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Conflict Between Respect for Autonomy and Care: A Grounded Theory Study on Action Strategies to Care for People With Physical Disabilities

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ABSTRACT

People with physical disabilities (PWD) are a large population group in Germany. Due to functional limitations of the body, they may be dependent on nursing assistance. PWDs' wishes for assistance can be expressed verbally to nurses. However, these wishes do not always match what nurses want to happen. As a result, nursing care and the autonomy of PWDs can be critically opposed to each other. Thirteen problem-centered interviews were conducted with nurses on the care of PWDs. According to Strauss and Corbin (2010), analysis was conducted using grounded theory. When caring for PWDs, nurses may be confronted with wishes and needs they cannot or do not want to fulfill. As a result, they experience a conflict between care and respect for autonomy. Nurses critically assess these situations, including professional, ethical, and legal-organizational aspects. They interact with PWDs as well as colleagues to manage the conflict. Positive outcomes result in the conflict being resolved; negative outcomes result in nurses stopping care. Ambivalence also exists, which is characterized by tensions in further care. Nurses want to support PWDs, enable participation, and promote independence. They want to feel comfortable with their decisions. Therefore, they weigh carefully whether wishes for nursing assistance are realized or denied. Decision coaching can be a new task for academic nurses to enable PWDs to make health-promoting decisions for themselves.

KEYWORDS: Grounded Theory; Physical Disabilities; Autonomy; Care; Ethics; PWD; People with Physical Disabilities.

KEY PRACTITIONER MESSAGE

1. Conflicts between autonomy and care can occur as natural phenomena in the nursing care of people with physical disabilities.
2. Ethics, nursing-medical expertise, and legal-organizational aspects must be weighed against each other to make decisions for or against desired nursing assistance.
3. People with physical disabilities can learn to make good decisions for themselves through decision coaching by nurses.

INTRODUCTION

In Germany, approximately 7.9 million people live with a severe disability, of which the largest proportion (58%) have a physical disability (Destatis Statistisches Bundesamt, 2021). People with physical disabilities (PWDs) may have a need for care due to accompanying physical functional limitations. Since 2017 in Germany, the need for care has been defined based on the degree of independence. The greater the loss of independence is, the more nursing assistance is required (Medizinischer Dienst, 2022).

Nursing care is defined as the autonomous provision and care of people of all ages in all life situations. Care promotes health, serves to prevent illness, and has the key task of safeguarding the interests and needs of care recipients (International Council of Nurses, 2022). From the perspective of nursing theory, the need for nursing actions can be justified by a lack of self-care. A self-care deficit can be compensated for by professional nurses. According to Dorothea Orem, actions can be supportive, advisory, and partially or fully compensatory (Dennis, 2001).

In Germany, the need for care is recorded and described according to six modules (Medizinischer Dienst, 2022). The modules have a percentage weighting that determines the extent of the need for care: organization of everyday life (15%), mobility (10%), cognitive and communicative abilities or behavior and psychological problems (15%), self-care in the sense of personal hygiene and nutrition (40%), coping with and independently dealing with therapy-related demands and burdens (20%) (GKV Spitzenverband, 2022). On this basis, nursing tasks may arise in the areas of mobility, cognitive and communicative abilities, behavioral and psychological problems, self-care, coping with illness/therapy-related demands and stresses, shaping everyday life and social contacts, and housekeeping (Wingenfeld & Büscher, 2017).

Due to the permanence of their disability, their superior level of knowledge about the disability picture, and the assistance they require, PWDs are experts with regard to themselves, their way of life, and the care they receive. PWDs can explicitly formulate their wishes for nursing support for their care and lifestyle nursing. In this context, one can speak of autonomy, in which self-determination and the ability to act in favor of more subjectivity and individuality are of great importance (Schopp et al., 2004; Wulff et al., 2010).

Autonomy is one of six ethical principles, and together with care, justice, dialogue, responsibility, and dignity, it is part of an overarching basic ethical orientation of nursing action (Rabe, 2017). The Charter of the Rights of Persons in Need of Assistance and Care also addresses the issue of self-determination in Article 1 (Bundesministerium für Familie Senioren Frauen und

Jugend & Bundesministerium für Gesundheit, 2018). Accordingly, every person has the right to help and support to lead as self-determined and independent a life as possible. Self-determination has its limits where the rights and development opportunities of others are affected (Bundesministerium für Familie Senioren Frauen und Jugend & Bundesministerium für Gesundheit, 2018). Care professionals are committed to the autonomy of affected persons and are guided by the principle of care (Kotsch & Hitzler, 2011). In Germany, nursing care is understood as a caring relationship that is emotionally supportive. Caring in the sense of worrying, helping, and providing care is also the core of professional nursing care (Schnepp, 2015). The Charter of the Rights of Persons in Need of Assistance and Care points out that conflicts can arise between care professionals' duties of care and the right to self-determination (Bundesministerium für Familie Senioren Frauen und Jugend & Bundesministerium für Gesundheit, 2018). Self-determination in nursing means realizing successful interactions between nursing and affected persons (Kotsch & Hitzler, 2011). Enabling self-determination in the context of nursing activities can be described as a genuine goal (Behrens & Zimmermann, 2006).

Conflicts can arise within the nursing practice when the wishes of PWDs regarding the realization of nursing assistance differ significantly from the realization by nursing. It is not known how nurses experience and describe conflicts within the care of PWDs.

Research Questions

The following questions were asked of the data: (1) Which of PWDs' wishes for nursing assistance are nurses unable or unwilling to fulfill? and (2) How do nurses deal with these wishes?

METHOD

Within this grounded theory research project, the question "How is the care of PWDs shaped by care professionals?" was researched. To answer this question, a total of 40 problem-centered interviews were conducted throughout Germany with two target groups: PWDs (N=27) and care professionals (N=13). This article focuses on nurses involved in the care of PWDs.

A qualitative research design was chosen to answer the research questions. Qualitative studies are widely used in nursing research and are particularly suitable for exploring the experience of coping with illness, promoting health, and accompanying processes of human existence. Grounded theory was chosen as the method for generating knowledge because of the central importance of the processes and associated interactions between PWDs and care professionals. The aim of this method is theory building (Boehm, 1994; Strauss & Corbin, 2010).

Ethical clearance was conducted by the ethics committee of the University of Witten/Herdecke (Application no. 22/2019). Compliance with the European General Data Protection Regulation (GDPR/DSGVO 2016) was ensured.

Data Collection

Between 2019 and 2021, 13 problem-centered interviews (Witzel, 2000) were conducted throughout Germany with care professionals working with PWDs (interview length, mean 39 min, mode 38 min). After a pretest, a guideline was developed in advance using the SPSS (collect, examine, sort, subsume) method (Helfferich, 2010). The interviews took place at the request of the interviewees either face to face (n=11) or, in the context of the SARS-CoV-2 pandemic, by telephone (n=2) (Ristau et al., 2021).

The study included nurses who had three years of professional training in health care and nursing (n = 5), geriatric care (n = 5), or curative education (n = 3). The professional experience of all interviewees varied from one to 35 years (mean 13.3, median 10). Seven interview participants were female, and six were male. Of the nurses, eight worked in outpatient settings, and four worked in inpatient settings. Another nurse worked in a medical care center. The nurses were asked about autonomy in the context of nursing assistance, among other things. They were also asked about conflicts and their effects on daily care.

Data Analysis

Data collection and evaluation were performed in an iterative process (Corbin & Strauss, 2015). MAXQDA was used as the software. Line-by-line, open coding of the interviews was conducted. The codes emerged inductively from the data material. The codes were reassembled in the axial coding phase by connecting and linking the categories. The coding paradigm was applied. In the last step, the main category was identified within the framework of selective coding, which was systematically and continuously developed from the data material (Strauss & Corbin, 2010).

RESULTS

When caring for PWDs, nurses may be confronted with wishes and needs that they cannot or do not want to realize. As a result, they experience a conflict between respect for autonomy and care. They critically evaluate these sequences. The evaluation process includes professional, ethical, and legal-organizational aspects. Nurses interact with PWDs themselves as well as with their colleagues to manage conflicts.

As a positive consequence, conflicts are resolved; as a negative consequence, care professionals refuse to fulfill the desired assistance. Ambivalences may also exist, characterized by tensions in further care (Figure 1).

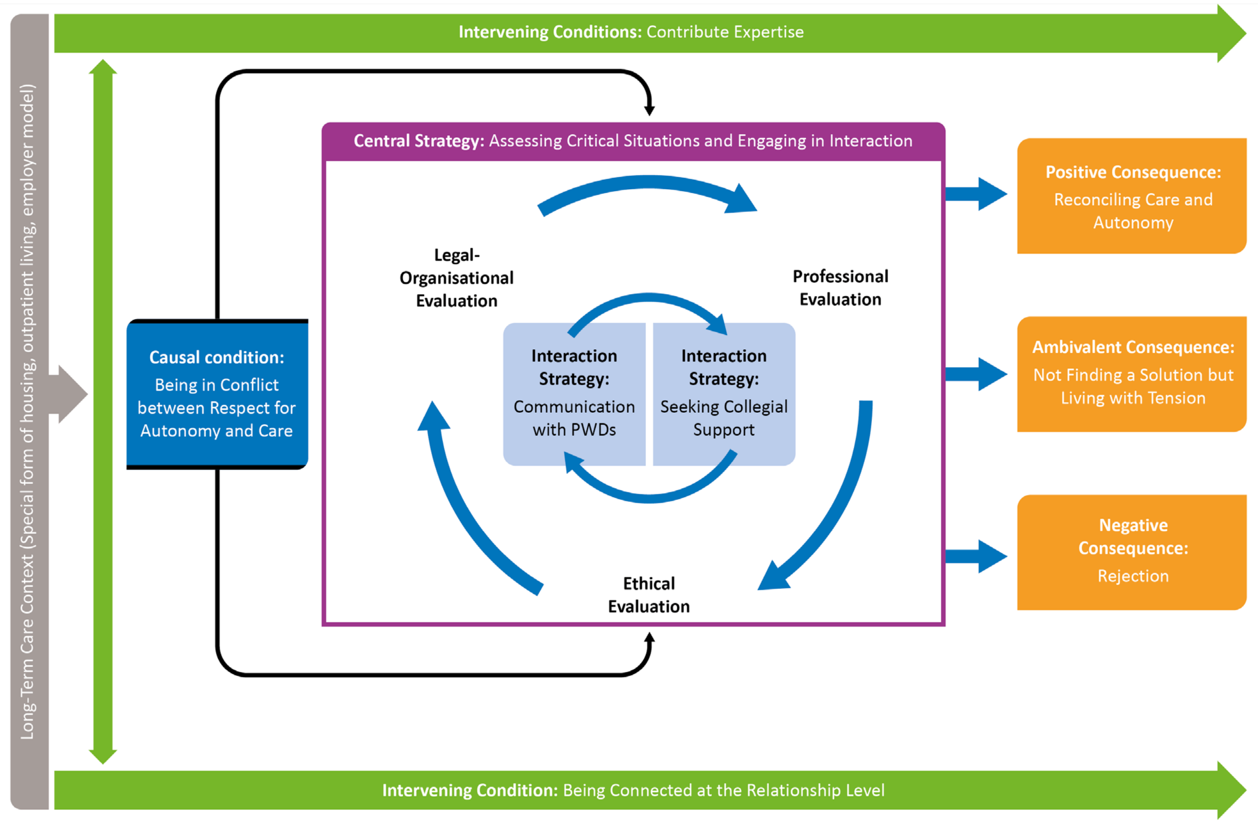

Figure-1. The evaluation process

Long-Term Care Context

The care of PWDs is provided in a long-term care setting. Long-term care can be provided in different contexts: inpatient, outpatient with care service, and outpatient with a personal budget in the employer model. All forms of care have in common that nurses and PWDs spend everyday life together over a long period of time, up to 24 h a day.

Causal Condition: Being in Conflict between Respect for Autonomy and Care

Conflicts can arise when clients' wishes for nursing assistance are incompatible with the professional understanding of the profession or how nurses perform the assistance. Nurses describe situations with a high potential for conflict in everyday life. Table-1 shows the reported critical sequences from which conflicts can arise in nursing care. For better illustration, the assessment modules used in Germany demonstrated some critical sequences in the care of PWD. The contents mentioned are taken from interviews with nurses.

The sequences shown have in common that PWDs can form or express their wishes within the framework of (nursing) care. At the same time, complete, sole realization is not possible due to their physical functional limitations.

Table-1. Critical Sequences From the Nurses’ Perspective

Mobility:

- Refusing to change position regularly in case of complete immobility, thus increasing the risk of pressure sores.
- Not wanting to use existing aids for changing position, e.g., patient lifter. Expect to be mobilized without aids.

Cognitive and communicative skills:

- Demanding moral support for private life decisions, e.g., dealing with one's own parents.
- Wanting to talk shit about colleagues.

Behavioral and psychological problems:

- Showing aggressive behavior (verbal, physical).
- Desiring a beer at 9:00 a.m.

Self-care:

- Neglecting a balanced, healthy diet and eating only fast food.
- Neglecting personal hygiene, neglecting outward appearance.
- Not wanting to brush their teeth.
- Not wanting to shower (for up to 6 months).
- Have strong body odor.
- Not having their hair washed.
- Wear dirty clothes.

Coping with and independently dealing with demands and stresses caused by illness or therapy:

- Desire simultaneous alcohol and medicine administration through PEG.
- Not wanting to take up further therapy, e.g., physiotherapy or occupational therapy.
- Abuse medication.
- Wanting help with cannabis use.
- Not provide physical relief for existing wounds on legs and feet.
- Want to drink cola if they have diabetes mellitus.
- Not wanting to comply with medical prescriptions.
    * Refuse compression stockings or adjust prescriptions (do not put them on before getting out of bed, but after showering).
    * Refusing to take prescribed medication
    * Refusing to follow a prescribed diet
    * Not adhering to the prescribed frequency of disposable catheterization and thereby causing medical complications.

Shaping everyday life and social contacts:

- Wanting help with tax returns (entering something into the tax return that is not true).
- Falsely expecting to do something together with the care professional, e.g., celebrate New Year's Eve
- Texting carers in their spare time asking for favors, e.g., running errands.

Extra-curricular activities:

- Neglecting social life, e.g., no longer going out, wanting to lie in bed all day.

Housekeeping:

- Neglecting household, having a messy/dirty flat / room

The sequences potentially harm PWDs' health or worsen their living situations if realized. Nurses are compensatory in nursing care, increasing independence and promoting health. They motivate PWDs to make self-determined decisions for their own lives. Decisions can be health-related, care-related, or private decisions. In this context, nurses have a professional self-image that includes a sense of responsibility for those who receive nursing care. They restrict the autonomy of people in need of care to protect them. Autonomy and care are balanced by care professionals.

> "I am a service provider and have to do my job as well as possible. On the other hand, I also have to do it as professionally as possible and make the most professionally correct decisions possible. And that also means I can't realize everything people with physical disabilities want. I also have a responsibility towards the people or the activities." (I14, item 48)

Being unable to realize wishes for nursing assistance is a dilemma for nurses. They move between autonomy and care and develop emerging conflict and solution strategies.

Intervention Conditions

Professional care is designed on both a professional and a relationship level. Both levels shape the nursing care of PWDs as intervening conditions. Assistance is required that necessitates nursing expertise (e.g., knowledge of disability patterns and associated phenomena; performance of activities in the context of self-care, such as personal hygiene, feeding, and medically prescribed therapy, such as administering medication). On the relationship level, a relationship characterized by closeness and trust develops over long intervals of nursing care (up to 24 hours a day over several decades).

Intervening Condition: Contribute Expertise

Professional knowledge comprises theoretical training content, professional experience in different settings, and professional experience. At the same time, a sound level of existing knowledge represents the potential to make professionally correct and good decisions. Nurses gain professional experience in different fields of activity. On the one hand, some nurses work in hospitals or care for older patients and then switch to the care setting for PWDs. Others spend their entire professional life caring for PWDs. A distinction can be made by years of professional experience. Depending on the amount of professional experience, existing or impending conflict situations are handled differently by nursing. Beginners in the setting may assess a situation more critically than competent nurses who have been in the field for longer and have been able to gain more professional experience in the area. At the beginning of a professional activity, nursing work with PWDs is described as ranging from demanding to overstraining. Rules, procedures, and limits are not sufficiently known, so one's scope of action as a nursing professional cannot be assessed. Experience is needed to ensure that PWDs want to be involved in nursing decisions, that proposed measures are rejected, or that wishes for nursing assistance are clearly expressed. One nurse commented on her entry as follows:

> Some don't want any help at all. So, you notice that it's more of a blocking, although you notice that they are getting worse. And, of course, you try to make yourself feel a bit better, but that is often very difficult. And sometimes it's also very demanding for you. Or even an excessive demand. When I started, it was definitely an excessive demand. (I39, item 18)

Textbook knowledge from training cannot be transferred unreflectively to PWDs. PWDs' partially altered body anatomy, expert knowledge, and high demand to make decisions differ from what is described in the textbook. What nurses have learned is questioned and adapted. Nurses' wealth of experience expands.

Intervening Condition: Being Connected at the Relationship Level

Due to long care intervals, nurses and PWDs get to know each other intensively and develop relationships.

> I think you build up some kind of relationship with someone, and there is a big difference between knowing them for three weeks and knowing them for many years. You have a different relationship. (I7, item 93)

Common interests are identified through small talk. Personal stories are exchanged. Nurses emphasize that they also reveal personal information about themselves, as this is the only way to build a relationship of mutual trust. Sympathy and antipathy decide with whom a special relationship develops.

> I think the chemistry just has to be right, and you have to find each other likable. (I1, pos. 16)

If there is sympathy, additional experiences, e.g., going on holiday together, are added to everyday life, positively influencing the relationship. Other activities include joint visits to discos, shopping trips, or excursions. Nurses reported having fun during their time together.

> I had a resident who grew very close to my heart. He passed away two or three years ago. That gave me a lift. We had a lot of fun; we went on two holidays. (I10, pos. 92)

If sympathy is lacking, nurses nevertheless carry out all necessary measures in a professional manner. However, communication may be more limited, and the atmosphere may be less relaxed.

Nurses reported that it is difficult to separate the professional and relational levels. There are interactions from one level to the other, which in turn influence nursing support as a whole. Sequences that have a high potential for conflict can exist on a professional level. Critical situations can be influenced and quickly alleviated if the relationship level is positive and trusting. However, critical situations can also exist at the relationship level and influence the professional level, e.g., when an idea or a measure is rejected due to a lack of sympathy.

Central Strategy: Assessing Critical Situations and Engaging in Interaction

The central strategy starts with a request for care assistance by people with physical disabilities. Nursing assesses whether a request for nursing assistance can be met by weighing up nursing-medical expertise, ethics, and legal-organizational aspects. A defined order of priority in the weighing process cannot be discerned. Rather, it seems that nursing considers all three assessment criteria and weighs them subjectively. The assessment process is complemented by interaction strategies with PWDs and colleagues to obtain further information.

Professional Evaluation

Nursing-medical expertise is formed from theoretical professional training and practical professional experience. Necessary nursing measures, as well as their positive effects, are known. The negative consequences of neglected care measures are also known, and nurses see it as their task to inform PWDs of these negative consequences.

> You have to show the consequences if, for example, he says he does not want to brush his teeth for six months. What are the consequences that this can simply also become life-threatening if there is inflammation in the mouth? (I4, item 85)

Taking care of recipients' wishes into account is essential to maintain or establishing autonomy within care interactions. When realizing wishes, nurses distinguish between basic and therapeutic care. Basic care activities such as body care are realized based on the wishes and habits of PWDs. Within treatment care, e.g., medically prescribed compression therapy or medication administration, nurses retain decision-making authority and place their professionalism and correct realization above the autonomy of PWDs.

> In personal and basic care, it is possible to do almost everything the person wants. With treatment care, of course, it's a different matter. Because people usually haven't learned that and have a clear idea of treatment care, but they can't realize it at all. (I14, item 4)

They cannot be realized if wishes are subject to risk, e.g., the risk of medical complications or interactions. Nurses refuse to take responsibility for conducting activities in this way.

Nursing distinguishes between ignorance of interactions or causal relationships and behavior that is consciously dangerous to oneself or others. In the first case, counseling is needed. In the case of a risk to oneself or others, nursing checks whether the person can make decisions for himself or herself or whether there are legal guardians who need to be informed.

Autonomy also plays a supporting role in professional assessment. Attempts are made to allow autonomy within nursing activities of self-care. In the case of activities within the framework of medical treatment, however, the focus is on professional and correct realization. Risks should be avoided, and the associated needs should be improved. Talks with the clients are seeking.

Ethical Evaluation

Ethics as a basis for action is of great importance for nursing. They move within the lifeworld of the persons concerned and cannot detach themselves from it. Rather, they are a part of it. Wishes for nursing assistants are also part of the subjective lifeworld. Questions about professional identity, limits of action, and values play a central role in professional activity. The interviewed nurses' values and understanding of their profession are reflected in their consideration of autonomy while providing nursing care.

> For me, autonomy and self-determination are the most important point. (I9, pos. 28)

Nurses evaluate the value of existing autonomy from an ethical perspective. As a result, nursing assistance is not imposed. Nursing assistance is provided individually with the participation of PWDs. The expressed wishes and needs have an orientation function. Care professionals can determine whether autonomy has been achieved by comparing the actual and target assistance.

In the second step, care professionals evaluate autonomy concerning care. Autonomy is opposed to a caring action in the sense of caring. The interviewed nurses are aware that PWDs can make decisions for themselves. Caring means understanding bad decisions on a human level but also accepting them. Nurses care and respect autonomy equally, without seeing themselves as superior.

> If someone is diabetic but insists on drinking their cola, I cannot force them, but I would explain that it just has health consequences. (I40, item 34)

Legal-organizational Evaluation

Care assistance must be more legally secure. First, the legal examination of a wish is carried out by care professionals. In this context, nursing speaks of responsibility for realization. Due to their existing knowledge as well as their involvement in medical therapy, they have a mandate that must be fulfilled responsibly and professionally. The legislative framework establishes a basic set of rules and protects care providers at the same time.

> If I make mistakes in the realization, do things that I know are not right, for which I could be legally prosecuted, I must, of course, see to it that I refrain from doing so as much as possible. (I14, item 10)

Nursing actions and decisions are also related to organizational conditions. In organizations, rules are in place that results from the corporate hierarchy and collegial interaction. These rules determine the collective behavior of the staff by defining uniform boundaries. The legal framework includes the documentation of deviations, consultations, and assistance provided or refused. This formal step legally safeguards nursing.

Nurses derive actions from the assessment. Thus, assessments and interactions are directly linked. They interact both with the persons concerned themselves and with colleagues. There is an alternating process between conversations, consultations, and collegial support. This, in turn, has an influence on the professional, ethical, and legal-organizational assessment of the individual nurse.

Interaction Strategy: Communication with PWDs

From the assessments, further strategies emerge that are of great importance for the ongoing assessment process. Ethics, professionalism, and law as overarching dimensions are complemented by concrete actions and thus flow into the assessment process. Part of the assessment and weighing process is to have conversations with PWDs. The discussions can have several objectives and take place on the basis of the objective and the current status (the phase between the first mention of the wish and the achievement of a solution). Goals can have an informational function or go as far as the desired behavioral change. Since nurses are initially confronted in the direct nursing process with demands for nursing assistance that are experienced as critical, they must initially decide which strategy is suitable for the specific situation. However, it can also be noted that strategies are subsequently discussed and reflected upon in a collegial exchange. (1) Desire to understand wishes and concerns and give feedback, (2) Professional counseling and discussion (3) Emotional-empathetic discussions (4)Desire to negotiate compromises and propose alternatives.

In long-term care, expressed wishes for nursing assistance, experienced as critical by nurses, can be communicated in different phases. A distinction can be made based on whether the wishes are communicated for the first time. In conversations, care professionals first want to understand the wishes and concerns. To do this, they ask specific questions to obtain information.

> Then, I ask again more often. I try to ask about ambiguities very precisely. This enables me to think of new solutions. (I8, item 26)

Information is used by nurses to gain more clarity about the situation and associated concerns. This enables nurses to assess whether it is ethical, legal-organizational, or professional concerns that they experience as critical. When nurses have developed an understanding, counseling or discussion follows if there are professional concerns. It is important that PWDs are willing to engage in a discussion about risks. First, nurses perceive whether there is an information deficit that can be remedied by professional information. From the previous questions, it can be deduced whether expressed wishes are meant seriously; whether knowledge about consequences, risks, and causal relationships is available; and whether the consequences are correctly assessed. Care professionals understand counseling as an individual process in which the needs of PWDs and the professional expertise of care professionals are brought into harmony with each other. For this purpose, requirements and wishes for nursing assistance are expressed, and possibilities of realization are enriched with professional expertise and thus individualized as much as possible. Counseling only takes place if the persons concerned want it. A reciprocal process of identifying needs or wants is created and enriched with nursing knowledge.

Professional discussions can be described as expert discussions. Nurses are professional actors and therefore have expert status. Due to their disability-specific traits and long-term experience with disability, PWDs are experts in their daily lives and have a specialized status. Conversations and discussions could lead to conflicts if no position supported by both sides can be found. This requires a different approach than a professional approach. In addition, the emotional-empathic approach is used in ethical conflicts.

If nurses do not have professional access to PWD or if the discussions do not lead to a solution, they conduct discussions on an emotional-empathic level. In this form of discussion, nurses do not argue exclusively on a professional level but on an emotional level and thus try to de-escalate impending conflicts on a professional level. These discussions are conducted with a trusted nurse. For this purpose, nurses on the team talk to each other to determine who can lead the talks. In addition, the atmosphere of the conversation is consciously influenced. It is easier to talk about difficult topics if it is relaxed and pleasant. Conversations are held with enough time and in a disturbance-free environment.

In the last step, nurses suggest compromises if realizing the desired nursing assistance is out of the question. They do this with caution, as interference in the autonomy of action of the persons concerned is to be avoided. No regulations in the sense of external determination are to be made. Compromises represent a balance between the desired assistance and its realization.

> There are always certain things that I simply suggest. Then, it is up to me to explain: Why is it important to do that? And to convince people of that. (I5, item 80)

The intensity of the talks varies. They take place repeatedly, if necessary. For care professionals and

PWDs, questions can also arise at a later point in the process, so that offers for later conversations are continuously maintained. In this way, processual action is created in addition to the original care process.

Interaction Strategy: Seeking Collegial Support

Supporting each other in the team is particularly important for nurses during decision-making and assessment. This makes the interviewed nurses feel less alone. Situations from practice are reflected upon, and solutions are developed together. On the basis of the evaluated interviews, it becomes clear that different collegial support options are chosen. A hierarchy can be identified here: (1) Conversations with trusted colleagues, (2) Talks with superiors, (3) Discussions with the whole team, under moderation if necessary, e.g., ethical case discussion or case discussion, (4) Discussions with the extended team (therapists, medical team).

If nurses feel overwhelmed, insecure, or uncomfortable, they first turn to direct colleagues who have more professional experience or have already experienced comparable situations. An exchange with team colleagues helps to reflect on one's impression of the subjectively experienced critical situation and to obtain an assessment of the situation from an outside person. Impressions, experiences, and tips are exchanged.

Nurses reported that they first talk to individual colleagues, which is easier than addressing a conflictual situation as a whole team. The focus is not only on how to deal with the situation but also on the situation of the person concerned. One nurse tells us about this:

> Most of the time, I first get someone on board with whom I also have a relationship, where I know that if I express it there now, it will definitely stay there. However, just to get another opinion, to ask: This is happening right now, and I feel uncomfortable with it. Is that how you see it? (I39, item 20)

Suppose the entrusted colleagues confirm the situation to be critical. In that case, the next higher level in the hierarchy is informed in the context of special inpatient forms of housing and outpatient care services. The situation is explained, and the next steps are discussed. Care professionals experience passing on information to superiors as a handing over of responsibility and relief. To obtain external help, e.g., in the form of ethical case discussions, the support of superiors and time resources are needed, which is why it is indispensable to inform the management level. Nurses report that there is a large amount of support from management, that they feel taken seriously, and that this is a relief for them.

In the context of the employer model, where PWDs are supervisors themselves, exchange with individual colleagues can occur when situations need to be reflected upon. Depending on the relationship level, the critical points can be clarified directly between the nurse and the PWD. Clarification is difficult because of the dual role of the supervisor and the person concerned.

Each critically experienced sequence has high significance from the perspective of an individual nurse and the whole team.

> And that's why it's always good to get the respective colleagues on board. And in fact, sometimes, to have a case discussion to look at things from all possible angles, to see: Am I missing something here? Am I getting lost in some situations? (I39, item 32)

Sometimes no solution is found within the team discussion that brings new insights for all. In this case, ethical case discussions can be helpful in examining the tension between autonomy and care from different perspectives of the actors involved. Since time resources must be available for organization and realization, ethical case discussions are rarely used and often as a last resort.

> Ethical case discussions help enormously to discover new perspectives in a reflective way. Our company has its own ethics team. They come into the teams and are neutral. Everyone talks. We use this for ourselves so that we become clear about what the problem is. (I8, item 18)

As a last resort, nurses talk to the extended team. Therapists and medical staff can be involved in an advisory capacity. In addition, a medical safeguard can be provided in the context of ordered therapies.

> When you lump them together, the one-sidedness of one professional group and the uniqueness of the other professional group can produce such wonderful things. (I7, pos. 81)

Before doctors or other actors are involved, all the strategies mentioned above should be used. Nurses want to hand over responsibility, so they are no longer prepared to bear it alone. If the PWD is informed about the communication, this can be interpreted as a breach of trust. Therefore, nurses think through this last step very intensively.

Continuous Consequences

Interaction strategies result in positive, ambivalent, or negative consequences.

Positive Consequence: Reconciling Care and Autonomy

As a positive consequence, nurses find alternatives or compromises that resolve the critical situation. When the previous interactions are successful, needs on the side of PWDs and concerns on the side of nurses could be reconciled. Nurses want to carry out the assistance they feel comfortable with, i.e., without a sense of doing something professionally, ethically, or legally wrong. Positive consequences can only occur if PWDs are genuinely interested in an alternative solution. They must be able to understand the concerns of the care professionals. In this case, joint, productive cooperation occurs. To give an example, consider the critical situation in which alcohol and medication were to be administered together via percutaneous endoscopic gastrostomy. First, medical advice was sought. Then, it was agreed that the medication could be administered first and with an interval of one hour for the alcoholic drink.

Nursing work is successful when causal relationships, expertise, and professional experience are used coherently to develop solutions for sequences experienced as critical. When the relationship level is characterized by trust, it is easier to develop compromise solutions. It is crucial that care professionals avoid the feeling of a "loss of autonomy" for PWDs. This can be achieved by continuously involving the people concerned in the process so that they do not talk about each other but with each other.

> It is important to know the alternatives. There is rarely only one possible solution. (I5, item 80)

Ambivalent Consequence: Not Finding a Solution but Living with Tension

Sometimes nurses do not succeed in resolving the conflict. This leads to ambivalent consequences. Consequently, PWDs can make bad decisions for their lives, and nurses cannot always avoid this. Acceptance of this condition is a major challenge. Nurses need to learn that they have no power to create a desired condition or realize what they think is best. Instead, it must be accepted that other people may have different ideas, even if it is difficult. It is challenging for nurses to continue to feel responsible even though they know they are not.

> It is unsatisfactory because you know it is not good and will cause a lot of damage to the client over time. But as long as the client is adequate enough to be aware of the consequences, this tension has to be endured. Then, there is no solution for the moment. That has to be endured. Perhaps there will be other solutions at a later time. (I9, item 54)

Even though the sequence experienced as critical is still experienced within nursing care, the deeper needs of PWDs are not recognized. Additionally, no more conversations initially take place to bring about a solution. Everyone is aware of the tensions. No change takes place negatively or positively. As a result, the condition is endured.

> For me, autonomy and self-determination are the most important point. (I9, pos. 28)

Negative Consequence: Rejection

On the one hand, care professionals can temporarily or generally refuse nursing care. On the other hand, PWDs may also reject certain care professionals and refuse the nursing assistance offered.

The fundamental question to be clarified is whether all team members experience the causal situation as critical or whether this is a subjective view of a single nurse. In the case of general problems and agreement among all nurses, nursing care may be discontinued, and another form of care must be sought for the PWD. In the context of the employer model, staff members quit when they no longer want to provide nursing care because they cannot be assigned to other clients.

Sometimes the refusal of care in the process is no longer primarily due to professional reasons. Rather, conflicts at the relationship level, which strengthen the process and create negative dynamics, can be a reason for refusal. The reasons are reciprocal: lack of trust, disregard for the autonomy of the people concerned, and a disparity in which the nurse symbolically places her views above the person with physical disabilities.

Occasionally, the caregiver does not reject the care but rather is rejected by the PWD. Here, too, it is mainly the relationship level that is the trigger. Lack of trust and sympathy are seen as reasons.

> In fact, behind the back of the person they don't want to have, they just talk shit about it and try to influence everything. And they also pass this on to the management: "So, I don't want him anymore. (I14, item 32)

In case of refusal, nurses try to make it possible for other nurses to take over the nursing care, for example, by changing the duty roster. This shows that conflicts can arise if causal conditions are not resolved. Nurses have a high level of professionalism, so they offer nursing care despite rejection if there is no solution.

DISCUSSION

This article shows how nurses deal with PWDs' wishes for nursing assistance that they cannot or do not want to realize.

Grypdonck (2005) distinguishes between two main streams of nursing science. On the one hand, Grypdonck speaks of an orientation towards the functioning of the human body and refers to this as medically oriented nursing science. According to this stream, nursing assistance is supportive in the establishment of function or the establishment of health. Participation in activities of daily living is thus the measure of potential quality of life. Grypdonck calls the second orientation "experience-oriented." This phenomenological approach aims to show that human reality is created by the meaning of a person himself or herself. Accordingly, illness is experienced by people themselves, which thus gives illness subjective meaning. Although Grypdonck relates her findings to the care of chronically ill people, the study's results show that PWDs also experience assistance from nurses who support them in conducting tasks of daily living. Applied to PWDs, this means that only the PWD experiences the situation himself or herself.

Thus, his or her wishes for nursing assistance have a natural, human meaning from his or her perspective. Wishes for nursing assistance that nurses do not realize can be evaluated as critical and cause discomfort, but from the perspective of PWDs, they can be taken for granted and have a specific reason. For example, the desire to administer alcohol and medication at the same time may serve to reduce pain. Hidden needs can come to the surface. The phenomenological approach points to another train of thought. Suppose a disability changes one's previous life and the meaning of life content. In that case, disability becomes a part of the individual's perspective. In her normative care theory, Grypdonck suggests that people with a chronic illness should succeed in positioning the illness at the margins of life or, better still, in elevating life above the illness. In this way, life becomes the center of attention, and it is possible to live with the illness. Transferred to PWDs, physical disability can also be placed on the margins, and life can be moved to the center. Through the existing basis of trust within the care process, nurses can enquire how exactly the specific wishes that cannot be realized come to be. By discovering PWDs' underlying needs, new nursing task areas can be opened up, which can be solved through nursing or medical approaches.

Nurses pursue the idea of a shared decision-making approach in nursing. The essential elements are in place: Information flows both ways within conversations, and professionalism is complemented by a personal, relaxed atmosphere. Our study shows that a genuine shared decision-making approach cannot be assumed. This would mean that nurses and PWDs make a joint decision not to perform an action. This essential element of shared decision-making could not be confirmed in the present study. In the end, it is often the nurse who decides, according to the paternalistic model (Simon et al., 2008; Solari et al., 2013), whether a wish is complied with, whereas at the beginning, based on the information model (Solari et al., 2013), the person concerned makes decisions for himself or herself that are to be realized by others. This phenomenon can also be called information asymmetry. According to this concept, care professionals provide information about different options and thus enable a decision between alternatives. The need for counseling exists because PWDs may have an information deficit (Behrens & Langer, 2020). The same applies in the opposite scenario: PWDs know more about their own lives and individual characteristics and need to share this information with nurses.

Complementary to the shared decision-making approach (Rahn et al., 2021), decision coaching can be offered in the sense of decision guidance. Here, the focus is on enabling and encouraging the persons concerned to make the right decision for themselves and their situations individually. In this coaching, PWDs can find arguments for and against nursing assistance and are accompanied by nurses. The needs underlying PWDs' wishes can be heard and appreciated. Ideally, decisions against assistance are made jointly and comprehensibly by both sides.

Internationally, the care of people with physical disabilities is becoming increasingly important. Requirements for inclusion and diversity should be implemented from a nursing science perspective. The results can enrich care and create awareness for justified action regarding requested nursing assistance. These are often seen as a wish to increase one's quality of life (Helbig et al., 2022) and offer the potential for discussion.

Quality and Limitations

The quality of the present study can be assessed based on the formulated criteria of procedural documentation, rule-governed ness, argumentative interpretation validation, proximity to the subject matter, and communicative validation (Mayring, 2015). According to Strauss and Corbin, the grounded theory methodology is convincing due to its clear proposal for data evaluation. The procedural steps were followed and documented with computer support. Relevant elements of the theory development were supported with citations to make the conclusions comprehensible. The results were continuously discussed among the authors. In addition, the research results were discussed among the faculty of the doctoral college of the University of Witten/Herdecke. In the last step, the results were presented to active nurses involved in the care of PWDs. The results have thus been validated communicatively.

The results offer initial insights into dealing with wishes for nursing assistance that nurses in the field of care for PWDs do not realize. The scope of the developed theory refers to nurses in different settings of long-term care who care for PWDs (small to medium scope). Due to the sampling, it can be assumed that the results offer realistic recommendations for action for inpatient and outpatient residential and support settings and the employer model. It is unclear how caregivers deal with the possible dilemma of implementing desired assistance against their will. Further research is needed here. The transferability of the results to other care and health systems is conceivable in principle. Wherever there are interactions between self-determined people with physical disabilities and care professionals, critical situations can arise. These can be assessed using the model presented. It should be critically noted that only 13 care professionals were interviewed. A sample of 25 care professionals would be desirable. Unfortunately, it was impossible to recruit more participants due to the coronavirus pandemic.

CONCLUSION

Nurses should always include professional, ethical, and legal-organizational criteria in the assessment of critical situations. The development and realization of decision coaching is a potential field of work for nurses. First, nurses can be trained on embedding autonomy and ethics within nursing assistance. This can prepare nurses to work with PWDs. Another advantage of training is that autonomy and self-determination can be reflected as a focus of one's nursing professionalism. Future research should address the experience of autonomy and care from the perspective of PWDs and create insights from the perspective of those affected.

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