Satisfaction and Coping of Younger Residents in Care Homes – a Qualitative Study

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ABSTRACT

Context: In Germany, about 7% of the care home residents are under 65 years of age. Little is known about the views of this age group about living in a nursing home.

Objectives: The aim of the study is to investigate how younger nursing home residents in Germany experience their life situation.

Methods: The sample consisted of eight residents, aged between 33 and 62, some living in facilities for older people, and some in facilities for younger adults. According to the principles of hermeneutics, qualitative interviews were conducted and analysed using qualitative text analysis.

Findings: Satisfaction with living in a care home was related to the possibility of having social relationships, adequate nursing care, a good staff-resident relationship, and privacy. Dissatisfaction was high when self- and co-determination were restricted. The younger residents used active, passive and re-appraising coping strategies.

Limitations: Only eight participants were interviewed.

Implications: The needs of younger nursing home residents should be addressed in nursing study programmes and further education. A specific assessment is needed. The care homes should then empower to co-determination.
INTRODUCTION

Living in residential care is often perceived as being care for older people. The proportion of adults aged between 18 to 64 living in this setting increased in the United States from 2007 to 2014 from 13 to 16% (Shieu et al., 2021). In Germany, there were 60,000 residents aged between 20 and 64 in long-term care facilities in 2019. This is a percentage of 7.3% of all residents (Statistisches Bundesamt, 2021). The average age for entering a long-term care facility is 82 (Senatsverwaltung für Gesundheit und Soziales, 2016). The characteristics of younger residents are different from older residents. In an international review they were described as being male in most cases, having a mental illness, and suffering from a traumatic injury (Shieu et al., 2021). This is the case in Germany as well, but additionally congenital disabilities and alcoholism were mentioned (Heinze, 2018; Schwinger, Waltersbacher and Jürchott, 2015). Younger people with severe disabilities often have no other choice than moving into a care facility for older people (Lai, 2021).

The quality of life is a multidimensional construct. The World Health Organization defines the “quality of life as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1998). The domains of this construct consist of physical, psychological, and spiritual aspects as well as the level of independence, personal beliefs and environmental factors. Younger residents (YR) often describe their quality of life as being low. Study results state a loss of autonomy, privacy, identity, and social roles in YR. They have limited activities in the community and complain about inappropriate activities inside the nursing homes. The younger residents wish to have more social contacts with people of the same age group as well as their family and friends (Oliver et al., 2020; Shieu et al., 2021). (Muenchberger et al., 2011) conducted a metaphor analysis in media content and formulated the metaphors of “captivity” (p. 1194) – being forced to remain in the nursing home – or “battelines” (p. 1197) – the ongoing fight for human rights and more appropriate services. A recent scoping review highlighted the lack of choice for daily activities or housing opportunities, unmet basic needs and a lack of financial resources (Oliver et al., 2020). A small German study with two interviews described younger nursing home residents as a forgotten group on the sidelines (Schmitt and Homfeld, 2020). The unique needs of younger residents should be assessed before they move into long-term care facilities. A specific assessment tool for younger residents was recently developed (Hazelton-Provo & Weeks, 2021). There is a claim for service shifts from a traditional care model to an integrated care model. The younger residents should be empowered as service users, and should be supported to growth and enablement (Crazier, Muenchberger and Ehrlich, 2015). In contrast to international findings, little is known about the life situation and well-being of younger residents in German care facilities.

OBJECTIVES

The aim of the study is to investigate the experience of working-age adults living in a nursing home in Germany and how they cope with their life situation.

The findings will be used to identify the needs and requirements of younger nursing home residents regarding appropriate care services as well as living environments. Recommendations for the relevant actors in the health sector will be derived from this.

METHODS

A qualitative design was used, based on an interpretative paradigm with the aim of understanding the view of the participants on their living conditions (Kelly, Dowling and Millar, 2018).

SAMPLING

A purposive sampling process was used. First, suitable care homes were chosen in the north and east of Germany, with both nursing and residential care homes being included in the study. Facilities from large cities, small towns, or rural areas, as well as those run by non-profit or private organisations, were to be distributed as evenly as possible. Inclusion criteria for the residents were an age between 18 and 64, the ability to communicate in German language and a minimum length of stay in the nursing home of three months. People using assistive devices to communicate were also included. People who were unable to communicate verbally, people for whom an interview situation could be too stressful, people with an intellectual disability, or with dementia were excluded. The care managers of the care homes asked suitable residents to take part. In total, four men and four women from seven care homes participated, equally distributed within facilities for older and for younger people. The sampling process lasted from October 2017 to April 2018.

ETHICAL ASPECTS

An ethical vote was obtained from the German Society for Nursing Science (No. 17-019). All interviewees gave written informed consent. In the event that an interested person wanted to participate but could not sign the consent form due to functional limitations, written
consent was obtained from a proxy in the presence of the participant.

DATA COLLECTION

Data was collected using guided interviews. The interview guideline was developed by the concepts of quality of life in care homes according to a systematic review of 31 studies ([Bradshaw, Playford and Riazi, 2012]). Five key concepts were identified there: 1) acceptance and adaptation, 2) connectedness with others, 3) a homelike environment, 4) caring practice and 5) autonomy and privacy. Additionally, the interviewer asked about the interviewees’ needs, daily routines and activities inside and outside the care homes. The interviews were taped using a recording device and saved in an encrypted file.

DATA ANALYSIS

The evaluation was carried out according to the content-structuring qualitative text analysis (Kuckartz, 2016; Shieu et al., 2021) using the MAXQDA 2022 software (Kuckartz, 2022). A transcript was prepared immediately after each interview. The rules of Kuckartz (2016) were used for transcription. Omissions of quotations in the results chapter are shown as square brackets. The interviews were anonymised using nicknames. Coherent text passages of the interviews were numbered subsequently.

First, the interviews were worked on intensively by the researcher and case summaries and memos were written. The interviews were then analysed sequentially, line by line, whereby the main categories were developed inductively to approach the interviews openly. Subsequently, the category system with main categories and subcategories was refined based on all the material collected.

The aspects of openness, reflexivity and intersubjective comprehensibility were considered (Helfferich, 2005). The coding of selected categories was repeatedly discussed with two colleagues experienced in qualitative research and reflected on whilst going through the interview material.

The entire data analysis was conducted in the German language. A professional translator translated the quotes of the interviewees into English language.

FINDINGS

The sample consisted of eight participants, four women and four men, living in seven nursing homes. Four participants lived in nursing homes for older people, three in residential facilities specialised in younger residents and one in a facility exclusively for young people in need of care. Three of the facilities were in a rural or small-town area and four in a large city in the north and east of Germany.

Five of the eight interview participants had lived in their own household before their current stay in the homes, while the others had previously been accommodated in another facility. All participants had been working or had a job prior to their stay in long-term residential care. At the time of the interviews, the participants had been living in the current long-term care facility for between 1.5 and 16 years. For further information about the sample see Table 1.

1. SATISFACTION ABOUT LIVING IN A CARE HOME

This main category contains expressions of satisfaction about life, care or services in the nursing home (see the category system at Table 2). Satisfaction is understood as being a cognitive process within humans with regard
to the objective living conditions as well as the subjective attribution of values (Kaltenegger, 2012). This includes the acceptance and the evaluation of one's living conditions. It was divided into three subcategories.

1.1 HIGH SATISFACTION
This category is related to an expression of high satisfaction with life, care or services at the care homes. Three of the residents showed high overall satisfaction when it came to living in the nursing home. They were happy if they could furnish their room to their own taste, and if the nursing home provided appropriate equipment. Mrs. Hase deliberately moved into the nursing home for older people because her self-care abilities had worsened, and she felt lonely in her own apartment. She told about her admission to the care home:

“It was very warm. I was assigned my room. I asked if I could hang up my own photos. They said, ‘Of course.’ They were brought to me from my old apartment. That means […] my legal guardian already had the photos; they were already hanging here. When he knew I was moving here, he organised them from the apartment. I told him exactly which pictures I wanted. I’m very proud of the photo opposite with the X Palace.” (Mrs. Hase, passages 100–101)

Social contacts with other residents were friendly. The participants valued the opportunity of being able to engage with others if they wanted to. One participant spoke about having a love relationship. He lived in a nursing home specialising in the needs for young residents.

“I am happy that I have my partner. We’ve been together for two years in October, almost two years in October. We are also engaged. […] The first lovers here in the house.” (Mr. Zobel, passages 38–44)

The interviewees stated that they were visited regularly by their family or friends. Sometimes, former therapeutical relationships with podiatrists or physiotherapists could be maintained. They had good relationships with the staff, and were satisfied about the nursing care they received.

“If I want privacy, I have a sign stuck on my door: ‘Do not disturb for one hour.’” (Mrs. Mierbach, passages 277–279).

1.2 RELATIVE SATISFACTION
This category means that the participants were content in principle, but this was expressed with restrictions. There are two conflicting statements in one sentence indicating ambivalence. The basic physical nursing care was mostly fulfilled. Not always, however, was the need for adequate interaction. Mr. Schulze was living in a care home for the elderly, and could not communicate with the other residents due to their cognitive impairment.

“So, to put it in a nutshell, as far as the home is concerned, I moved in because there was no other way I could manage and I feel I am in good hands here, but very neglected. There is no communication.” (Mr. Schulze, passage 373).

Mrs. Mierbach (living in an area for younger residents) compared her situation with those of others who are worse off, and concluded that she had to be content with her situation, despite other wishes she may have.

“Otherwise, I have to say that overall, I’m satisfied. I might have imagined something different for my world or for my future, but what hasn’t happened yet won’t happen at all. Or? You must be satisfied with what you have. Others have much less. […] Look, there are enough people who must sleep under a bridge, who don’t have an apartment, who are homeless. Or people who can’t even buy food for themselves, for whatever reason.” (Mrs. Mierbach, passages 426–428)

Mrs. Lorbeer was institutionalised in a senior care home due to a severe deterioration in her health status. Despite several complaints about living in a nursing home she was just thankful for being alive at all.

“But otherwise, I think I’m satisfied so far, first of all that I’m still alive, for this you have to be grateful.” (Mrs. Lorbeer, passage 226)

1.3 DISSATISFACTION
This subcategory deals with complaints about concrete problems with life, care or services in the home. The problematic situations were explained more precisely by the interviewees and could be summarised into further sub-subcategories.

1.3.1 Unsuitable environment
Some residents who lived in a facility for older people complained about an inappropriate age structure of the other residents, a lack of opportunity for social interaction and no offer of any suitable cultural and leisure activities.
“I guess that people, if they are still in full possession of their mental powers, and then somewhere from 50 upwards to max. 64, I want to take this as a basis, that there are quite a few who are dissatisfied with what is happening here. In between there were also very intelligent people here but they left again. Yes, because they didn’t want to do that to themselves here.” (Mr. Schulze, pass. 330)

Mr. Schulze missed an adequate opportunity to communicate because many of the other residents had limited ability to communicate or were living in the past.

“There is no communication. You can’t communicate with most of the inhabitants and those with whom you could communicate, well, the question is, do you want to communicate with them? Because, they live emotionally in a world that has nothing to do with the present.” (Mr. Schulze, pass. 373)

Some interviewees felt that they were out of place in the care home because of their age (“[…] I am too young for this home […]”, Mr. Schulze, pass. 212). This was accompanied with not feeling well.

“[…] I always thought: ‘At this age, in a nursing home, no, this is not fitting.’ So, I didn’t feel comfortable at all.” (Mrs. Lorbeer, pass. 70)

Leisure activities were offered for older people with limited mobility, or cognitive resources that didn’t meet the needs of the younger residents.

“[…] I say: ‘There is senior bowling with a little ball and plastic cones.’ I say, ‘Unfortunately, that’s not for me.’ It’s like that (laughs). I mean, it’s good for them, they should do it. That’s not the case for me though.” (Mrs. Lorbeer, pass. 74)

1.3.2 Inadequate quality of care and service
Regardless of whether the respondents lived in a care setting for older or younger people, they reported specific problems related to a lack of nursing care and supply. A lack of nursing staff was criticised by several interviewees. This resulted in a long waiting time after calling for staff as well as restrictions in personal hygiene.

“Yes, of course, because I thought I don’t just want to be soaped up. I also want to shower properly once a week. […] It would be nicer if it were even more often, but more is just not possible now.” (Mrs. Mierbach, pass. 342–346)

Due to the lack nursing staff, the care homes often must use leasing personnel. This staff doesn’t know the personal needs of each resident due to a lack of initial training.

“Then they bring in leasing staff instead, who have absolutely no idea about all this stuff, who know neither the people nor the anamnesis, yes, and are not even trained.” (Mr. Schulze, pass. 574)

Other concerns were made about unfair food distributions. When Mrs. Lorbeer complained to the staff about too little food for supper, she got the answer:

“‘You are entitled to two slices of bread and then two slices of sausage of each kind.’ This is difficult for me to understand. […] whoever came last (to the mealtime), almost didn’t get anything.” (Mrs. Lorbeer, pass. 119)

1.3.3 Lack of co-determination
A lack of co-determination in the care home was complained about. In Germany, the co-determination of residents, and their relatives or confidants in an Advisory Board is laid down by law. The members of the Advisory Board are democratically elected, and should stand up for the interests of the residents. (Bundesamt für Justiz, 2002). Mr. Schulze, as a member of the Advisory Board, talked to the nursing home manager on several occasions about residents’ complaints about the care services, but he didn’t recognise that any changes were made.

“I say (to the manager): ‘You do not change anything because of our advice, to involve us in things that from the legal side of things are actually in your area of obligation, you do not do that either.’” (Mr. Schulze, passage 323)

In other cases, it was difficult to reach the Advisory Board because it consisted only of external people such as relatives. When Mrs. Lorbeer wanted to complain about the shortage of food supply on behalf of the residents, she had no direct contact partner in the care home.

“Yes, but that’s the problem, the Advisory Board is outside the home. […] In any case, there is no resident in it.” (Mrs. Lorbeer, passages 131, 133)

1.3.4 Difficulties in activities outside of the care home
Some interviewees wished to have more participation in cultural activities outside the nursing home like going to the cinema. Wheelchair users in particular, who needed assistance while going outside, reported problems with structural barriers in cultural establishments.
“[...] we wanted to go to the cinema [...]. They all got into the cinema, but I did not. [...] In case of fire, they wouldn’t be able to evacuate so quickly.” (Mrs. Mierbach, pass. 171–173)

Participation in road traffic and public transport is sometimes difficult due to narrow pavements or streets that were not barrier-free.

“I don’t take the main road, it’s far too narrow and the pavements are too narrow and too crooked. You’re afraid you’ll tip over.” (Mrs. Liebig, pass. 177)

Leisure activities couldn’t be conducted like before. This was accompanied with feelings of sadness and loss.

“It’s sad when I can’t just no longer walk, and I can’t go to a fair and ride a carousel. I can’t go to a park and sit on the grass.” (Mr. Schulze, pass. 521).

1.3.5 Low autonomy
Constrains in self-determination, freedom of choice and action were defined as being low autonomy. This also means restrictions in the daily routine, or in the design of the immediate environment.

“Because, either I’m dependent on the people here or on my supervisor. One is always dependent on someone.” (Mrs. Mierbach, pass. 362)

2. COPING

A variety of coping behaviours could be observed. Coping means acquiring, or further developing new competencies to face (new) challenges, or to be able to satisfy one’s own needs. It can also be about evaluations and attitudes, e.g., focusing on one’s own state of health, and the current living situation.

2.1 ENGAGEMENT WITH OTHERS
Some residents explained how they became engaged with other residents, but also with the nursing staff. This could be in the context of one’s function as a member of the Advisory Board in the nursing home, or in specific situations where someone needs help or support. Participants mentioned the fact that they became actively involved when they recognised that other residents were not able to ask for help for themselves, or when they observed malpractices by the staff. Others patrolled the living quarters in their wheelchairs. Those who could go outside offered to buy small things for other residents.

“... there are some people who [...] attack the staff and even if it is only with a raised voice and (when) I’m outside of my bed in my wheelchair, then I go there and tell them: “Come down again! Don’t shout around here! The nurses only do what they have to do. You are not alone here. [...]” (Mr. Schulze, pass. 361)

2.2 ASSERTIVENESS

Some interviewees assert for one’s own needs with energy, and at times also with aggressive behaviour. They try to set boundaries, and sometimes react with anger. This behaviour may be directed at the staff, or at the other residents.

“Or the dementia patient, who is in the room right next to me, who sometimes comes to me at night and then wants me to do something. That’s why I lock the room at night now, which is unusual for me, but she also often comes during the day, when I sometimes explode. There have been occasions where I’ve just pushed her out. ‘I don’t feel like discussing this now, get out!’” (Mrs. Lorbeer, pass. 148)

2.3 PURSUING OWN INTERESTS AND HOBBIES

Some participants maintained their former activities outside like going to sport events, strolling around or going shopping. One ambulatory participant worked as a volunteer in the parish, and in a neighbour’s garden. Some explored new hobbies, e.g. painting or learning more about politics by watching TV. Others liked to hear music, read, watch movie classics or play mobile games.

2.4 NOT ASKING FOR HELP

Some participants don’t ask for help when seeing that the staff are very busy. They have a bad conscience, and prefer to wait, or try to do it by themselves. For other interviewees, it is a source of acknowledgement by others.

“Yes, at least I have the recognition for not talking about my illness. I process this for myself and people think that’s right, they find that admirable.” (Mr. Schulze, pass. 565)
2.5 ADAPTATION
Adapting to rules, norms of the nursing home, or desires of others may be a coping strategy to achieve relevant goals for oneself, e.g. recognition or attention from others. One participant called it a “code of law to fit in” (Mr. Schulze, pass. 448). Another interviewee described that she participated in the leisure activities in the nursing home in order to satisfy the staff, and to “not be annoyed” by them. (Mrs. Mierbach, pass. 256).

2.6 HUMOUR
Some residents bear the challenges of living together with different people in a care home with humour, and try to laugh at their situation and make the best of it.

“It’s not always easy. And well, we can do it! I always take it with humour, but sometimes the humour somehow is gone. (Laughs at the statement).” (Mrs. Mierbach, pass. 425)

DISCUSSION
Although many problems with living in a care home were stated, most of the participants were partially satisfied with their living conditions. They put their life situation into perspective by comparing themselves with others who are worse off, or with poorer health conditions. This relativization and adaptation to illness, care dependency and the associated changes in their life situations is also described elsewhere (Kaltenegger, 2012).

One of the challenges for the interviewees was an environment which was not age-appropriate. It is recommended that long-term care facilities, or certain sections for younger residents should provide at least some spatial possibilities for social interaction, Wi-Fi, personal computers, a fitness room, and a craft room. The offer of a gym, an exercise pool, a garden for recreation, a kiosk, and a café would be optimal (Pape & Silze, 2019).

The coping activities of the younger residents could be divided in three approaches: active, passive and reappraisal of situations.

Engagement with others, and assertiveness are active strategies indicated by an active approach to others with the goal to solve problems. The active approach could be compared to the problem-focused coping strategy of the Lazarus and Folkman transactional model of stress and coping (Abshire et al., 2016). When they observe situations where others need help, they commit to them. They take spontaneously the role of an advocate or a mediator. Some of the interviewees tried to participate in decisions to improve the services, and environment inside the care homes. They wish to have the possibility of co-determination to improve services, and life in the institution. Despite legal requirements, they don’t feel successful as members of Advisory Boards. The care home managers should take their complaints seriously even if they are expressed with anger.

Some participants reacted with assertiveness when they wanted to fulfill their needs. This is also an active approach which is sometimes not convenient, or suitable. Sometimes, it is related with aggressive behaviour. Staff could see complaints as ‘annoyance’ (Crozier, Muenchberger and Ehrlich, 2015). The staff should ask which actual needs are not satisfied, and use a person-centred approach.

Pursuing own interests and hobbies is another active coping strategy. This was also reported by (Winkler, Sloan, & Callaway, 2007). At admission, the residents should be asked about their interests, and if they wish to learn new skills.

In some situations when needing help, the residents use passive coping activities. This behaviour is related with not asking for help or adaptation. They try to estimate the wishes, and needs of the staff. If the nursing staff is stressed, they react with withdrawal. They adopt to rules or norms of the care homes even if they don’t agree with them. Residents should be empowered by individual or group interventions to increase their self-determination (Schoberer, Leino-Kilpi, Breimaier, Halfens, & Lohrmann, 2016).

Laughing at problematic situations could be seen as re-appraising this situation. Humour seems to be a way to distance oneself from the problems, and to preserve one’s own identity. It could be interpreted as ‘benevolent
humour’ which includes a sympathetic view on an imperfect world, and is related to character strength (Ruch, Heintz, Platt, Wagner, & Prayer, 2018).

LIMITATIONS OF THE STUDY
The sample consisted of only eight participants. The recruitment process of suitable care homes and participants was difficult and time consuming. Achieving data saturation is therefore questionable. In retrospect, the use of qualitative text analysis may not have been the best choice. The use of grounded theory methodology would have allowed us to reflect more deeply on some phenomena.

CONCLUSION
Satisfaction with living in a care home was linked to the key factors: maintenance of social contacts with family and friends, being happy about making new acquaintances, contentment with the nursing care, valuing the nursing staff, and having privacy. Dissatisfaction was related to inadequate social contacts and activities, problems with nursing care, lack of participation inside and outside of the institution, and limited co-determination and self-determination. Coping strategies could be active such as helping others, seeking co-determination, and pursuing hobbies. To assert oneself is also an active coping behaviour. Adaptation to the norms and rules of the care homes, and not asking for help are seen as passive coping strategies. Humour can be helpful to see problematic situations from another point of view.

RECOMMENDATIONS
The unique needs of younger residents should be assessed before they move into long-term care facilities. Staff should be educated about the specific needs of younger people with disabilities or chronic diseases and should take a person-centred approach. Empowerment strategies are needed to increase self- and co-determination. Care managers should encourage the residents to engage in Advisory Boards and appreciate their contribution.

COMPETING INTERESTS
The author has no competing interests to declare.

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