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SELF-DETERMINATION IN PATIENTS WITH INTENSIVE CARE NEEDS: CARE MANAGEMENT IMPLICATION

Abstract:

Highly vulnerable people, such as those on permanent ventilation, are heavily dependent on medical, nursing and social support. The aim of the treatment of these patients is to make them independent of the ventilators - insofar as there is a potential for weaning from ventilation. This requires a considerable amount of time, especially for people with multimorbid diseases. In a clinical setting, the necessary resources for this are not available.

In a newly created transitional living form for out-of-hospital ventilation weaning, patients are closely supervised and supported in the weaning process by a multidisciplinary team in a homely environment. The transitional housing form is supported by research carried out by the Ostbayerische Technische Hochschule Regensburg. The evaluation of self-determination in a complex disease situation is one aspect of this research.

This paper is based on a study that included 54 guideline-based, semi-standardised interviews which were conducted with the patients themselves and/or relatives covering the aspects of medical and therapeutic care as well as housing and self-determination. The interviews were evaluated using content analysis. In a first step, the categories of the analysis of self-determination are described. Furthermore, the results are exemplified with a case study.

Results of the study show that the perception of quality of life is closely linked to the possibilities for self-determination. The comprehensive medical, nursing and therapeutic support contributes to the well-being of the sick people, who should be informed about and involved in the treatment. The case study illustrates by way of example how self-determination can be achieved in the case of severely diseased patients (e.g. referring to their mobilisation, visits, spare time activities) and how compliance can be increased. It became evident that even in the case of lethal dis-

eases whose progression cannot be influenced, a self-determined life is still possible.

Keywords: ventilation, weaning, out-of-hospital transitional form of living for weaning, self-determination, Case and Care Management

Introduction

In modern intensive care medicine, ventilation therapy is an essential and often indispensable component of many treatments (DGP 2019, p. 9; Windisch et. al. 2017, p. 726). Although this therapeutic intervention is life-saving, it is nevertheless associated with considerable risks for patients (Kabitz/Dembinski 2018, p. 10). Especially in the case of multimorbidity, there is an increasing risk that the termination of ventilation therapy or withdrawal from artificial ventilation (so-called weaning) will lead to complications (Karagiannidis et. al. 2019, p. 674; Dreher et. al. 2017, p. 56). These patients remain in hospital for a very long time to stabilise their state of health. If, despite all efforts, weaning did not succeed and the rehabilitation potential was also estimated to be low, there has so far been a transition to an out-of-hospital intensive care setting (e.g. in specialised residential communities) for status-preserving care (DGP 2019, p. 115; Karagiannidis et. al. 2019, p. 674). However, studies have shown that considerably more than 50% of these patients have a weaning potential which means that their health status could be improved (Schönhofer et al. 2016, e170; Bornitz et al. 2020, p. 208; Paul et al. 2022, p. 404 et seq.), provided that they get individualized treatment.

Patients who are in permanent intensive care perceive their quality of life as reduced even if sufficient care and medical equipment are available (Huttmann et. al. 2015, p. 316; Huttmann et. al. 2018, Schönhofer et. al. 2025, p. 141 et seq.). This is partly due to the fact that they are in a fragile, latently life-threatening condition and are, therefore, heavily dependent on permanent intensive care nursing (Ewers/Lehmann 2018, p. 418). Since the 1990ies, the concept of "quality of life" is understood as a multi-dimensional concept comprising among others the physical, psychological and social well-being (The WHOQOL Group 1995, p. 1.405).

Literature on people in care situations emphasizes that self-determination is an essential part of what patients consider a good quality of life (Dichter/Schmidbauer 2016, p. 125). The UN Convention on the Rights of People with Disabilities[1] defines the concept of self-determination further, stipulating that basically every person, irrespective of his or her degree of impairment is capable of self-determination and has a capacity to act and make legal decisions (Lachwitz 2013, p. 69).

[1] Convention on the Rights of Persons with Disabilities (CRPD) of 06.12.2006 and its Optional Protocol (A/RES/61/106) of 13.12.2006 (https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf, accessed on 01.07.2025).

In the Western political and moral tradition, individual freedom and the right to make one`s own choices in life and control one`s own destiny are of high significance (Beauchamp 2021, p. 74). This implies that in a care situation the decisions about the services to be given should be made without any organisational pressures (Miles-Paul 2006, p. 34 et seq.). In intensive care, the perception of quality of life is closely linked to the possibilities of self-determination. This, however, is principally endangered when communication is restricted (Nelißen et al. 2018, p. 520 f.). Before the Intensive Care and Rehabilitation Strengthening Act[2] was passed in Germany in 2019, a debate developed about the care needs of persons in intensive care. Looking at this debate, one got the impression that the self-determination and thus the quality of life of these patients was in danger (Richter 2022, p. 16).

In 2020, the Intensive Care and Rehabilitation Strengthening Act was finally passed establishing a right to having the weaning potential checked (Arndt 2020, p. 569; Jauernig et al. 2022, p. 267 f.; Biehler et al. 2025, p. 2 et seq.). This includes that according to §§ 8 f. of the intensive care guideline (AKI-RL)[3], a specialised physician has to examine the patient, determine the weaning potential and ensure that appropriate measures are taken (s.a. BT-Drs. 19/19368, p. 23).

Prior to the reform of the health insurance law, weaning was exclusively carried out in clinical settings. The greater flexibility which the new legal provisions opened up in 2021 made it possible that this is now also done in transitional living (s.a. Richter 2022, p. 25 et seq.). Adult patients that are ventilated or have been tracheotomised and are in need of prolonged weaning according to classification 3 of the guidelines for treatment are now accepted for individual and person-centred treatment (DGP 2019, p. 16; s.a. Boles et al. 2007, p. 1.036). The out-of-hospital setting offers accommodation in comfortable single rooms and includes a more flexible and extended time contingent for multidisciplinary rehabilitation than in a regular clinical environment. With a maximum of twelve treatment places, patients can be given appropriate individual care.

Since this out-of-hospital transitional form of living is a new concept in German social law, it was approved on a trial basis provided that scientific support was guaranteed (Art. 17 para. 3 of the Bavarian Care Housing Quality Act – PfleWoqG).[4] What is relevant for the living environment of ventilated people in the corresponding settings has not yet been researched much (similar to Ewers/Lehmann 2018, p.

[2] Law to Strengthen Intensive Care and Medical Rehabilitation in Statutory Health Insurance (Intensive Care and Rehabilitation Strengthening Act – GKV-IPReG) of 23.10.2020 – BGBl. I p. 2220.

[3] Guideline on the Prescription of out of Hospital Intensive Care (AKI RL) dated 19.11.2021, last amended on 18.06.2025.

[4] Act on the Regulation of Care, Care and Living Quality in Old Age and Disability (Bavarian Care and Housing Quality Act – PfleWoqG) of 08.07.2008 - GVBl. p. 346, last amended by § 1 of the Act of 24.07.2023, GVBl. p. 431.

421). Therefore, the quality of life and in particular the description and analysis of the possibilities of self-determination of sick people is one aspect of the accompanying research.

Methods

According to relevant research in the specialist literature (scoping review), out-of-hospital weaning has so far been researched mainly from a medical and specialist nursing perspective (Schiegl/Schroll-Decker 2025). So far, there is little evidence of indicators that can be used as decisive for assessing self-determination. Therefore, it seemed appropriate to conduct exploratory research using qualitative methods (Döring 2023, p. 25 f.).

Between 2021 and 2024, 64 interviews have been conducted with patients in the transitional housing form and/or their relatives and family members referring to aspects of self-determination (e.g. inclusion of the patients in debates on treatment and care, the relevance of a room of one`s own, decisions on visits and contacts in the housing arrangement, a self-determined everyday life including watching TV, when to get up, etc.). These were analytical interviews that are methodologically characterised by the fact that they describe social issues, the results of which are compared with theoretical considerations and concepts (Lamnek/Krell 2016, p. 317). In addition, the interviews were guideline-based and semi-standardised. Partial standardisation was considered useful because that way special topics which emerged spontaneously in the course of the interviews could be detected and pursued further. Thus, in a field that has not yet been explored, narrative elements that emerged in the interviews could be included (for the narrative interview, see e.g. Przyborski/Wohlrab-Sahr 2021, p. 106 et seq.).

The evaluation was based on qualitative content analysis according to Mayring (Mayring 2023, p. 97 et seq.; Mayring 2022, p. 11 et seq.). In addition, the defined analysis phases of Lamnek and Krell were taken into account (Lamnek/Krell 2016, p. 379 et seq.). These phases mainly included transcription of the interviews, individual analysis, generalising analysis of all interviews, and a control phase during which reference was made to the original interview transcripts (Lamnek/Krell 2016, p. 379 et seq.). The MAXQDA software was used (Rädiker/Kuckartz 2019, p. 3 et seq.). The deductive evaluation codes referred to the research questions. Of the 54 evaluated interviews,1.045 codes were included in the definition of self-determination (as of July 1st, 2025).

Until the end of 2024, 133 patients were admitted to a transitional housing form. Based on this population, we got a participation of 48,12%. A special sampling method was therefore not necessary (for sampling, see Przyborski/Wohlrab-Sahr 2021, p. 231 et seq.). The patients were informed about the study in consultation with the team of the transitional housing form, they were fully informed

about the methods and aims of the study and were then free to decide for or against participation. Data was only collected and evaluated if the written consent of the interviewee or the legal representative had been obtained. However, the state of health of the patients had an impact on participation. In particular, if the patients had serious communicative problems or could not be interviewed due to the severity of the disease (on the communication barriers, Weber et al. 2014, p. 15), relatives and family members were interviewed. However, it was possible for the patients to be present at the interview if they wished and, if necessary, to be included in the evaluations by means of gestures (e.g. nodding their heads). Video recordings or the like were dispensed with to ensure integrity. If the patients were verbally restricted, but did not have serious cognitive problems, the questions could be answered in writing as an alternative. 84.4% of the participating patients were over 50 years old and 60.9% were male. The patients came from all over southern Germany. In most cases, there was no prior connection with the social environment of the transitional housing facility. Almost 80% of participants were transferred to the transitional housing from hospitals (intensive care units) where they had previously been medically treated.

Overall, emphasis was placed on an inclusive survey design, as the research was oriented towards the needs and requirements of those affected. However, the usual qualitative research methods reached their limits in view of our particular population. Even though it can be assumed that relatives or family members are most likely to be able to assess the needs and wishes of the patient (Salomon 2015, p. 332), their judgements may not always be in accordance with the patient's perception. However, the risk of misassessments could be kept as low as possible if the patients themselves were present. In principle, regular reflections were carried out in the team of researchers to ensure the quality of the research results, whereby Mayring's criteria (e.g. procedural documentation or rule-based nature of the research process) were - among other things - used as a guideline (Mayring 2023, p. 122 et seq.). During the collection and evaluation process, personal data were pseudonymised. Due to the vulnerability of the group of people, the research project obtained an ethics vote from the Joint Ethics Committee of the Universities of Applied Sciences in Bavaria (GEHBa) in 2021. Respect for dignity and integrity, as well as the protection of seriously ill people, was a priority at every stage of data collection and analysis. Personal data was therefore encrypted several times in close consultation with the university's data protection officer. Patients and their relatives were only interviewed once the patient's health had stabilised sufficiently.

Results

Summary analysis of all codes for self-determination

Almost 250 codings illustrate a high restriction of self-determination (operationalised among others by patients`passiveness). When changing over into transitional living, patients are hardly capable of expressing their own needs and wishes due to considerable impairments resulting from their disease and are thus highly vulnerable. In the course of treatment or when individualised rehabilitation measures are taken (e.g. with regular physiotherapy), the possibilities for self-determination increase among patients (for the individualisation of rehabilitation, see Wade 2023, p. 875). However, this process is of a gradual nature and it is difficult to produce hard data. Basically, determination of progress is based on observation and subjective perceptions. In the interviews, self-determination was frequently associated with increasing self-sufficiency (e.g. regarding mobility) and decreasing dependence on medical devices. The use of a speaking valve also makes communication easier, which reduces misunderstandings, for example with the nursing staff. In addition, more and more activities can be taken over independently in personal hygiene (e.g. body care). These advances are correlated with the increasing possibilities for self-determination. In addition, more than 50 codes indicate an increasing self-determination of patients in everyday life: They can use the balcony or terrace when mobilised or run errands in the grocery store nearby. They also benefit from unlimited visiting hours. Ideally, self-determination can be understood as a process from the hospital to admission and treatment in the transitional form of housing, which can be represented as follows:

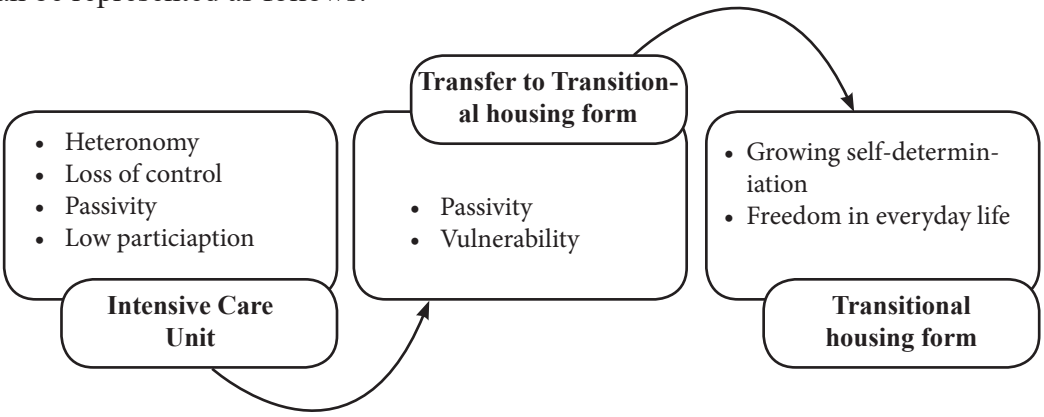

Fig. 1: Process to regain self-determination.

This process is only one characteristic of self-determination. The evaluation of the 1.045 codes shows further dimensions. In the case of intensive care, self-deter-

mination affects both the individual side and the systemic level, especially in the health care system.

Individual level

Due to the severity of the diseases, patients can also be so impaired during weaning treatment that infections profoundly worsen their state of health. This means that self-determination is fundamentally up for discussion, particularly if there is a continuing relationship of dependency (e.g. vis-à-vis nursing staff or medical technology). Self-determination does not always proceed in a linear and smooth way. In addition, in the case of severe cognitive impairments due to illness, patients can have an ambivalent understanding of self-determination and care (see Beauchamp/ Childress 2012, p. 101 et seq.). Considering the findings in the interviews (e.g. interview 073 or 060) the idea of self-determination can become contradictory. On the one handside restricting self-determination can be perceived as being given more security and affection; on the other hand, it can be perceived as paternalism and heteronomy (e.g. if a decision on medical measures is made without consulting the patient). Self-determination vacillates between heteronomy and autonomy and it depends on the subjective impression of a patient how certain measures are perceived.

However, the self-determination of patients is not only up for discussion because of complex diseases. Relatives and family members can also act in a paternalistic manner towards the sick people, for example by placing too high expectations of success or treatment on them, exerting pressure, for example with regard to rapid weaning from ventilation. We must acknowledge that patients are in a (not necessarily positive) social relationship with their relatives and family members and that decisions are made within the family unit. Self-determination thus does not describe a self-sufficient state, but must be defined in relation to the social environment.

Systemic level

In addition to the restrictions on a personal level, the self-determination of patients is also endangered by systemic constraints (especially resulting from the health care system). In particular, the high density of actors involved in the social services sector should be pointed out here. Due to specific social law requirements in Germany, not only an internal team of doctors and nurses is involved in the treatment in the transitional housing form. For adequate weaning treatment, expertise not directly employed in the transitional form of housing (such as physiotherapists or speech therapists) is consulted. Patients have little influence on scheduling appointments and therapy density, for example. There are also restrictions on self-determined decision-making options in the organisation of follow-up care after the stay in the out-of-hospital transitional form of living, as the choice of options for

continued care is limited, especially in the event of a weaning failure (s.a. Ewers/ Lehmann 2018, p. 421).

The explanations so far show how complex self-determination is in the transitional housing form and how many aspects are affected. Self-determination can thus be described as a term with several dimensions:

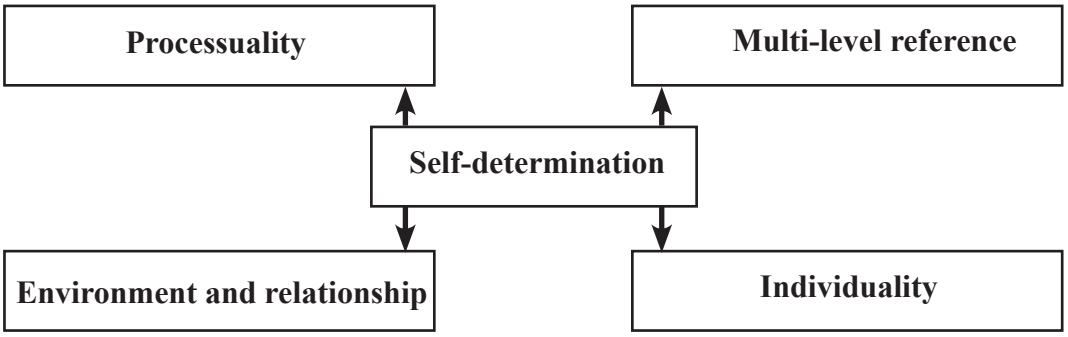

Fig. 2: Dimensions of self-determination.

An exemplary case study illustrating the concept of self-determination

A case study can be used to show what self-determination can mean in an individual case. It is to illustrate the dimensions of self-determination focusing a single social element (Lamnek/Krell 2016, p. 286). After the description of the particular case, the dimensions of self-determination that can be derived from the interview are explained.

Sociodemographic and disease-related data

We are dealing with a nearly 50 years old male patient (pseudonym: 080) who was admitted from a clinical setting to the transitional form of living. The underlying disease is amyotrophic lateral sclerosis (ALS), a degenerative muscle disease. The patient is already severely limited in his mobility and is therefore permanently dependent on the support of nurses and caregivers. At the time of the interview, there is non-invasive ventilation (NIV), which is medically supervised in the transitional living form. The patient rejects further invasive treatment measures (such as the insertion of a tracheostomy tube). To support him, the guardianship court appointed a professional guardian who must respect the wishes and will of the patient in all activities that require intervention of the guardian (on German guardianship law, see Beetz 2022, No. 42 para. 2 et seq.). Since there are no cognitive and communicative impairments of the patient, he is fully capable of making decisions and is undoubtedly capable of self-determination (with regard to the fundamental rejection of substitute decisions or the like or to (human) legal capacity, see Degener 2015, p. 59; Degener 2016, p. 17).

Dimensions of self-determination

In the interview, it first becomes clear that, due to his disease, the patient is dependent on multidisciplinary care by various qualified specialists. This includes close medical supervision, the continuous use of therapies and constant specialist care. With regard to medical care, it seems important to the patient that daily medical check-ups take place documenting potential changes in the degenerative underlying disease and ventilation. In view of his serious illness, the patient assumes that difficult decisions of a medical nature could be pending (not specified in more detail by the patient).[5] Therapeutically, the patient prioritizes physiotherapy (especially physiotherapeutic exercises). With regard to care, the patient states that the professionals in the transitional housing form are always available for him should he have any questions. The patient is free to decide on basic care as well as on mobilisation in the wheelchair (e.g. when and for how long). The patient apparently feels that his wishes and needs are sufficiently taken into account by the team of the transitional living arrangement, which speaks for a relationship of trust. In general, there is open and close communication between the multidisciplinary team and the patient with regard to the interventions. Thus, it can be assumed that the patient is granted space for self-determination and co-determination in his difficult situation. The transparency in the transitional housing form thus supports self-determination and gives the patient the opportunity to decide for himself about possible treatment alternatives after having been given sufficient information. In addition to these treatment aspects, it has been shown that everyday decisions can also be made by the patient himself in the transitional living form. For example, the housekeeping personal can get him personally important things (e.g. in the nearby grocery store):

> *"The housekeeping, [...] they go shopping [...] and all you have to do is say what [they] bring with them [...] [should] […]. And then they bring it with them." (Interview I-080, item 113)*

Likewise, the patient is free to decide on the morning wake-up times as well as on the television and streaming programs, as can be seen in the following original quote:

> *"[...] [J]a well, the basic care, so like today, for example, there was [I] think at 8 [o'clock] someone [from the care] had been there for the first time [...] and there [...] [I] then said, [...] because I was [...] still tired, give [...] [me] still [...] [a] hour or so [...] and then [...] [at] half past 10 someone came again." (Interview*

[5] In the event of an acute deterioration in health, for example, an emergency transfer to the intensive care unit would be considered. This can be rejected by the patient in advance (such as the invasive measures that were already refused at the time of the interview). He can also refuse resuscitation in an emergency, for example. These possibilities always raise complex ethical questions and make multidisciplinary support (e.g. by medicine or psychology) seem unavoidable.

I-080, item 33)

Accommodation in a single room, which also allows the use of entertainment media, is of central importance to him. The realisation of self-determination depends largely on the reliability of the nursing or support staff, as the patient needs help, e.g. when switching on the television. It is equally important to him that he can always receive visitors and that they are allowed to bring things that are personally relevant to him, as the following quote illustrates:

"[They] (= the visitors) [...] [can] actually bring anything with them [...]. [A] Buddy [...] recently brought me cookies. Since [...] [they] have already baked cookies [...]. So [...] [that] everything is possible." (Interview I-080, item 81)

Other aspects that could be associated with self-determination are considered less important by the patient. Thus, the personal design of the single room is largely irrelevant for him. Amenities that could be offered to him outside of the treatment (such as a wheelchair trip to the surrounding area or reading something to him aloud) are considered secondary. This shows that self-determination is a very individual and subjective factor. In other interviews the possibility of bringing and displaying personal photos was rated as essential for well-being (such as in interview I-087).

Conclusions of the summary analysis and from the case study

What has been described so far allows the conclusion (this correlation has been described in the introduction) that more self-determination and co-determination in treatment decisions as well as in everyday life contributes to the well-being of patients. The more patients see themselves as being able to influence and decide on certain aspects of their lives, the higher the quality of life they perceive (see Fig. 3):

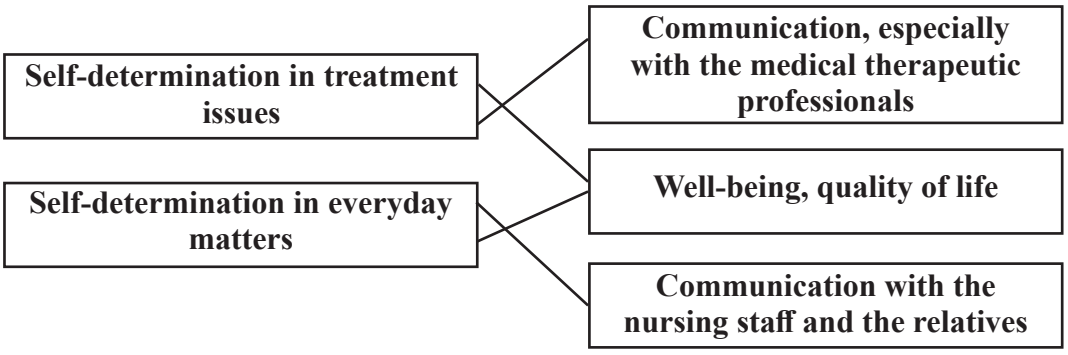

Fig. 3: Self-determination in treatment and in everyday life in the transitional housing form.

Thus, communication can be identified as the most essential factor determining the possibilities of self-determination as well as the resulting well-being and quality of life particularly in the case of people in intensive care or with weaning needs. While communication with doctors and the therapeutic professions (e.g. physiotherapists or speech therapists) is mainly important for basic treatment issues, when it comes to everyday aspects, it is primarily communication with the nursing staff, but also the communication with relatives and friends that is of importance. This classification results from the fact that planning of treatment is to be defined in principle as a medical and therapeutic task (s.a. Dreher et al. 2017, p. 57 et seq.). At the same time, the nursing staff and relatives are continuously active with the diseased persons and are therefore the contact persons for all questions regarding everyday life. Also, it is crucial for self-determination that patients are treated by professionals and relatives as being on an equal level. Thus, for patients to have a self-determined life, a number of diverse conditions have to be fulfilled.

Discussion

Both the empirical results of the summary analysis and the in-depth case study show how multidimensional the concept of self-determination is. Based on basic human rights assumptions, self-determination is a legal right (Beckmann 2017, p. 35; Teubert 2023, p. 29). These legal concepts imply not only that it should be avoided to patronise patients and restrict their ability of realising their legal rights; moreover, they have to be informed about their right of self-determination and what that means in actual practice (Teubert 2023, p. 29). Our evaluation confirms that self-determined living is only possible in relation to the social and ecological environment, i.e. the realisation of self-determination always depends on the support of other people. Accordingly, self-determination is to be defined as a "humane concept of relationship", which is particularly evident in situations of increased vulnerability, for example in the case of serious illnesses (similar to Bielefeldt 2017, p. 71). Flexibility in decision-making regarding medical treatment as well as in everyday life for the patient always requires the commitment of others (e.g. nurses) and the solidarity of others. However, restrictions in self-determination can also arise due to systemic requirements.

Open and honest communication with patients by the multidisciplinary treatment team is crucial for the feeling of self-determination in existential illness situations (similar to Lemm et al. 2018, p. 251). In the case of chronically progressive diseases, the early integration of palliative care should also be considered, as this allows planning for the future in the event of a worsening of the disease (Schlau 2021, p. 856). At the same time, dynamic or continuous communication with patients regarding their needs and requirements is recommended, as those affected should have the freedom to change opinions or previous decisions (Diaz de Teran et. al. 2019,

p. 562). Reciprocal intensive communication and interaction are therefore – as has already been worked out in the conclusions (see p. 12 f.) – essential for self-determination and quality of life.

Although a self-determined life in care practice is based on the interpersonal communication of equal partners, it is also embedded in a care concept that is determined by a complex social system. It is, so to speak, a managerial task to handle instead of to manage the dependencies of the individual patients who are moving in a complicated care system, to assert their rights and entitlements and to guide them through a labyrinthine social system (e.g. the social law). Caretakers of various descriptions carry out that task for the vulnerable patients. For this purpose, the concept of „Case Management“ was implemented in the transitional housing form.

Inference: The action concept of Case Management as a structuring framework

Case Management describes the needs-oriented control of an individual case and the handling of personal problems. It works within an organisation and in the regional care structure (Mennemann et. al. 2020a, p. 2). Case Management is only suitable for cases the handling of which is difficult and time-consuming (Monzer 2024, p. 2). It comes into consideration under the following circumstances: a) if there is a complex need situation with several interacting factors, b) if there is a high density of actors, c) when standard care pathways are not sufficiently effective and d) when the resources of the person concerned are not sufficient to compensate for the need for support (Mennemann et. al. 2020a, p. 5). With regard to the complex illnesses described here, it can be assumed that the defined prerequisites for the use of Case Management are in place: The situation is difficult due to the high personnel and technical demands and requires the coordination and cooperation of various stakeholders (Windisch et. al. 2017, p. 741). The number of actors usually to be taken into account can be illustrated as follows.

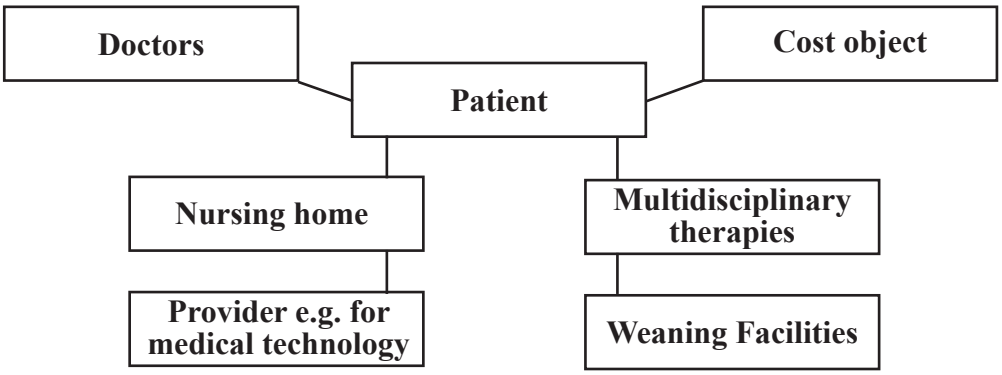

Fig. 4: Actors to be supervised.

The need for coordination becomes particularly virulent when a transition between institutions is imminent (s.a. Kippnich et al 2023, p. 274). If, for example, the patient from the case study leaves the transitional form of living after treatment has been completed, the need for support remains with regard to basic care, but also with regard to medical technology care. The transition to the subsequent care arrangement requires a high level of organisational effort which the staff of the transitional housing arrangement is largely responsible for. What is needed individually must be determined carefully and in communication with the patient and, if necessary, the relatives and family members (Köster-Steinebach 2018, p. 15). For example, it must be clarified whether care can be guaranteed by an outpatient intensive care service in the patient's original residential environment. Here, for example, architectural barriers that could previously be overcome by the patient can make home care impossible. Likewise, if there is a continuing need for intensive care or ventilation, an outpatient care service must be found that takes over the care in the patient's home environment. In view of the current shortage of specialist staff in nursing and the overburdening of nursing services, to organize this can be challenging under certain circumstances (Rebnitz/Sonntag 2018, p. 19). In order to protect the patient's self-determination despite these structural impairments, it seems appropriate to guide the patient through these at least partially separated sectors by means of Case Management. This implies that the patient is not left alone in contact with the stakeholders, but always has a contact person available for questions or problems (see similarly Riesner et. al. 2021, p. 140 et seq.), as the following graphic of the piloting process illustrates:

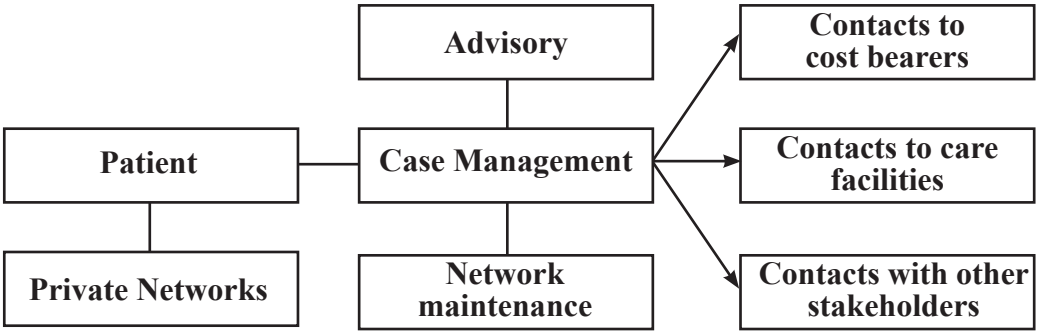

Fig. 5: Piloting process through Case Management in the case of intensive care.

In order to provide competent advice (even beyond the issues described in the case presented above), the supervising Case Managers need to have comprehensive knowledge, for example on social law issues (Wendt 2012, p. 13). At the same time, reliable networking is required, in which Case Management takes on a bridging function between the private networks of patients (e.g. supportive neighbour-

hoods) and professional networks (such as networks of care facilities or municipal networks for care provision) and establishes cooperation between people who offer individual assistance and professional services in addition to care counselling. (Löcherbach 2020, p. 55, s.a. Jauernig et. al. 2022, p. 268; Biehler et. al. 2025, p. 6). In order to meet the self-determined needs and wishes of patients, appreciative and empathetic communication is once again indispensable, which, depending on the situation of the patient, may also include alternative modes of communication (for example, written communication if verbal communication is not possible). The patient with his or her needs and requirements is at the center of all planning (Wendt/ Löcherbach 2023, p. 71). In the case of the most severe illness-related impairments, however, the involvement of relatives and family members is inevitable, even if decisions made by others are to be viewed critically if the principle of self-determination is to be respected (Degener 2016, p. 28). For Case Management, however, the most preferable version is that the sick person should express his or her wish directly or that there should be very good reasons to make assumptions about what the person would want so that self-determination can be respected as far as possible (Mennemann et. al. 2020b, p. 41).

In transition living form the setting itself offers the necessary preconditions for self-determination (e.g. providing a single room). Also, a qualified staff principally respects the self-determination of the patients and helps realizing that self-determination. In addition, it must be clarified what claims and entitlements the patient has towards the social and the health system and steps have to be taken to facilitate cooperation of service providers in order to create an adequate care arrangement. This means that the realisation of self-determination can only be realised within a complex support network. This confirms that human life always takes place in a "basic structure of interdependence", which underlines the fundamental vulnerability of humans (Maio 2024, p. 17).

People with intensive care or ventilation needs are particularly dependent on what a particular social and care system provides for (for example, social law requirements). Due to the sectoral structure of the social system in Germany, there are numerous limits that can be overcome by means of Case Management. In the most favourable case constellation, a „pilot" (a person who helps to navigate through the system) who knows what the wishes of a patient in a specific case are and who is also well informed about the legal and organisational situation in a particular field will show "paths" through the labyrinthine social security system. This makes it easier for patients to deal with this complex situation (Mennemann/Frommelt 2023, p. 1 et seq.). This can also create spaces for self-determination, as detailed information about what the health system offers and what health care regulations are in place will make it possible for the patient to make well-founded decisions (for example, choosing a care setting). In addition, since Case Management is always associated

with the extent of care offered by providers in a specific region, attention can be drawn to structural care deficits (for example, inadequate care services in a region) and working towards a care infrastructure in a given community can be facilitated (Wendt 2023, p. 113). We can venture to conclude that the facilitation of self-determination for people with intensive care or ventilation needs correlates positively with the nationwide implementation of Case and Care Management structures.

Study limitations

In order to avoid producing biased results, data collection was done with great caution, and the evaluation process went through several stages. One of the measures taken to avoid bias was to make a double coding per interview. Nevertheless, misinterpretations cannot be completely ruled out, as the interviews were conducted under difficult conditions due to the sometimes very pronounced communicative limitations of the patients and the noises associated with medical technology (e.g. ventilators). Statements that are difficult to understand and partly expressed in dialect require a level of understanding and interpretation, which does not exclude errors. However, if patients decided to participate in the research, the interviews were carried out, also in order to achieve the greatest possible inclusivity of research. In the case of the most severe impairments, interviews were conducted with their relatives and family members in the presence or absence of the patients. Here, again, it is conceivable that the needs and wishes of the patients were superimposed by those of relatives and family members (dealt with in more detail in the chapter on methodology).

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