spezialisierten, ambulanten Palliativversorgung) in a home care setting. People being looked after by SPC-teams in a palliative phase are, according to German law, being entitled to the specialized palliative treatment by SPC-teams, free of extra personal payments. Usually, neurological expertise in SPC-teams is not very high, that is why it can sometimes be difficult for the teams to deal with neurological diagnoses in their patients or with neurological symptoms, especially if these symptoms only occurred recently and the nearest neurologist is a long way away and/or the patient has already severe limitations in her or his mobility (Weck et al., 2019). That is why this study was conducted. Five SPC-teams throughout Bavaria were equipped with a mobile tele system that enabled them to contact the experienced neurologists at the study center on a 24/7 basis. The study center was the neurological ward at Argatharied hospital in Bavaria (Germany), prepared with technical infrastructure and two experienced neurologists, having specialized in palliative care. The SPC-teams phoned the study center when neurological expertise was needed. Following the initial call an appointment was made. The teleconsultations took place via a webcam. Throughout the study period 37 teleconsultations were analysed. Technically the tele medical consultations worked well. The patients' satisfaction with the tele medical consultations was generally high despite the inability of the neurologists, to reduce the neurological symptom burden in some cases. The fact alone that "everything" including a teleconsultation with experienced neurologists was done to help reduce symptoms led to an increase in patients` satisfaction.

The third publication in this thesis by in der Schmitten et al, 2014 explores a pilot trial focusing on the implementation process of an Advanced-Care-Planning-Process in German nursing homes. The aim of this study was to measure the rise of completed Advanced Directives within this controlled trial in German nursing homes. The main intervention was that some voluntary nursing staff who were employed in the nursing homes gained the qualification that enabled them to do the Advanced-Care-Planning conversations in a structured manner with nursing home residents and whenever possible and/or wanted with caring families involved in these talks. When the resident whished or was incapacitated -and a relative was the legal guardian, the caring family members were also invited to participate in the Advanced-Care-Planning-process. The concept of involving family members into these conversations is, that it is far more likely and easier for caring family members to decide when necessary, what the resident would wish when being present at an early stage and throughout the whole process. The qualification of the nursing home staff was a German adaption of the US-concept of „respecting Choices® ". Family doctors who looked after the nursing home residents and medical and paramedical rescue staff were also trained. Throughout the 16,5 months' observation period the incidence of newly established Advanced Directives (ADs) rose nine times. A high percentage of the new ADs were signed by a physician, usually a proxy was named, and the AD usually had an emergency plan that had been adapted from the US POLST-form: physician order for life sustaining treatment A recent study from Germany shows the need to develop PD specific Advanced Directives e.g. what medical interventions are wanted or unwanted when swallowing problems occur in which a feeding tube application is indicated which is the most frequent end-of-life decision in PD patients, other frequent scenarios include levodopa substitutions or complications, for example, the occurrence of severe personality disorders, psychosis or dementia (Klietz et al., 2020).

After in der Schmitten´s et al. study has been published it gained a lot of public attention. As it was the first controlled German nursing home study which was able to show, that a considerable rise in structured and available Advanced Directives is possible when educating nursing home staff accordingly. The German Hospiz und Palliativgesetz (HPG) is valid from 8. Dezember 2015 onwards and advance care planning which is to be offered to people in need is part of the HPG. It is largely based on in der Schmittens study (Bundesregierung, 2015). In the German Hospiz- and Palliativgesetz it is stated that German nursing homes are encouraged to offer a structured advance care planning process to all their residents (Bundesministerium für Gesundheit, 2017). This structured communication process is to tackle individualised, extensive medical, nursing psychosocial and spiritual care in the last days of life (Bundesministerium für Gesundheit, 2017). In addition, the full costs of this structured program are covered by the statutory health insurance companies (Bundesministerium für Gesundheit, 2017).

The study by Weck and team is continuing in a larger form. Dr. Wecks new project, based on the pilot study described in the publication (Weck et al., 2019) will be funded by the Innovationsfond and will look at telemedical structures for patients with palliative needs in a far bigger scale.

A new research project that started in 2019 and that is funded by the EU HORIZON 2020 program under the name: PD_PAL- (Palliative Care in Parkinson`s Disease) links two of the three subjects tackled in this thesis: the difficulties in advanced care planning and the specific care needs people in advanced PD-stages and their relatives have to face. The intention of PD_PAL –a consortium of 10 participating groups from universities in seven European countries (Estonia, Greece, Austria, Netherlands, UK, Germany and Italy) is to assess the effectiveness of a specific palliative care intervention for people in the middle stages of Parkinson`s Disease (from H & Y ≥3). One of the many publications which PD_PAL is based on, is the study by Lex et al., 2018. The main palliative care intervention consists of a community based, specific offer for a structured Advanced-Care-Planning-process by specifically trained nurses. These trained nurses (so called PD_PAL nurses) will start Advance-Care-Planning (ACP)-conversations with PD-patients and their relatives. The newly developed “Parkinson-Support-Plan” can be the basis for a valid Advanced Directive. In Austria guidance of a legal expert is obligatory for this step. In the accompanying scientific study measurements at three predefined points in time are scheduled. T0 at baseline and two follow-up assessments: T1 after 6 months and T2 after 12 months. Well-established, randomized and valid assessment instruments and neurological tests will be used to describe and compare patients and relatives’ situations. For example, the Zarit Caregiver Burden Interview will be used to show in detail what obstacles caring family members must face. After bereavement, a guided interview with caring family members is planned to gain insight into the experiences with the end-of-life-face.

On top of that, a Massive Open Online Course (MOOC) on late-stage Parkinson's Disease is developed. Aim of the MOOC is to educate everybody interested (patients and their carers as well as professional health care workers) on the obstacles which they might have to face when being confronted with advanced PD-stages. With PD_PAL the researchers expect to help PD-patients to get access to a high-quality specific Advanced-Care-Planning process integrated into a larger palliative care intervention. Another goal of PD_Pal is to show that it is possible to develop patient-centred individualized care plans for severely affected PD patients in several different European countries.

3. German Abstract

Alle Publikationen, die diese Dissertation bilden, beschäftigen sich mit 3 wesentlichen Aspekten, die bei der Versorgung schwer erkrankter Patientinnen und Patienten (unabhängig davon, ob sie mit einer neurodegenerativen Erkrankung leben müssen. oder nicht), häufig auftreten:

- Medizinische Aspekte
- Pflegerische Versorgung
- Und vorbeugende Maßnahmen (Advance-Care-Planning).

Dieses etwas weitere Thema wählte die Autorin, um die drei Publikationen, die diese Schrift bilden, miteinander zu verbinden. Grundlage der vorliegenden kumulativen Dissertation ist die Publikation „A Pilgrim`s Journey - When Parkinson´s Disease Comes to an End in Nursing Homes“ (Lex et al., 2018). Diese Studie untersuchte die Situation von Menschen in einer späten Krankheitsphase des Morbus Parkinson, die in Seniorenheimen in Salzburg und im Salzburger Land lebten. Auch die Perspektive der pflegenden Angehörigen beleuchtete das Forschungsteam. Methodisch nutzten die Wissenschaftlerinnen und Wissenschaftler einen Mixed-Methods-Ansatz für dieses interdisziplinäre Projekt. In dieser Studie kombinierten die Forschenden verschiedene neuropsychologische Tests und diverse bewährte Assessmentinstrumente miteinander, um zunächst zuverlässig einschätzen zu können, in welcher Krankheitsphase sich die Bewohnerinnen und Bewohner befanden. In einem zweiten Schritt nutzten die Forschenden leitfadengestützte Familieninterviews, um das Erleben der Betroffenen und ihrer Angehörigen besser verstehen und beschreiben zu können. Bis dato gab es keinerlei empirisches Wissen dazu, wie Seniorenheimbewohnerinnen und -bewohner im österreichischen Kontext diese Situation erleben und welche Erfahrungen sie und die pflegenden Familien in dieser Lebensphase machen. Obwohl alle Studienteilnehmenden erheblich in ihrer Alltagsmobilität eingeschränkt waren und bei nahezu allen Aktivitäten des täglichen Lebens (ATLs) erhebliche Pflegebedarfe hatten, waren sie doch weit weniger durch die aktuelle Situation herausgefordert als man dies aufgrund der wissenschaftlichen Literatur erwarten würde. Das Autorenteam der Publikation „A Pilgrim`s Journey“ ist davon überzeugt, dass ein großer Teil der überzeugenden Pflege- und Versorgungsqualität, von der die Studienteilnehmenden profitierten, der hochwertigen Pflege in den Salzburger Seniorenheimen zu verdanken ist.

Die beiden weiteren Publikationen, sowohl der Short Report „Telemedicine in Palliative Care: Implementation of New Technologies to Overcome Structural Challenges the Care of Neurological Patients “ (Weck et al., 2019) als auch die zweite Originalarbeit

“Implementing an Advance Care Planning Program in German Nursing Homes [3]“ deuten mögliche Lösungsansätze an, um das „gute Leben bis zuletzt“ (im hospizlichem Sinne) bzw. eine qualitativ hochwertige medizinische Versorgung, auch bei starker Immobilität, gewährleisten zu können.

Die Publikation (Weck et al., 2019) beschreibt eine prospektive Pilotstudie, an der sich insgesamt fünf SAPV-Teams (Spezialisierte Ambulante Palliativversorgungsteams) aus dem bayrischen Raum beteiligten. Hintergrund war, dass es (vor allem im ländlichen Raum) zu wenige Neurologinnen und Neurologen gibt. Gleichzeitig verfügen die SAPV-Teams zwar über eine hohe palliativmedizinische Expertise, aber meistens nicht über umfassende neurologische bzw. neuropalliative Kompetenzen. Aus diesen Überlegungen erwuchs die Projektidee. „Wenn die Neurologin/der Neurologe nicht Teil des SAPV-Teams ist, dann holen wir sie/ihn per Tele Medizin dazu“. Kriterien für die Telemedizinischen Konsultationen waren entweder eine neurologische Grunderkrankung oder neu auftretende neurologische Symptome, beispielsweise im Verlauf einer onkologischen Diagnose. Bis März 2018 konnten insgesamt 37 telemedizinische Konsultationen mit 21 Patientinnen und Patienten analysiert werden. Vier dieser Patientinnen oder Patienten hatten eine Parkinsondiagnose. Das häufigste neurologische Symptom waren Schluckstörungen (Weck et al., 2019).

Selbst wenn die Therapieempfehlung der per Kamera zugeschalteten Neurologin/des zugeschalteten Neurologen keine Lösung des Symptoms erbrachte, waren sowohl die teilnehmenden Teams als auch die Patientinnen und Patienten sowie deren Angehörige äußerst zufrieden, da ja „alles“ versucht worden war, um das belastende Symptom zu lindern. Eine umfangreiche statistische Auswertung dieser Pilotstudie war, ob der geringen Teilnehmenden Zahl, nicht möglich. Die Forschenden gehen davon aus, dass sorgfältig ausgewählte telemedizinische Unterstützung dazu führen kann, Symptome und Leid in der letzten Lebensphase zu lindern.

Auch die Studie (in der Schmitten et al., 2014) ist eine Pilotstudie. Ausgangslage war der Wunsch, die Effekte einer regionalen Advance-Care-Planning-Intervention im Rahmen einer kontrollierten Studie zu untersuchen. Die Studie fand in zwei verschiedenen deutschen Städten statt. Hauptintervention war hier, das Anbieten von Gesprächen zur Vorsorgeplanung durch speziell qualifizierte Seniorenheimmitarbeiterinnen und –mitarbeiter. Die Qualifizierung der Gesprächsbegleitenden lehnte sich eng an das US-amerikanische Gesprächsprogramm „respecting Choices®“ an. Diese qualifizierten Personen gingen auf die in den Seniorenheimen lebenden Bewohnerinnen und Bewohner zu, mit dem unverbindlichem Angebot Gespräche bzgl. einer gesundheitlichen Vorsorgeplanung zu führen und diese in einem prozesshaftem Geschehen abschließend auch schriftlich zu

fixieren. Darüber hinaus wurden im Sinne einer regionalen Intervention weitere relevante Zielgruppen, etwa Krankenhausmitarbeitende und Hausärztinnen und Hausärzte der Seniorenheimbewohnenden geschult bzw. bzgl. der Intervention informiert. Primärer Endpunkt dieser Studie war die Inzidenz der in der Interventionsgruppe neu entstandenen Vorausverfügungen (Patienten- und Vertreterverfügungen). Mit einer neunfachen Erhöhung der neu entstandenen Vorausverfügungen in der Interventionsgruppe im Projektzeitraum konnten die Forschenden um in der Schmitten et al. erstmals in Deutschland nachweisen, dass eine regionale ACP-Intervention durchführbar ist. Auch die Qualität der entstandenen Verfügungen überzeugte das Projektteam, die überwiegende Zahl der entstandenen Vorausverfügungen waren zusätzlich mit einer hausärztlichen Notfallanordnung kombiniert. In den allermeisten neuen Vorsorgedokumenten war eine Stellvertreterin/ein Stellvertreter benannt, die/der dann im Notfall auch entscheidungsfähig und über die Wünsche der Bewohnerin/des Bewohners informiert war.

4. English Abstract

This cumulative dissertation is based on three already published articles. In the study „A Pilgrim`s Journey - When Parkinson´s Disease comes to an End in Nursing Homes “(Lex, Larkin, Osterbrink. Lorenzl, 2018), the authors investigated the situation of patients in a late stage of PD who lived in residential homes in the city and the surrounding areas of Salzburg. The team also analysed the situation of the caring relatives. For this study a Mixed-Methods-Approach was chosen. Different neurological and neuropsychological tests and assessments were combined to enable the research team to assess the stage of the residents’ illness. In a second step, residents and their caring relatives were invited to participate in guided family interviews to gain a more detailed insight into their PD-experiences. Although all participating residents were severely burdened by the illness and were care dependant for nearly all activities of daily life, they were much less moved by their situation than the researchers had expected on account of the research literature. The authors are convinced that a high percentage of the residents’ satisfaction with their current situation is due to the thoughtful care residents receive in Salzburg’s nursing homes. The other two publications forming this thesis (Weck et al., 2019) and (in der Schmitten et al., 2014) explore possible concepts for living well until death even when being extremely dependant on the care of others.

In (Weck et al., 2019) the authors present a prospective pilot study in which 5 SPC-teams throughout Bavaria were fitted with technical equipment which enabled these teams to conduct tele medical consultations with neurologists who specialised in palliative care when the patient either had newly developed neurological symptoms or has had already a neurological diagnosis. The background for this study is that, although nearly everywhere in Germany well-equipped, multidisciplinary SPC-teams are available and paid for by the German Social Security System and that these teams do have a high expertise in palliation, they usually do not have the expertise to manage difficult neurological symptoms that newly occur and/or persist. Until March 2018 the researchers analysed 37 tele medical consultations with 21 patients altogether. Four of these patients were diagnosed with PD. The most frequent reason for a tele medical consultation of these patients was dysphagia (Weck et al., 2019). Even if the suggested treatment brought no improvement, the patients as well as participating teams were highly satisfied, as “everything possible” was done to reduce distressing neurological symptoms. A detailed statistical analysis was not possible due to the limited number of participants. The researchers anticipate that carefully selected tele medical tools can help in reducing symptoms in advanced stages of the illness.

Aim of (in der Schmitten et al., 2014) also being a controlled, pilot study was to demonstrate the effects the intervention of a structured Advanced-Care Planning-process can have. The trial was conducted in two cities in North-Rhine Westphalia. The main intervention was the work by specially trained nurses in nursing homes, so called “facilitators”, who were able to initiate and complete conversations about Advanced-Care-Planning with volunteer residents from the nursing homes and their caring family members. The qualification was adapted from the US-program „respecting Choices® “. Apart from the ACP-conversations other relevant health professionals in the regional setting were qualified, received information on ACP and the controlled study as well. These included GPs who cared for the nursing home residents and health care specialists at the emergency ward from the local hospital. Advanced Directives and/or living wills as the results from completed ACP-processes raised nine times. In der Schmitten and team showed that structured ACP-interventions on a regional level are feasible in the context of German nursing homes. Most of the newly conducted Advanced Directives named a proxy as well and were usually combined with an emergency plan, signed by the responsible GP.

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