

Shaping Quality of Life with Nursing Assistance. A Grounded Theory Approach to Nursing Care for People with Physical Disabilities and Interactions with Carers in Long-Term Care



RESEARCH

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ABSTRACT

Context: Although the number of people with physical disabilities who need nursing support is increasing, there is a lack of empirical knowledge about how they experience necessary care support. This knowledge is a prerequisite for enabling self-determination in the provision of care and for providing care based on needs and requirements. People with physical disabilities live in residential institutions and their own homes with the support of care services, and they are dependent on permanent nursing assistance.

Objective: This qualitative grounded theory study describes the importance that people with physical disabilities ascribe to the provision of care and how they organise their cooperation with caregivers.

Methods: Twenty-seven problem-centred interviews with people who had a permanent physical disability and a need for care were analysed using the grounded theory approach.

Findings: People with physical disabilities and a need for care want to enhance their quality of life with assistance. Quality of life is influenced by their wishes regarding assistance, acceptance of the physical disability, (previous) experience with assistance and the possibility of actively influencing the implementation of necessary assistance. The development and maintenance of a friendly relationship with professional carers represent a strategy for achieving quality of life.

Limitations: This study focuses on people with physical disabilities who receive care from a professional service. Questions about the influence on family carers remain unanswered.

Implications: For successful social participation, people with physical disabilities should be supported by nursing professionals to identify and express their priorities and needs.

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INTRODUCTION

Over 1 billion people worldwide live with a disability, and this number is increasing (World Health Organization, 2020). In Germany, approximately 7.9 million people live with a disability, 58% of whom have a physical disability (Destatis Statistisches Bundesamt, 2020). Physical disabilities can be congenital or acquired during the course of life, for example, through an accident or illness.

In Germany, disability is understood as part of human diversity (Charta der Vielfalt, 2020; Umsetzungsbegleitung Bundesteilhabegesetz, 2021). A possible need for nursing support can arise, for example, from a loss or partial loss or functional limitations of limbs, the spine or the trunk, as well as from paraplegia or cerebral diseases and associated impairments of independence (Helbig et al., 2020).

Caring activities influence the perceived quality of life. For example, carers who are aware of the individual routines of people with physical disabilities are more popular than carers who are unaware of them. Little communication and the feeling of being treated like a child, on the other hand, lead to discomfort (Winkler et al., 2011).

To increase the quality of life by satisfying needs, a suitable place of residence should be available (Winkler et al., 2015). In Germany, people with disabilities live in different places and with different forms of assistance (Helbig et al., 2020). Possibilities include living in private households with the support of outpatient care services; the so-called employer model, in which people with physical disabilities hire employees in a self-organised way and act as their employers; and living in inpatient facilities (Bundesregierung, 2016). Independence, well-being and social inclusion are overriding goals in the area of housing and associated support services for people with disabilities (Seekins et al., 2011; Winkler et al., 2011). According to the UN Convention on the Rights of Persons with Disabilities, an independent lifestyle for people with disabilities can be achieved through a housing option that is oriented towards their own needs and provides free choice of where to live and barrier-free access to individually required support services. In combination with the removal of existing barriers, full effective and equal participation in society for persons with disabilities can be achieved (Beauftragter der Bundesregierung für die Belange von Menschen mit Behinderung, 2017). A study conducted by Winkler et al. (2015) found that living in an inpatient care facility under outpatient conditions improved decision-making possibilities regarding meals, bedtimes and leisure activities.

Being dependent on permanent nursing support is part of the environment of people with physical disabilities and directly interacts with nursing support. Without these

insights, it is difficult to ensure high-quality assistance provision oriented to the individual needs of persons with physical disabilities (Behrens et al., 2012; Büker, 2014; Khalifa, 1993). As a result, there is a lack of fundamental understanding of empirical findings that address elements of autonomy in relation to the permanent need for care (Schoeller et al., 2018) and simultaneously place the perspective of persons with a physical disability at the centre of nursing interaction (Helbig et al., 2020). In particular, there is a lack of knowledge and description of the basic experience of the use of nursing assistance, the subjective attribution of meaning to nursing measures and interaction with professional carers. A scoping review we conducted with the aim of identifying theories and models of care for people with disabilities revealed that the literature is predominantly concerned with transitions between different forms of housing and with family carers and counselling in relation to improving independence (Helbig et al., 2020).

Against this background, this article answers the following research question: what meaning do people with a physical disability attribute to nursing assistance, and how do they shape their cooperation with staff? By answering the research question, we contribute to theory building to improve the understanding of disability and care from the perspective of people with a physical disability.

MATERIALS AND METHODS

A qualitative approach was chosen for this study. By focusing on interactions and the goal of developing theory that is inductively derived from the phenomenon, Corbin and Strauss's (2015, Strauss & Corbin, 2010) grounded theory approach was chosen. Symbolic interactionism, as the scientific theoretical basis of grounded theory methodology, considers focused interaction processes.

ETHICS AND DATA PROTECTION

The Ethics Committee of Witten/Herdecke University approved the study design (application no. 22/2019). Prior to the interviews, the interview participants received an information letter about the objective of the study as well as a written consent form. A clear commitment to honesty, equality and mutual respect was made at the beginning of the interviews. The data protection of the participants was ensured through the application of the European General Data Protection Regulation (DGSVO 2016).

RECRUITMENT, SAMPLING STRATEGY AND DATA COLLECTION

Participants were recruited via e-mails to outpatient care services and inpatient facilities that listed a focus of

care for people with physical disabilities on their website. Interest groups that advocate for the needs of people with physical disabilities were contacted. Furthermore, calls for interview participation were made in Facebook groups. The basic ideas of theoretical sampling were taken into account in the case selection (Corbin & Strauss, 2015; Strauss & Corbin, 2010). The search for participants covered all of Germany.

People between 18 and 60 years of age with a permanent physical disability and a concurrent need for care provided by professional carers were included. Physical disabilities could either be congenital or acquired in the course of life. If the disabilities were the result of an accident or injury, then for ethical reasons the event should have occurred at least five years previously to ensure as much as possible that there was no acute trauma among the participants. People with a physical disability who also had a learning disability or legal guardianship were excluded.

To maximize the sample variations in people's ways of living with a physical disability, participants from inpatient and outpatient residential settings (i.e., community-dwelling) were recruited. In Germany, inpatient facilities are places where people with a need for nursing assistance are cared for. Several people live together and are cared for by a pool of staff 24 hours a day. They are long-term care facilities. The use of outpatient care services with different care models was present. In Germany, it is possible to live in one's own home with an outpatient care service. People with physical disabilities can also employ staff themselves and organise the staffing themselves (employer model). Through theoretical sampling, we deliberately selected broadly contrasting cases to be able to determine and analyse the differences based on the data.

Following a scoping review on concepts, theories and models of nursing care for adults with physical disabilities (Helbig et al., 2020), a guideline for conducting problem-centred interviews (Witzel, 2000a, 2000b) was developed. The guideline was tested and evaluated in advance by means of a pretest and was continuously developed in the course of the study based on the iterative procedure of grounded theory. Within the interviews, mainly open, narrative-generating questions were used. Central themes were the importance of self-determination in relation to care support services, experiences of different places of residence, existing needs and the implementation of assistance.

A total of 27 interviews were conducted. Data saturation was achieved. Due to the coronavirus pandemic and the associated contact restrictions during the study period, telephone interviews (Ristau et al., 2021) took place in addition to face-to-face interviews.

The interview length varied between 20 and 120 minutes (mean 55 minutes).

In the course of the research process, sampling became increasingly selective in line with data analysis and evolving theoretical considerations (Corbin & Strauss, 2015; Strauss & Corbin, 2010). For example, a deliberate search was made for transitional experiences between inpatient and outpatient living contexts as well as for participants who were living alone for the first time and needed care support.

DATA ANALYSIS

The interviews were recorded and transcribed, and computer-aided analysis was conducted with MAXQDA software (version 2020). The data were openly coded line by line, organised and reduced through the formation of superordinate categories (Corbin & Strauss, 2015; Strauss & Corbin, 2010). The formation of categories was accomplished by grouping similar codes into overarching concepts (Boehm, 1994; Corbin & Strauss, 2015). The categories were then systematically differentiated in terms of their characteristics and dimensions. In the axial coding phase, the categories were related to each other by identifying causes, strategies, intervening conditions and consequences (Strauss & Corbin, 2010). In the final step, the elaborated concepts were selectively arranged around the main category. Following the ideas of grounded theory, constant comparisons of the phenomena were conducted, and generative questions were addressed to the data material to increase theoretical sensitivity (Corbin & Strauss, 2015; Strauss & Corbin, 2010). Data analysis and data collection were carried out in parallel.

RESULTS

Table 1 presents a detailed overview of the descriptive characteristics of the study participants. The mean age of the study participants is 42 years (range 21–60 years). Fifteen participants were male, 12 female. Twenty-two participants lived in an outpatient setting and received nursing assistance from a nursing service. Four of the 22 participants used the employer model. Five other participants lived in residential care. Nine participants had already gained experience with different forms of housing and assistance. The participants had a high need for care (Care level 5) as well as a high degree of disability (100).

Of particular importance for our sampling was the causal physical disability that led to a need for care support among the study participants (see *Table 2*). In Germany, the need for care is determined on the basis of the degree of existing independence and is divided into five degrees. Grade 5 describes the highest limited independence

CRITERION	EXPRESSION	VALUE
Age	Mean value	42
	Range	21–60
Self-identified sex	Male	15
	Female	12
	Diverse	0
Type of housing	Outpatient living environment	22
	Which employer model	4
	Inpatient living environment	5
Experience in other forms of housing	Number of participants	9
Degree of disability	Mean value	99.6
	Modal value	100
Care level	Mean value	4.04
	Modal value	5

Table 1 Sampling of the study, own representation.

CAUSAL PHYSICAL DISABILITY FOR CARE NEEDS	ACQUIRED (A) OR CONGENITAL (C)	NUMBER OF PARTICIPANTS
Spastic paralysis	c	7
Spinal paraplegia	a	6
Muscular dystrophy	a	6
Multiple sclerosis	a	2
Poliomyelitis	c	2
Neurological disease, unspecified	a	2
Stroke	a	1
Dysmelia	c	1
	a = 17 c = 10	27

Table 2 Sampling of the study-causal physical disability, own representation.

(Medizinischer Dienst der Krankenversicherung (MDK), 2021). An existing disability is defined by degrees of 10, where 100 describes the highest and 20 the lowest degree of disability (Beauftragter der Bundesregierung für die Belange von Menschen mit Behinderungen, 2021).

The main category identified in this study was the phenomenon of shaping quality of life with assistance. Quality of life is determined by an evaluation of the assistance received in comparison with one's own wishes and requirements and can have a high or a low level. Satisfaction, feeling good and a relaxed atmosphere are central characteristics of positively assessed consequences. A negative evaluation of the assistance received can result in the negative consequence of feeling uncomfortable, which can be expressed by low satisfaction and a tense atmosphere. The person with a physical disability must decide at this point whether to

act or to accept the current situation. There are three possible interventions: (1) changing the context, (2) reflecting and, if necessary, adapting the intervening conditions and (3) remaining uncomfortable.

In the analysis, two interaction and action strategies were identified with regard to how people with physical disabilities influence their quality of life with assistance. The first is the acceptance of nursing assistance. The second is the development and maintenance of a friendly relationship with carers, a strategy that describes the relationship quality of interactions. Action and interaction strategies are decisively influenced by four intervening conditions: one's own wishes regarding assistance, acceptance of the physical disability, (previous) experience with assistance and influencing the implementation of nursing assistance. **Figure 1** shows these main findings of the analyses in a detailed model.

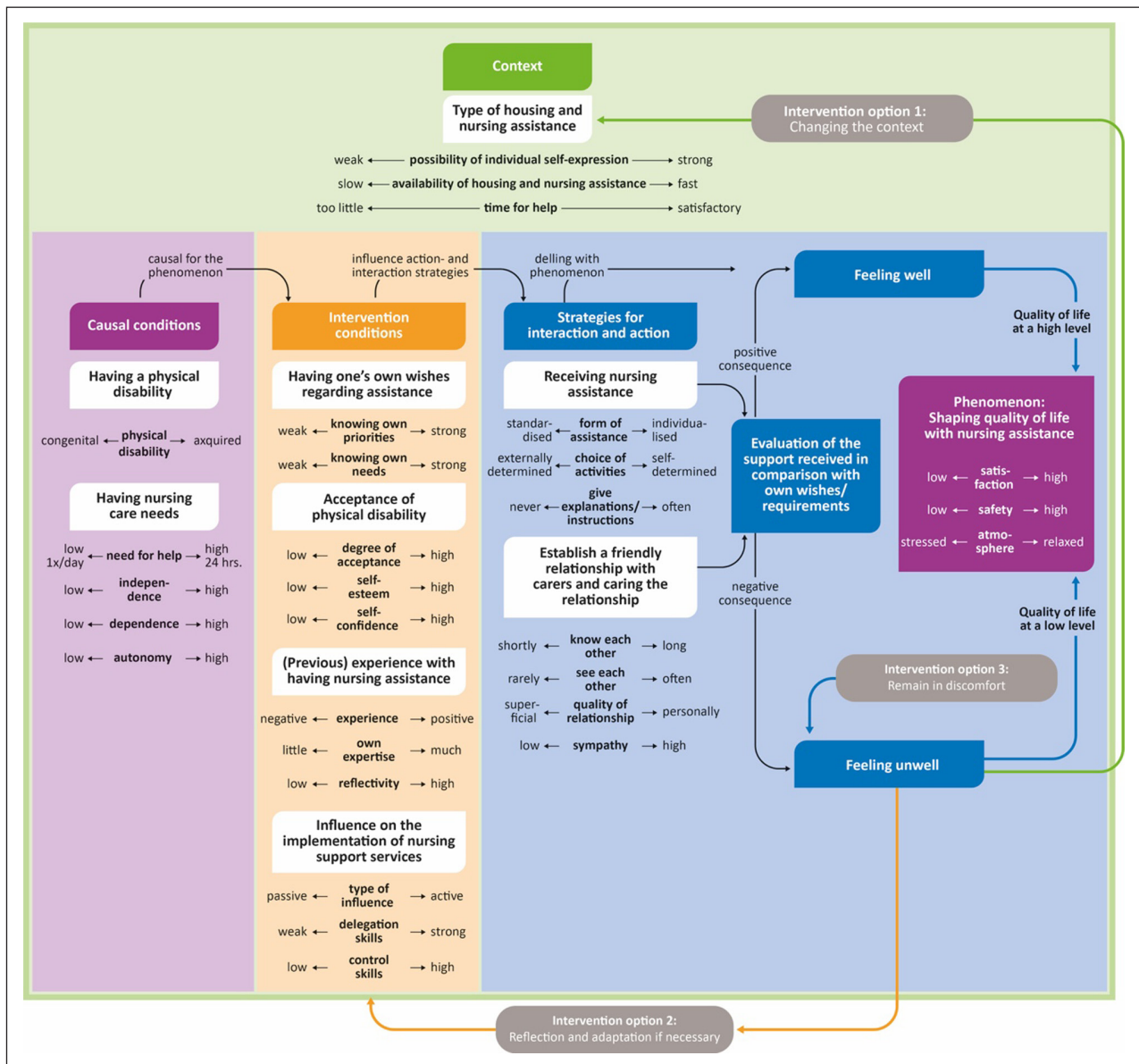


Figure 1 Model of care for people with physical disabilities. Own representation.

DESCRIPTION OF QUALITY OF LIFE

People with a physical disability and a need for care want a high quality of life and want to be able to influence it. They want to feel comfortable in and with their individual lives. In the interviews, well-being was expressed, for example, by the importance of a high level of satisfaction with the assistance provided or a relaxed atmosphere during care-related assistance, which leads to a feeling of relaxation and security.

It's about harmony, about contentment, about, yes, a sense of security perhaps. At home I want to feel safe and content and not fight against anything. I always exaggerate that a little. And, yes, harmony and coming down and relaxing from everyday life and so on are, I think, very, very important points there. (IP15)

For people with physical disabilities, influencing quality of life with assistance represents the achievement of a desired standard for one's own life. This standard depends on one's own definition of a beautifully designed life as well as on the provision of assistance by carers according to one's own wishes and requirements.

You know you can rely on it, and that's when you can arrange your life to be as nice as possible. (IP20)

The consideration of wishes, for example, regarding personal hygiene, is important for well-being. Here, individual preferences must be identified by carers to increase well-being or to prevent discomfort. Identifying and perceiving one's own priorities is an intervening and decisive success factor for the correct and thus self-determined provision of assistance. The more that needs

and individual steps can be explained in detail, the more precise the provision of help by carers can be. Security, which can be achieved through consistency and routines, among other things, is created.

Um, consistency, so that's at the top again; security, and I get that, I get a secure feeling from the fact that it's consistent and, as far as possible, uh, as far as care is concerned, it's always the same, because I (...) know how it goes (...) it works well, and the whole thing then also means that I don't (...) have any energy or that I don't worry about it. (IP15)

To classify the existing quality of life, an evaluation process occurs regarding the care assistance received. A person with a physical disability evaluates the assistance provided in comparison with his or her own wishes and requirements. If the requirements and the assistance received are close to each other, a feeling of well-being arises and the quality of life is described as high. If there are discrepancies within the match, a feeling of discomfort arises.

On this basis, three intervention possibilities can be observed. The first possibility is to change the context. The context involves the type of housing and form of assistance and can limit individual development due to structural circumstances (living space, available time for assistance). As a result, a move or a change in the form of assistance may be sought. The second possibility involves reflection on and, if necessary, adaptation of the intervening conditions. Quality of life can be adjusted by reflecting on one's own wishes regarding assistance, dealing with acceptance of the physical disability, consciously reflecting on experiences and assistance and actively influencing the direct implementation of nursing assistance. The third intervention option is a passive one: people with physical disabilities can fail to influence their quality of life and remain in a state of discomfort without any intention to act.

CAUSAL CONDITION: HAVING A PHYSICAL DISABILITY AND A NEED FOR NURSING ASSISTANCE

As a causative condition, a physical disability can lead to a permanent need for care assistance. The accompanying need is not described by people with a physical disability as care but as help. The term help, in contrast to care, is not associated with the respondents being old and ill and contributes to the provision of the necessary support.

I feel better when I can say I need help than when I say I need care, just from the designation and from a basic classification that one always

associates care, to some extent, with being old and ill. Help, but not. (IP6)

The extent of necessary assistance depends on the degree of independence due to the existing physical disability. If there is a high need for help and a high intensity of nursing assistance (up to 24 hours a day), dependence on the staff may be perceived as high and the individual's own independence and self-determination as low. In this situation, carers must provide much assistance.

I am still 100% dependent on the person's help. So, I feel, as far as that's concerned, dependent. Completely. (IP6)

With a low need for help and few necessary nursing aids, most activities and necessities can be carried out independently. In this case, perceived dependence on staff is low and self-determination is perceived as high.

INTERVENING CONDITIONS

Four intervening conditions were identified in this study: having one's own wishes regarding assistance, acceptance of physical disability, having (previous) experience with assistance and influence on the implementation of nursing assistance.

The extent of the dimensional characteristics influences the directions of the interaction and action strategies. People who have their own wishes regarding assistance are aware of their own priorities and needs, which can be clearly communicated accordingly. This contributes to the fulfilment of wishes and needs. In some cases, people with physical disabilities write down essential schedule-related information for caregivers. These notes can be read by the caregivers to obtain essential information and clarity about the necessary procedures and the specifics.

I have such an information sheet. (...). I just write on it what is important to me, and everyone who starts with me gets this sheet. (IP22)

If one's own priorities and needs with regard to necessary assistance are not known, ambiguities can arise within implementation by carers, who are unable to correctly address needs and implement wishes. A lack of clarity of one's own priorities and needs has a negative influence on delegation competence. Unclear delegations to carers, who in turn implement wishes imprecisely, can be a result. The immediate consequence can be discomfort due to unconsidered needs.

Maybe I didn't communicate that in the beginning that I would like to have that. (IP2)

In addition, the acceptance of physical disability plays an essential role in well-being. Our analysis showed that it is better for the well-being of people with a physical disability if they can accept the accompanying limitations. This makes it possible to assess existing bodily functions as well as the existing need for help and to accept help. Part of the acceptance process for people with a congenital physical disability is detachment from parental care.

I had to learn that because I, like probably many other people, first lived in my parental home and practised that with my parents. But it's something completely different when you're cared for by your own parents, and at some point you don't want to do that any more, right? (IP24)

For people with an acquired physical disability, coming to terms with their earlier life is at the forefront of the acceptance process.

A person who only 'acquires' his or her disability in the course of his or her life will experience this loss, which begins immediately, as very serious. Things that one didn't even think about before now have to be articulated to the environment, usually even justified. (IP17)

A high level of self-awareness and self-confidence leads to an increase in the delegation competence described above.

I deal with this right from the start, in plain language. Then I say that nutrition is your part. And if you want to drink and eat, coffee is free here. (...). I say that straight away. (IP22)

People with a physical disability and a low level of self-awareness and self-confidence do not dare to express their needs clearly and thus deliberately refrain from carrying out activities.

If I don't stand up for myself with self-confidence, which many people don't do (...) then it's difficult in care. (IP15)

The goal of acceptance is to see the disability not as a deficit but as a strength. This state of complete acceptance forms the basis for freedom in terms of quality of life.

I have always used my disability as a calling card for the fact that I have a disability, that it makes me stronger in many areas and not weaker. I tend

to see my disability as a strength. This makes me more attentive to other things, so to speak. (IP27)

Previous experiences with support also shape interactions with carers. Depending on positive or negative experiences with regard to personal support, experiences can be used as an opportunity for learning. By consciously reflecting on these experiences, continuous inner development takes place so that repeated mistakes are not made or alternative approaches are developed.

Yes, you learn that quite simply through experience. (...). Quite simply because I now have more experience over the years and have also learned better to formulate my needs and to pay attention to what is important to me and not to please a counterpart. (IP23)

A low level of reflection contributes to a situation in which existing discomfort cannot be perceived and thus cannot be actively changed.

I have been on a ventilator for almost 37 years, and I have dealt with the subject from the beginning, both privately and professionally, because I have also worked in this area. So from that point of view, you definitely can't tell me that I don't know. (IP21)

In contrast, a lack of knowledge about one's own disability or the associated care measures has a negative influence on the perception of one's own needs and their satisfaction.

Whether it is possible to actively influence the implementation of nursing assistance also shapes the interaction with carers. When delegation competence is strong, it is also very detailed. This competence contributes to clarity for the staff in relation to the implementation of assistance.

You inevitably learn to express your needs very clearly (...). There are a thousand such details in a day. (IP24)

If assistance is experienced as passive, people with physical disabilities often feel at the mercy of others and are unable to influence the implementation of nursing assistance. With active influence, on the other hand, a person with a physical disability proactively shapes and influences the provision of care. This clarifies the process responsibility of people with a physical disability within the implementation of self-determined assistance. On the one hand, people with physical disabilities share responsibility for the implementation of care; on the other hand, they have a direct possibility to control the provision of assistance.

CONTEXT: TYPE OF HOUSING AND ASSISTANCE

Identifying the appropriate form of assistance and the appropriate place of residence is a necessary prerequisite for people with a physical disability and an accompanying need for assistance to live a self-determined life to the greatest extent possible according to their own ideas.

Two types of residence can be derived and differentiated by corresponding subtypes and forms of assistance: (1) living in inpatient facilities for integrated assistance and (2) living in an individual's own domesticity with a care service or employer model.

No type of housing option and no form of assistance is generally better than another. Rather, each housing option and the accompanying forms of assistance are characterised by advantages and disadvantages. The weighing is done by the person with physical disabilities by taking into account individually set minimum requirements, expectations and wishes. The person's own ideas about life should match the structural possibilities of the form of housing and assistance so that individual development of the personality can take place.

Yes, like every other person, I can live a self-determined life from morning to night, just as I imagine it, depending on how it is necessary; I can work, I can be with other people, but also I can have leisure time and so on, I can share all the areas of life that make up a fulfilled life, participate, so to speak, both in the house and outside the house. (IP24)

Inpatient residential locations are more readily available than outpatient forms of housing as the approval process for the former is uncomplicated due to lower costs compared to other forms of housing. This context is characterised by a high level of care security up to 24 hours a day and a complete package of barrier-free living space and nursing assistance, which is provided by a pool of employees in a three-shift system.

Barrier-free living space is needed for outpatient assistance, which is mostly not available in older flats and is only gradually being standardised in new buildings. In addition, approvals must be obtained from the various cost units (e.g., integration assistance, long-term care insurance, social assistance). Given the necessity of 1:1 care in an outpatient setting, the security of service provision is a fragile construct due to staff absences. There is more flexibility in this form of housing due to higher individual time quotas.

However, there are high hurdles to living outside of these institutions. You need a barrier-free flat where assistants also have a place to retreat. You need an assistance team. You need a commitment

from a funding agency to cover the costs. And you need all of this at exactly the same time. If even one parameter doesn't work out, the whole house of cards collapses. (IP17)

If the structural conditions of the form of housing and assistance are no longer sufficient for individual development, alternatives to accommodation or care can be sought. Increasing dissatisfaction and the growing desire for the individual development of one's own life can generate pressure to act, which can lead to concrete and proactive steps to obtain a new form of housing.

Again and again it spins in my head: I want it to be like this and like that, this way and that way it will be. You go round and round in circles. And that's what I wanted at some point. You become dissatisfied. Something builds up inside you, and that's hard. And it usually erupts in unfavourable situations. (...). And I just didn't want that any more, and that's why I said, 'I have to get out.' (IP29)

An interview participant reported that the framework conditions for assistance had continuously deteriorated over time.

So for 33 years I was in (name of provider) in (name of place). (...) it was all wonderful at first, I didn't want to leave at all. But the last few years it got worse and worse (...) far too few staff, they had too little time, and I always wanted to do more. And then I got more and more upset. (...) And then I said to myself, either I have to be upset all my life (...) or I have to change something. (IP18)

The available time resources of the staff vary greatly within the structure of residential settings. In the inpatient setting, the staff have limited time resources to take individual wishes into account. This means that it is difficult to meet individual needs in terms of time. In outpatient contexts, care may be provided at a 1:1 ratio over 24 hours. Time resources influence the individual implementation of nursing assistance.

It is easy to reel off a care programme, let's say, a morning routine or something like that, but to always be aware of the person, where they are today, how are they today, can I do it today like yesterday and what can they still do themselves, i.e. where can they support me. That all takes time, which is important, but which is often not granted or given in everyday nursing care. (IP15)

ACTION AND INTERACTIONAL STRATEGIES

In our study, two strategies were identified. Action and interactional strategies describe the ways people with a physical disability deal with their self-influenced quality of life.

Receiving nursing assistance

The care support provided due to a physical disability is diverse and can vary from basic care activities, domestic support and treatment care to recreational support and accompanying everyday support. Due to individual physical disabilities, the desire for nursing support is also individualised, so standardised implementation 'according to the textbook' (IP21) is contrary to person-specific care.

External determination can be expressed in the form of a lack of decisions and a lack of involvement in the type and form of the necessary assistance. In this case, the carers make the decisions alone, without involving the person. A consequence is also that wishes are not taken into account in the implementation.

Then someone else came every day, and they didn't know you at all. Then it went even faster. Then they put your shirt on and you're back in your bed, right? But then it was always head over heels, quick, quick, quick. Then you still wanted to get creamed, but there was no time for it. (IP20)

There are also positive effects when people with physical disabilities can transfer some responsibility to the carer. By transferring responsibility, the person with a physical disability is relieved of decision-making as well as strength-consuming explanations.

It is important to me that people want to work on their own responsibility, yes? So it's no use to me if someone doesn't have common sense or something. So you need a certain independence to act here. (IP24)

Deciding for oneself about the implementation of nursing assistance means deciding for oneself about the type and implementation. Due to their experiences over a long period of time, people with physical disabilities are experts on their own individual situation.

I am the decider, because I am able to say that I can best assess what I, or my body, can do and what is not possible. (IP6)

Activities, wishes regarding the activities to be performed, as well as wishes regarding the implementation of these activities are communicated concretely.

I can say myself how I would like things to be done, how I should be washed or that I want to climb into the wheelchair myself and not be lifted. I can decide all that freely myself. (IP12)

Within the framework of codetermination, explanations are given about the type and implementation of nursing assistance for people with physical disabilities. This should create both understanding and awareness that actions are automatically carried out as required by the individual situation.

I have very short arms, and that's why I have to make sure that I can reach the things I need to reach. I also explain that to the helpers, for example, when I say, put a bottle of water down for me in the evening, that it can't be half a metre away because my arm is only thirty centimetres long, right? So this sensibility for it, you have to awaken it in people every time. (IP24)

Demanding care assistance or carrying it out oneself also ensures self-determination and thus leaves the responsibility for their own life with the people with physical disabilities themselves.

When it comes to care or any kind of support, I think it's important that it still takes into account the highest possible degree of self-determination. Because if I have to support someone or if someone needs care, then there are certain things that they can perhaps still do themselves in the situation. (IP15)

This also applies to all activities that can be carried out independently with existing bodily functions.

Um, and not to have too much taken away from me. That is, I always say, I'll do this and that, and then you do this and that, please. And that is, that is especially noticeable with people who are not often with me. (IP14)

Thoughtful or attentive behaviour on the part of carers can have a positive effect on interactions. The prerequisite is that the person with physical disabilities explicitly wants this and sees the non-assigned assumption of activities as positive.

Well, when I have the assistant sitting next to me and she sees that I can't reach the water glass and then brings it over to me, or simply noticing when help is needed without having to tell a novel. Of course, you have to know each other to do that, right? (IP26)

Establish and maintain a friendly relationship with carers

Due to a high demand for nursing and other supportive assistance, nursing assistance is provided over many points in time or over many hours a day. In this way, people with physical disabilities form the basis of a personal relationship with themselves as recipients of care and the carers as providers of care.

Well, it plays a role in that if you see the people more often, you actually build up a personal relationship with them. So I care about them in that sense, they are not anonymous, and through that I naturally also develop an interest in the people, who definitely also think about me, how I am doing. (IP6)

The relationship with carers is a mixture of friendship and working relationships. The personal relationship involves closeness, humanity and taking the same perspective, which means respecting each other completely. The relationship is therefore not one-sided in the sense of a robot that carries out orders. Rather, it emerges from the personal involvement of the carers and fun with each other.

They are not machines, thank God, but people. And what I need, as someone who needs so much help throughout the day, I have to be able to empathise with the other person, right? (IP24)

The greater the sympathy between the person with a physical disability and the carer, the more personal the quality of the relationship. One interview participant reported that when sympathy is high, valuable conversations and shared laughter have a positive influence on the assistance provided. If there is a lack of sympathy, in contrast, only the most necessary things are discussed. If people are sympathetic to each other, misunderstandings are solved more quickly or the provision of help itself is more individualised and results in greater satisfaction. Trust between the person with a physical disability and the carer has a great influence on the relationship as well as the implementation of necessary assistance. Trust is developed over time.

Impersonal, distant relationships with caregivers appear superficial at the relationship level. People with physical disabilities who do not manage to build a personal relationship state a lack of trust in the staff.

Because if someone says, 'I know what is good for me, for you,' then I have to explain to them that they don't know that. Because I can only be the one who knows, and I have had such conversations quite often. And they know how to do it, they claim,

and it is very difficult with people like that who are not open to the self-determined living model, I have a hard time with that. (IP26)

Carers' belief that they know what is good for others creates a sense of unease, which results in pressure to justify oneself and the idea of self-determination *ad absurdum*. A lack of interaction at eye level leads to a person with physical disabilities feeling that he or she is not taken seriously. An unequal perspective can be created by 'cuddling' (IP19), for example.

It is often the case that most people pamper me and then it doesn't work out, like, 'You poor disabled person' (laughs), I do everything for you. And that doesn't work at all. (IP19)

DISCUSSION

The results of our study show that the importance of caring assistance for people with physical disabilities is directly related to individual lifestyle and a high quality of life. Subjective quality of life is positively influenced not only by the quality of personal relationships and a high level of sympathy with carers but also by a suitable structural framework for housing and assistance.

A study published at the beginning of 2021 addresses the challenges that people with a spinal cord injury experience in the transition to their own home (Hall et al., 2021). In particular, this study finds that the planning of the new life is a great challenge for these people. There is a high need for information on how to deal with the disability and the associated health effects, as well as the consideration of individual needs (Hall et al., 2021). Our study design stipulated that physical disability should have been present for at least five years at the time of the interview. The interview participants had expert status as they were in a phase of life in which physical disability had already been incorporated into their identity.

It is known from the field of inpatient care for the elderly that the relationship between care recipients and caregivers exists on a personal level. The competence of carers to understand the needs of care recipients is important for the well-being of the latter (Nakrem et al., 2011). The well-being of residents is thus interdependent with the caregiver-resident relationship (Haugan et al., 2021). Our study also shows that a friendly relationship level is essential for the successful implementation of nursing assistance.

Another study shows that carers find it difficult to implement wishes in favour of the self-determination of the person concerned, although they are aware of the importance of autonomy (Whitler, 1996). Whitler attributes this to an insufficient understanding of

conceptual content, such as consent and decision-making capacity. Consideration of these two concepts is crucial to the emergence of autonomy (Whitler, 1996). If carers do not respect and comply with the wishes of the people concerned, this leads to disturbances at the relationship level.

The primary goal of nursing support services should therefore be to remind people with a physical disability of their own capacity to act, to develop this capacity and to continuously expand it. This can be accomplished through our identified intervening conditions by identifying concrete ideas about support services and working on acceptance of physical disability. People with a physical disability should be consciously empowered to reflect on and learn from their experiences with support services. In the social sciences, agency is understood as the capacity of a person to act intentionally and effectively on him/herself or the environment, even in the face of limiting conditions (Raithelhuber, 2018). Within development policy discussions, it is assumed that people who experience their actions as self-effective can become 'agents of change.' People's agency is increased through the promotion of participation, empowerment and emancipation (Raithelhuber, 2018). The results are in line with earlier findings in which care is understood as self-care and the individual identity of affected persons is emphasised (Ribeiro do Lago & Maruyama, 2014).

THEORETICAL FRAMEWORK

The aim of our study was to contribute to the development of theory on the care of people with physical disabilities and thus increase the understanding of physical disability and care. The development of the theory is accomplished through the level of abstraction and the scope of the theory (Kean, 2013). The present theory can be described as substantive and represents a theory of small to medium scope that focuses on the area of care for people with physical disabilities in the home. Domesticity involves all forms of housing in which people with physical disabilities live and receive necessary care support. According to Haller (2000), domain-based theories are characterised by generalised statements about relationships of events and facts. Patterns in social processes as well as a varying spectrum of patterns of action and interaction can be identified (Haller, 2000).

Our study findings are embedded in two main social science theories: the stages of comeback (Strauss & Corbin, 2017) and status passage (Glaser & Strauss, 2009). Strauss and Corbin (2017) explored the question of how people with a chronic illness or acquired disability manage to find their way back into life (Kuster, 2000). The theory shows that a comeback after the onset of a chronic illness or disability takes place in phases. The goal of the

comeback is to reconstruct one's identity. This is achieved through the interaction of past, present and future. The motivation of the affected persons is supported and channelled by professionals during the process (Kuster, 2000; Strauss & Corbin, 2017). Strauss and Corbin (2017) identified six stages of comeback: (1) discovery, which involves discovering what has happened to the body as well as which possibilities are still available or no longer available; (2) embarking, which means finding one's way in the new situation and embarking anew; (3) finding new pathways, which involves finding new ways within existing limitations; (4) scaling the peaks, which represents a phase in which the goals set for oneself can or cannot be achieved and an assessment takes place; (5) validation, also called 'the final stage of comeback,' where a trial with the new life takes place; (6) transcendence, which involves the experience of seeing more meaning in life than before the onset of the illness or disability (Kuster, 2000; Strauss & Corbin, 2017). Our study results are located in the fifth or sixth stage of the theory. Experiencing life with the new self or experiencing more meaning in life after the event than before (Kuster, 2000) increases the quality of life and can be sustainably enhanced by the identified intervening conditions of our study.

Transitions at the structural level (e.g., from an inpatient residential setting to an outpatient living setting) can be explained by and located in the theory of status passage (Glaser & Strauss, 2009; Schläpfer, 2000). Transitions are characterised by the direction (ascending, descending) and the course (constant, stationary). The theory distinguishes between predetermined, discovered and developing transitions. When opportunities for transitions are discovered, the persons concerned should be empowered or should empower themselves to take control of the transition. This raises a fundamental problem regarding the issue of control during transitions. Central questions are who controls the direction of the transition and who controls the course. Direction and control can be regulated, for example, by caregivers or by care recipients themselves. An essential prerequisite for successful transitions is the quality of the support provided by caregivers (Glaser & Strauss, 2009; Schläpfer, 2000). In our interviews, transitions always occurred when the structural conditions (e.g., the number of caregivers and the time available for assistance) no longer corresponded to wishes for individual development. Thus, our theory is also applicable here.

STUDY LIMITATIONS

This study presents findings that are available for the first time in the form of theory that depicts the long-term characteristics of care for people with physical disabilities in the home. Data saturation was reached in this study. The sampling and data evaluation according to the methodological characteristics of grounded theory met

the demand to systematically develop the experience of nursing assistance from the perspective of people with physical disabilities.

Internal validity was established by building consensus among the researchers during the data analysis. Communicative validation of the results took place. Additionally, the results were discussed in a workshop with people with physical disabilities. Regarding external validity, people with physical disabilities around the world have different experiences due to different health and social systems. We assume that creating quality of life with support is a general wish of people with physical disabilities and that the identified categories have the potential for generalisation. At the same time, we recommend that the findings be generalised with caution and checked beforehand for international conditions.

CONCLUSION

People with disabilities should be encouraged by carers to advocate for themselves clearly and confidently and to express their wishes. They should be supported by carers to identify their own priorities and needs, to develop delegation skills and to accept their physical disability. This increases their self-awareness and individual self-confidence. If these framework conditions exist, the perception and execution of nursing support services make an essential contribution to social participation by achieving a high individual quality of life. Within the practice, the definition of quality of life for the persons concerned should be explained in discussions, and nursing support should be oriented towards this definition.

Knowledge about the importance of nursing assistance and the importance of the relationship level between people with a physical disability and staff should be conveyed in training and further education. In this way, self-determination can be implemented and enabled in practice in a sustainable way. The importance and tasks of advanced nursing practice and disability care should also be rethought with regard to people with disabilities to increase the added value of these concepts in practice.

Future research should always be able to claim that it focuses on the perspectives of people with physical disabilities themselves. Other stakeholders in health care, such as therapists and doctors, should also be included.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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