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QUALITATIVE PAPER

‘Firstly, I’m not treated like a fool.’—the perspective of people with dementia on a dementia-friendly hospital

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Abstract

Background: Dementia-friendly hospitals are increasingly discussed in healthcare, politics, research and society as a way to improve hospital stays for people with dementia. However, the perspective of people with dementia is often underrepresented, and current definitions and concepts are primarily based on the expertise of healthcare professionals.
Objectives: To identify characteristics of a dementia-friendly hospital from the perspective of people with dementia.
Methods: A qualitative design embedded in a case study was used. We conducted 15 semi-structured interviews with people with dementia during their hospital stay. The interviews were analysed using reflexive thematic analysis with an inductive approach. In our study, we adopted a participatory approach and actively involved people with dementia and other stakeholders in the development of the interview guide and in the data analysis.
Results: The participants expect *more than what’s necessary* from a dementia-friendly hospital, as presented by eight characteristics identified: (i) *The most important thing is how we treat each other*; (ii) *Someone cares about ME*; (iii) *No hully gully! I want professional care*; (iv) *Focusing on my goals*; (v) *LOOK! I’ve still got capabilities*; (vi) *Skipping Groundhog Day*; (vii) *A bit of both: mingle and single,* and (viii) *Recognising what relatives mean to me.*
Conclusion: Our results highlight the importance of involving people with dementia in the development of dementia-friendly hospitals as only they have the lived experience and a different perspective from that of healthcare professionals.

Keywords: cognitive impairment; involvement; qualitative research; dementia-sensitive care; participatory; older people

Key Points

- People with dementia accept and adapt to their hospitalisation, circumstances and situation, but at a certain point when many things do not meet their expectations, they have had enough of hospitalisation and want to go home.
- For people with dementia, a dementia-friendly hospital offers *more than what’s necessary*. It is characterised by pleasant interactions, someone who cares, professional care, recognition of their individual capabilities and goals, variety, opportunities to be alone or socialise, and consideration of the individual role of their relatives.
- People with dementia expect information about their dementia to be used to empower and support them as active partners in their hospital care by recognising their abilities and goals and enabling social inclusion without stigmatising them.

Background

Hospitalisation is often accompanied by negative experiences for people with dementia. Disorientation, anxiety, discomfort, boredom, power inequalities and exclusion are some of the feelings described by them during hospitalisation [1–4]. Additionally, hospitalisation for people with dementia poses a high risk of delirium, falls, dehydration, malnutrition, physical and cognitive decline, infections, in-hospital death, nursing home admission and longer hospital stays [5]. Nevertheless, hospitalisation is not always avoidable for people with dementia [6]. They have a greater risk of hospital admission than older people without dementia [7], and the prevalence of dementia or symptoms of dementia among older patients in hospitals is high [8, 9]. In Germany, 40% of patients aged 65 and older in hospitals have a cognitive impairment, including a prevalence of dementia of 18,4% [9].

To improve the hospital care of people with dementia, dementia-friendly hospitals (DFHs) are becoming increasingly popular in healthcare, politics, research and society. According to current descriptions of DFHs, these are characterised by *continuity, person-centeredness, consideration of phenomena within dementia, environment, valuing relatives* and *knowledge and expertise* [10]. Definitions and concepts of DFHs are mainly based on the perspective of healthcare professionals and dementia experts [10, 11]. The perspective of people with dementia is underrepresented, so it is unclear what characterises a DFH from their point of view. However, it is particularly important to consider their perspective to develop DFHs that are really dementia-friendly as only people with dementia are experts by experience and can describe what it is like to be a person with dementia in a hospital [12–15]. Moreover, this lack of involvement contradicts the principles of dementia-friendly initiatives, which aim to enable people with dementia to participate in society, strengthen their autonomy and reduce the stigmatisation associated with dementia [16, 17].

To close this research gap, we investigated the perspective of people with dementia on DFHs guided by the following research question: 'What are the characteristics of a DFH from the perspective of people with dementia?'

Methods

In our overall DEMfriendlyHospital study, we conducted a qualitative case study with a multiple-case holistic design [18, 19] to gain an in-depth understanding of the different perspectives of people with dementia, their relatives and professional dementia experts on DFHs. Each of these perspectives represents one case and were analysed as an independent study in a within-case analysis. This article focuses on the perspective of people with dementia.

Semi-structured interviews with people with dementia were conducted during their hospital stay to investigate their hospital experiences, wishes, expectations and views on DFHs. We used a participatory approach to involve people with dementia and other stakeholders at various research steps (recruitment, development of the interview guide, and data analyses). The involvement took place to different degrees [20–22]: *contributing* by providing their views, experiences and feedback; *influencing* by discussing and agreeing on the recruitment material, interview guide and results; as well as *engaging* by making decisions on the interview guide or naming of the themes (more details are given in the following method sections). We used the COREQ checklist to report our study (Appendix 1). The study was approved by the ethical committee of Witten/Herdecke University (application number 209/2019).

Sample and setting

We used the purposive sampling technique [23] to recruit participants with various characteristics (e.g. age, reason for hospitalisation, dementia diagnosis/severity, and social environment (with/without relatives)). We included hospital in-patients with a dementia diagnosis (ICD-10-GM: G30.-, F00.-∗, F01.-, F02.-, F03.-, F06.7) in general hospitals regardless of the reason for hospitalisation and the department. Patients were excluded if they were in intensive care, in the terminal phase or unable to communicate verbally or in writing.

To reach our target group, we developed flyers and posters together with a stakeholder group consisting of one dementia activist, one representative of the regional Alzheimer Society, two dementia-specialist nurses, one geriatrician and three researchers (CM, DP, MR).

We used gatekeepers (e.g. dementia experts, healthcare professionals, hospital managers and representatives) to support the recruitment of people with dementia during their hospitalisation and to give us access to the target group. We sought them via two networks consisting of healthcare professionals who improve the care of people with dementia in hospitals and/or work as dementia experts in hospitals, the faculty of health of Witten/Herdecke University and regional Alzheimer's societies. Additionally, we contacted dementia experts and hospital managers directly. Using the snowball principle [23], the enquiry was forwarded to other hospitals and networks (e.g. universities, dementia networks). Those agreeing to act as gatekeepers received recruitment material to display in their organisations and a briefing about the inclusion criteria that allowed them to distribute the flyer to potential participants. Additionally, we presented our study at conferences, network meetings, and a podcast and invited people to support the study (as gatekeepers or relatives) or participate in the study. Although we used recruitment strategies allowing people with dementia to become aware of our study themselves or through a relative, all participants were recruited via gatekeepers.

One researcher (CM) visited people with dementia interested in the study and provided them with information. Informed consent was obtained by this researcher (CM). This researcher received information from the physicians on the capacity of the people with dementia to consent. Irrespective of the capacity of the person with dementia to consent, all participants were informed about the study and their written or verbal assent was obtained and monitored during the interviews via ongoing consent [24]. This means that the initial assent was checked during the interview; therefore, the researcher who conducted the interviews paid attention to any verbal or non-verbal signs of the participant that indicated that consent was no longer given (e.g. silence, turning away, agitation). In the case of legal guardians, we additionally obtained their written informed consent (n = 7). Potential participants who were not able to give legal informed consent and did not have a legal guardian were excluded from the study.

A total of 19 people with dementia were interested in participating in the study. Four of them did not participate because of scepticism about signing the informed consent form (n = 2), health status (n = 1) or discharge (n = 1).

Data collection

We developed the interview guide with the participation of the above-mentioned stakeholder group in three 180-min online meetings. In the first meeting, we exchanged experiences and collected and discussed topics that were important regarding the hospitalisation of people with dementia. After the meeting, the researchers (CM, DP) formulated general and topic-specific questions. In the second and third meeting, we checked the wording and understandability of the questions and reflected on their appropriateness for the target group and the research aim. We reworded or deleted questions and decided together on the questions for the interview guide. We also decided to use the general questions primarily and the topic-specific questions as follow-up questions or if the participants needed more support.

The interview guide was pre-tested with two participants for understandability and relevance of the questions (Appendix 2). Based on this pre-test, no changes were made to the interview guide and these interviews were included in the data analysis.

One researcher (CM) conducted the interviews face-to-face in the hospitals between June 2022 and May 2023 (the researchers' characteristics are presented in Appendix 3). The interviews were conducted during the participants' hospital stay at a location they preferred, e.g. the patient's room, sitting areas, or the terrace. At the participants' request, a trusted person could be present during the interview. Four participants opted to have a relative with them. Three of these interviews were conducted as dyadic interviews (the person with dementia and their spouse), and in one interview, the daughter-in-law supported the person with dementia with clarifying information and prompts. Informed consent was also obtained from the relatives for the dyadic interviews, because they were also participants in the overall study (to gain the perspective of relatives). In the dyadic interviews, the relatives were interviewed about their perspective and the people with dementia about theirs.

The researcher audio-recorded the interviews and wrote field notes about the interview situation and contextual information. Verbatim transcripts of the interviews were prepared by a professional transcription agency and checked by one research assistant and one researcher (CM) to ensure accuracy. Additionally, the researcher collected socio-demographic (e.g. age, education) and health-related data (e.g. dementia diagnosis, cognitive screening scores, reason for hospital admission) from the participants (self-reports and hospital records) via a questionnaire to describe the sample.

Data analyses

The interviews were analysed by two researchers (CM, MRM) using reflexive thematic analysis with an inductive approach [25, 26]. We used semantic and latent coding to analyse explicit and hidden meanings. The analysis was an iterative process and followed the six phases of Braun and Clarke [26]. After the two researchers familiarised themselves with the transcripts separately and noted their initial ideas, they analysed the interviews together in regular meetings. In the meetings, the researchers generated initial codes, generated themes, reviewed potential themes, and defined and named themes [25]. We analysed the three dyadic interviews at the end; only the parts contributed by the person with dementia were analysed. We conducted the analysis using the qualitative software program MAXQDA 2022 [27]. Appendix 4 contains a coding example.

To ensure trustworthiness and comprehensibility, the themes and thematic map were discussed with two researchers (CK, MR) not directly involved in the analysis. Additionally, the themes were discussed with three dementia activists and one relative of a person with dementia in a 180-min online meeting. The focus of the meeting was validating and discussing the results and naming the themes so that people with dementia could identify with them.

Results

Sample characteristics

A total of 15 people with dementia were interviewed during their hospitalisation in four hospitals in Germany: two public hospitals (i.e. run by cities, municipalities, federal states or the federal government) and two non-profit hospitals (i.e. run by religious, humanitarian or social organisations) with ∼260 to 1500 beds. The hospitals had different dementia-specific services and a modern to traditional hospital environment. The characteristics of the people with dementia are shown in Table 1.

The interviews lasted 16 to 85 min, with an average of 35 min. Three interviews were dyadic interviews (people with dementia and their spouse). Two spouses were hospitalised with the person with dementia due to their own illness, and one spouse made use of rooming-in.

Table 1. Characteristics of the participants

Name*	Age	Gender	Origin	Education/occupation	Dementia diagnosis	Cognitive Screening	Reason for hospital admission	Length of hospitalisation¶	Department¶	Care arrangement before hospital admission & planned changes	Degree of care needed†
Ms. Hansen	91 years	Female	Germany	1-year commercial college—'Handelsschule'[a] after secondary school No information about occupation	Unspecified dementia (F03)	n/a	Fractured femur, after falling	8 days	Trauma surgery	Nursing home No changes planned	3
Ms. Grothe	85 years	Female	Germany	Year 8 secondary school Beautician	Unspecified dementia (F03)	n/a	Leg ulcer	5 days	Orthopaedics	Nursing home No changes planned	3
Ms. Wagner	78 years	Female	Germany	No information about education Nurse	Unspecified dementia (F03)	MMSE: 19 CDT: 2	Tongue cancer	37 days	Geriatrics	Lived alone at home without home care or domestic support Home care support through outpatient care in planning	none
Ms. Schimanski	88 years	Female	Germany	Year 6 secondary school No information about occupation	Alzheimer's disease with late onset (F00.1*)	MMSE: 25	Fractured femur, after falling	10 days	Geriatrics	Lived alone at home, care and domestic support by family members, neighbours and domestic help No changes planned	3
Ms. Keller	75 years	Female	Germany	Year 9 secondary school No information about occupation	Alzheimer's disease, atypical or mixed type (F00.2*)	MMSE: 21	Lacerated head, after falling	10 days	Geriatrics	Lived in sheltered accommodation with home care and support by family member No changes planned	2
Ms. Müller	87 years	Female	Germany	1 -year commercial college—'Handelsschule'[a] after secondary school No information about occupation	Unspecified dementia (F03)—results were still pending; suspected Alzheimer's disease	MMSE: 11 CDT: 4	Suspected dementia (official); Care gap at home due to husband's hospitalisation	9 days	Geriatrics/ specialised dementia ward	Lived at home with her husband; care and domestic support by her husband Moving into a nursing home on discharge	none
Ms. Schmidt-meier	73 years	Female	Germany	2 -year commercial college—'Handelsschule'[a] after secondary school Commercial clerk	Unspecified dementia (F03)—Results were still pending	MMSE: 14 CDT: 5	Suspicion of dementia, wound management	107 days	Geriatrics/ specialised dementia ward	Lived alone without support Moving into a nursing home on discharge	3
Mr. Nörenberger	80 years	Male	Germany	Year 13 secondary school, General university entry qualification Businessman, sales representative	Unspecified dementia (F03)	MMSE: 18 CDT: 3	Transcatheter aortic valve implantation	4 days	Cardiology/ private ward	Lived at home with his wife; care and domestic support from his wife No changes planned	none

(continued)

Table 1. Continued

Name[*]	Age	Gender	Origin	Education/occupation	Dementia diagnosis	Cognitive Screening	Reason for hospital admission	Length of hospitalisation[¶]	Department[¶]	Care arrangement before hospital admission & planned changes	Degree of care needed[†]
Ms. Roggenkamp	91 years	Female	Germany	Year 8 secondary school No information about occupation	Unspecified dementia (F03)	MMSE: 15 CDT:4	Vertigo of unknown origin; recurrent falls	16 days	Geriatrics/specialised dementia ward	Lived alone at home, domestic support by her family members Home care and domestic support through outpatient care in planning	3
Mr. Berg	89 years	Male	Germany	Year 8 secondary school Construction worker	Unspecified dementia (F03)	MMSE:13 CDT: 5	Malnutrition, sarcopenia, recurrent falls, care gap at home	40 days	Geriatrics/specialised dementia ward	Lived alone at home, domestic support by son; Moving into a nursing home on discharge	3
Ms. Falk	92 years	Female	Germany	Year 9 secondary school No information about occupation	Unspecified dementia (F03)	MMSE: 15	Commotio cerebri and bruises after fall	25 days	Geriatrics	Lived alone at home, care and domestic support by daughter and outpatient care Moving into a nursing home on discharge	2
Dr. Baumgartner	84 years	Male	Austria	Year 13 secondary school; General university entry qualification, University, doctoral degree Managing Director	Unspecified dementia (F03)	n/a	Cardiac decompensation	3 days	Cardiology/private ward	Nursing home No changes planned	2
Dr. Fischer	78 years	Male	Germany	Year 13 secondary school; General university entry qualification, University, doctoral degree Physician	Unspecified dementia (F03)	MMSE: 24 CDT: 4	Bradyarrhythmia absoluta with known atrial fibrillation	5 days	Cardiology/private ward	Lived at home with his wife; care and domestic support by his family and outpatient service No changes planned	none
Ms. Kretschmar	92 years	Female	Germany	Year 7 secondary school No information about occupation	Mild cognitive impairment (F06.7)	MMSE:23 CDT: 5	Fall, vertigo of unknown origin, pain in the leg	18 days	Geriatrics/specialised dementia ward	Lived alone at home, care and domestic support by outpatient care Care arrangement on discharge unresolved	2
Ms. Zimmermann	82 years	Female	Germany	Year 10 secondary school Housewife	Alzheimer's disease (F00.-*)	MMSE: 20 CDT: 4	Sarcopenia, dementia with aggression (official), care gap at home due to husband's hospitalisation	14 days	Geriatrics/specialised dementia ward	Lived at home with her husband; care and domestic support by her husband, household assistance and 24-h care No changes planned	3

Note. [*]Pseudonymised; [¶]at the time of the interview; [†]degree of care needed: classification of the need of long-term care according to the provisions of the Long-Term Care Insurance Act in Germany [28], ranges from 0 to 5, higher scores indicate higher dependency on care; MMSE = Mini-Mental-Status-Examination: ranges from 0 to 30, lower scores indicate lower cognitive function; CDT = Clock Drawing Test: ranges from 1 to 6, higher scores indicate lower cognitive function; [a]'Handelsschule' An institute offering a 1 to 2-year course in commerce, to obtain a 'middle school' leaving certificate or an entrance qualification for universities of applied sciences.

Table 2. Examples of interview quotes for *more than what's necessary*

More than what's necessary
Bare essentials
Because I mean, just marching through rooms and the patients get up, wash their faces a bit, brush their teeth, put them back to bed. And then they stay there until the evening. And then you wash them again, lay them down until the next morning. And then you get up again and it's the same thing all over again. And so it goes on day after day. [Ms. Wagner]
Impact of bare essentials
[. . .] sitting around for months and then you can play with your big toe. That's not right. No matter how much lunch you make et cetera, et cetera [. . .] you go mad, you go crazy. You, you lose, you lose your own intelligence. [Ms. Schmidtmeier]
It's okay vs. it's enough
Christina: How did you feel about the waiting time and the many examinations during the day?
Mr. Nörenberger: Well. Oh, it was fine in itself.
Mrs. Nörenberger [wife]: Yes. Of course it was stressful for him, but that's always the case. They have to check so much and beforehand. . .
Mr. Nörenberger: You have to expect that. . .
At the beginning—you didn't see it that way, but over time, you have to try to put your-self in that position. You come, you're here [. . .] where we are now, I'm sitting here, you're sitting here and that's it. Then we go to lunch, to dinner et cetera, et cetera then you have contact with others who are in the same position, who are just as frustrated. [Ms. Schmidtmeier]
It does bother you, but—if you're unwell for the first few days, it won't bother you if you get a prick. Afterwards you say: What's this? But you must be feeling well. [Ms. Kretschmar]
Beyond bare essentials
Christina: How do you know that you are in good hands here?
Dr. Baumgartner: Yes, first of all, [. . .] the care. I mean, first of all, I'm not treated like a fool. And when I say, oh, how nice it would be to hit a few balls here now, nobody says, come on, get that out of your head, you know you're not allowed to play golf. It's bad for you.

Key findings

The participants expect *more than what's necessary* from a DFH, as presented in the eight DFH characteristics identified: *The most important thing is how we treat each other*; *Someone cares about ME*; *No hully gully! I want professional care*; *Focusing on my goals*; *LOOK! I've still got capabilities*; *Skipping Groundhog Day*; *A bit of both: mingle and single*, and *Recognising what relatives mean to me*. In contrast, other aspects, such as the physical environment, were *not worth speaking about*.

The following section contains examples of interview quotes, more examples are shown in Table 2 and Table 3. The names of the participants behind the quotes are pseudonyms.

More than what's necessary

Hospital care limited to the bare essentials is not enough for the participants. Functional orientation, reduction to basic care, hectic pace and speed, not being seen, unfriendliness, restrictions and lack of involvement are some of the aspects that are perceived negatively. They reported negative consequences of such care, including immobility, loneliness, cognitive decline, insecurity and discomfort.

In general, the participants accept and adapt to their hospitalisation, its circumstances and their situation according to the principles 'what must be, must be' and 'you have to accept that, it's no use' [Ms. Hansen]. However, at a certain point when many experiences do not meet their expectations and they are in better health, they have had enough. This is often associated with the desire to return home because 'the best place to recover is usually at home' [Ms. Wagner].

In contrast, hospitalisation is experienced positively if the care provided goes beyond the bare essentials. The participants expect ***more than what's necessary*** from a DFH, as presented in the eight DFH characteristics (Fig. 1).

The most important thing is how we treat each other

For the participants, the most important thing is pleasant interaction, which they associate with the quality of hospital care. The type of interaction they expect is characterised by friendliness but also politeness, patience and respect and is perceived as supportive. Cheeky, rude, annoyed, and aggressive behaviour from staff has a negative impact on them and they highlight that this type of interaction is undesirable.

Above all, it is important to the participants that all people are treated equally and without prejudice regardless of their dementia disease, age or origin. They described fear of being treated like a 'fool', 'idiot' or 'laughing stock' due to being labelled with dementia and are afraid of humiliation, not being taken seriously and deception.

You know, if you become a laughing stock, that's bad. I was taken seriously, and it was important to me that they treated me seriously. And I don't think I want to be an object of laughter or suchlike. [Ms. Grothe].

Additionally, openness and honesty are important to them, especially regarding memory tests, admission to a dementia ward or the labelling of cognitive impairment using a bracelet.

Following the principal *you are treated as you treat others*, they also see themselves as responsible for pleasant interactions through friendliness, patience and understanding for hospital staff, who are often under pressure and overwhelmed. However, they also understand their right to react to negative behaviour accordingly.

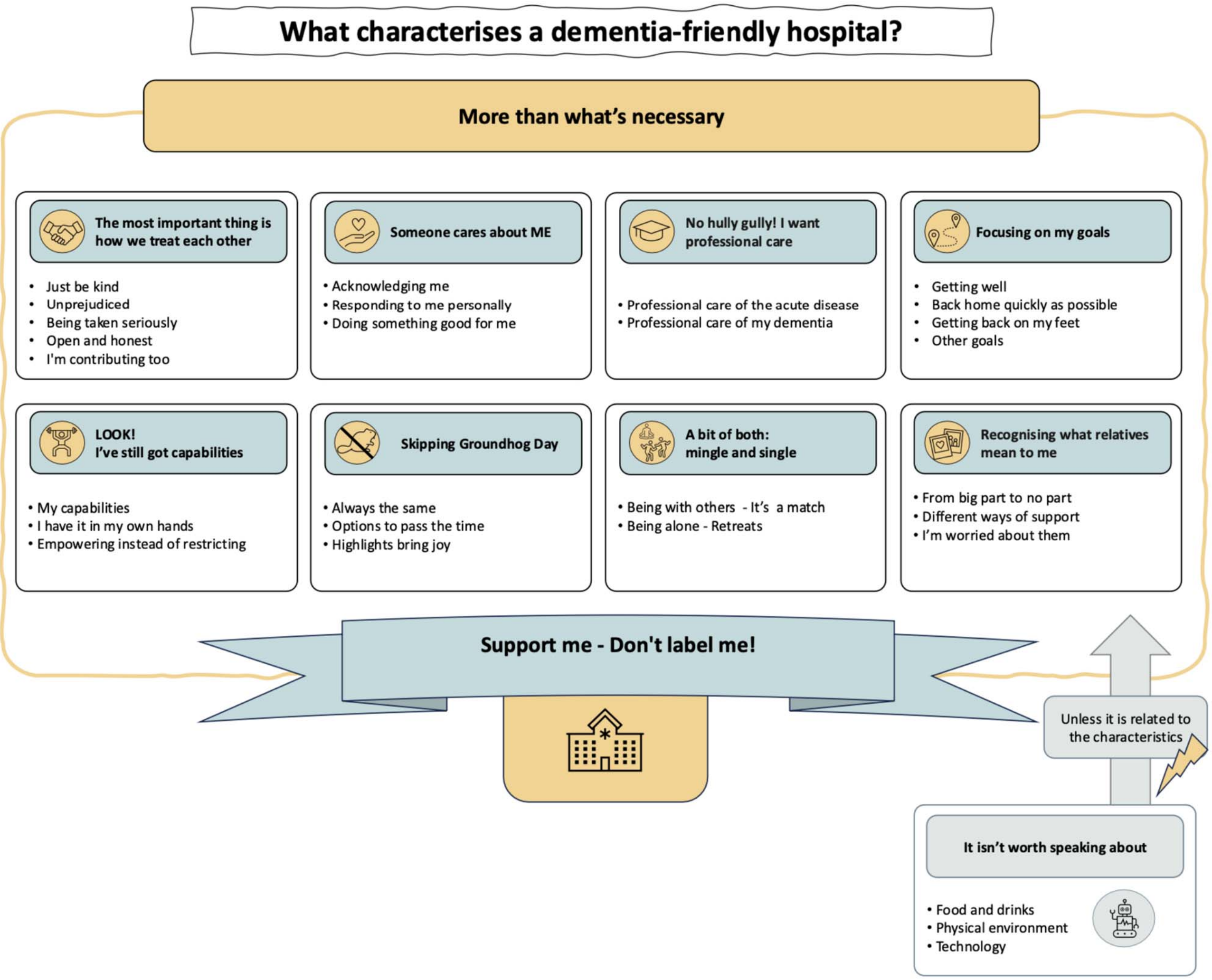

Figure 1. Characteristics of a DFH.

Someone cares about ME

It is important for the participants to be recognised and seen. They are pleased when staff actively seek contact with them, look after them, greet them by name in the corridor and make them feel welcome. In contrast, they have a negative perception of hospital care making them feel that *nobody knows and sees me; I know and see nobody*.

They want the staff to respond to them and show interest in their person. Participants described their concerns during their hospitalisation. The acute situation or the previous fall is often experienced as a crisis and must first be processed. The participants also talked about fears, worries and uncertainties, especially about their future, or their grief for loved ones. They are lonely, have hopes and dreams, indulge in memories and thinking about death. They desire emotional support and for someone to listen to them. Additionally, the *little things in life,* e.g. sleeping, eating and digestion, are often of great importance to them during hospitalisation. Recognising their needs, addressing their concerns and considering their preferences and habits is crucial for them, otherwise this will have a negative impact on them and their well-being. In particular, the consideration of their own pace (e.g. during rehabilitation or intensity of exercise and 'bit by bit') is essential.

Participants would like to feel cared for and are glad when staff offer support or do something good for them without asking for it. For example, asking if something else is needed, listening and taking time make the participants feel cared for. This can also be achieved through the environment, e.g. a coffee machine in the waiting room. They appreciate it when staff do more than just their *work*, if this 'is not too much for them' [Mr. Nörenberger]. It also means a lot to the participants when the staff are happy to see them and to be important to them as a person.

> [. . .] I think they would say that if you no longer existed, we would be sad [. . .] we would miss something. [Dr. Baumgartner].

No hully gully!—I want professional care

For the participants, professional care for acute health conditions is essential. They associate professional care with comprehensive diagnostics and therapy, the presence and skills of healthcare professionals, good organisation and a holistic approach to care rather than fragmentation. In particular, the reliability of the staff, i.e. they are there when something is needed, come when the bell is rung and keep their word, e.g. keeping appointments and providing agreed-upon care, is an important aspect.

Furthermore, it is important to the participants that their dementia does not have a negative impact on professional care for their acute disease and that healthcare professionals try to improve their health condition despite the lack of a cure for dementia. Additionally, they expect healthcare professionals to have an understanding of dementia and recognise it as a disease.

Because they have to, they have to (. . .), it's a disease, dementia; they have to be able to respond to people. Sometimes it's annoying, I think, they already do a lot in the hospital anyway, but that's just the way it is. And the patient with dementia doesn't think so, and they don't know what's going on [. . .]. [Ms. Zimmermann].

The participants described a wide range of symptoms that they experience due to dementia, e.g. forgetting, speech problems, hallucinations, and agitation. Dementia-related symptoms often cause them to feel insecure and lead them to doubt themselves and question their own capabilities. Uncertainties arise as to whether they have passed on important information, taken care of their health, and carried out treatment. They have doubts about their reality and fear the reactions of others if they speak openly about their dementia-related symptoms.

I first checked myself and thought: Am I alive? Am I still here? And I didn't want to tell anyone. I thought, I'll tell someone later and then people will think I'm crazy or something. [Ms. Grothe].

Instead of reinforcing this insecurity, the participants expect healthcare professionals to support them in compensating for their symptoms and mastering these situations. They expect healthcare professionals to recognise individual symptoms, acknowledge them as illness-related, respond to them appropriately and provide interventions as part of professional care.

Focusing on my goals

The participants have their own goals that go beyond getting well and expect the healthcare professionals to support them in achieving these goals. Returning home is their main goal and their ray of hope. It is important for them to be discharged as quickly as possible and to return home to familiar surroundings. For some of the participants, the care situation at home is unstable because of the acute situation and their new care needs or the existing care deficits prior to hospitalisation. The participants are aware that changes at home are necessary and that they need support from outpatient care or a domestic service to be able to continue living at home. In this context, they often talked about an uncertain future and the fear of not being able to return home. They look for solutions, make plans and hope that these plans will be considered.

Another goal is to 'get back on my feet' so that they can walk again, go home or pursue their hobbies, e.g. going out with the dog or playing golf. In this context, the participants expect to receive regular therapy, group exercises, walks with company and motivation.

Other goals arise from the negative effects of hospitalisation on people with dementia, e.g. getting back to thinking due to the lack of cognitive stimuli or having more autonomy again due to restrictions experienced.

LOOK! I've still got capabilities

The participants proudly spoke about their capabilities in terms of mobility, a well-groomed appearance, assertiveness, and capabilities related to their former profession, but also about previous capabilities and what they had achieved in their lives. They develop strategies to manage and compensate for their dementia-related symptoms, e.g. calling relatives, writing things down, asking for help, and using aids.

When I get lost, that's when you get a bit panicky, and then I ask the nearest person. If that's also a patient, then I say, 'Oh, excuse me', and otherwise I try to find the nurse. [Ms. Zimmermann].

They see themselves as having the capability and responsibility to contribute to getting well again, achieving their goals and assisting the hospitalisation and discharge process. Their contribution depends on their capabilities and ranges from walking around and performing exercises on their own to believing in themselves or praying.

For the participants, their capabilities mean independence, feeling 'alive' and being able to contribute. It is important to them that healthcare professionals recognise and acknowledge their capabilities. However, they often experience the opposite during their hospital stay. Their capabilities are denied, and their self-determination is restricted: 'They wouldn't let me do it anyway' [Ms. Wagner]. They reported a lack of involvement, regulation and control by healthcare professionals in relation to hospital care, therapy or discharge. The participants stated that they often had no influence and that they had to accept things. In particular, the restriction of freedom, e.g. not being allowed to go outside alone, leave the ward or go onto the terrace, is a burden for the participants and is experienced as being 'locked up' or 'tied down'.

We can't go down to the lower floors. We can't get anything anywhere here. I'm not allowed to do that. I'm just asking, we're grown-ups. [Ms. Schmidtmeier].

The participants expect 'proper information' about their health status, hospital procedures, discharge, further care or the outside world (e.g. finances, housing), but this is often lacking. They feel like 'Charly Clueless', which leads to uncertainty and anxiety.

Their independence and self-determination are important to them. Accordingly, they expect support and empowerment from healthcare professionals or an advocate. They demand to be involved by being listened to, actively informed, advised and able to (co)decide and co-create. 'I wouldn't anyway, not actively on the side, but I would be involved one-to-one.' [Ms. Schmidtmeier].

Skipping groundhog day

The participants described their day in the hospital similar to the ***Groundhog Day*** as 'always the same' and 'nothing special', characterised by everyday activities and recurring routines (e.g. personal hygiene, meals and mobilisation). Some of them experience this as negative and described it as 'doing nothing' and 'sitting around'.

They look for ways to pass the time, e.g. reading, walking around, watching television, talking, thinking and sleeping. If the opportunity to organise activities to pass the time is removed or restricted, this has a negative impact on them.

I think I've now got a lady [fellow patient] who is bothered by the television, although I have it very quietly. But I have to listen to a bit of something or other, otherwise you snap. [Ms. Keller].

Going outside, visiting the trout pond, virtual cycling and visits from relatives are highlights that are associated with joy and well-being. Overall, they want more variety than the usual hospital routine.

A bit of both: Mingle and single

'People need company. That's absolutely clear.' [Ms. Schmidtmeier].

Being around people such as staff or other patients is important for participants during their hospital stay. They would like to have someone to talk to and someone they can get to know and build a connection with. They like the opportunities to socialise with other people in group activities, shared meals and day rooms. Especially for participants who lived alone at home, being in company was experienced as positive, even if it was sometimes alienating to share a room.

That you can see a bit, that you can hear a bit, that you can laugh a bit. I like to laugh [. . .] I'm alone at home [. . .] There's always someone here [. . .] that's definitely better. [Ms. Roggenkamp].

According to the participants, an important aspect is that the people matched them. In this context, similar interests 'who also loved the pond' [Dr. Baumgartner], similar character traits 'is also very reserved' [Ms. Roggenkamp] and support and consideration play important roles. Especially in connection with the fellow patients in the room, matching is of enormous importance for the participants. If there is a match, the fellow patients can become reference persons during the hospital stay; otherwise, conflicts can arise. Mismatches were also mentioned in the context of other people with dementia, such as if they had advanced dementia, were unable to communicate or exhibited behaviour that the participants experienced as challenging.

[. . .] if you are here like this and you go to the front [common room] and someone is sleeping, one says where is my wife, the other calls his daughter; then make sure you get to the terrace where there is no one. [Ms. Kretschmar].

Besides being with others, the participants also enjoy being alone and the peace and quiet. They appreciate retreats, e.g. the terrace or a single room. Being alone can also have negative effects on the participants and can be experienced as loneliness.

Recognising what relatives mean to me

Relatives and significant others have different meanings for the participants during hospitalisation. For some participants, relatives e.g. their spouse, children or daughter/son-in-law are essential and play a big part. For others, relatives play a small or no part. This is related to their relationships, support needs, relatives' time and opportunities, and lack of relatives. For example, a husband or son may be essential whereas a sister or neighbour may be less important, and contact during hospitalisation may be undesirable and stressful. Deceased spouses are also highly important and are associated with grief and loneliness.

Most participants have contact with their relatives during hospitalisation in the form of visits, telephone calls or joint hospital stays. Their relatives are indispensable and provide great support, especially those who stayed in hospital with the participant.

Christina: Is it a support for you to be here with your husband?

Ms. Zimmermann: Definitely. I'm, well, I just feel more secure there. That's it. So to be here alone—I would be lost, and my husband and I, right Heinz? We'll work it out, then you'll do something.

Relatives support the participants by compensating for dementia-specific symptoms and providing reassurance when symptoms cause uncertainty. Additionally, they are diversions and highlights of the day, ensure that the participants have everything they need, get presents for the staff and are *door openers* for leaving the ward, going to the terrace or visiting the chapel. They also initiate, organise and monitor healthcare before, during and after the hospital stay and support the participants as advisors, advocates or surrogates. Particularly regarding decision-making, the participants rely on the opinions of their relatives and seek advice, make decisions together or pass decisions on to their relatives. The participants are grateful for the support they receive but also worry about their relatives, want them to be well and do not want to burden them. They see hospitalisation as a form of relief for their relatives as their care is assured. Participants without relatives do not have this support, are left to their own devices and need more support from the hospital.

Table 3. Examples of interview quotes related to DFH characteristics

Subthemes	Example interview quote
The most important thing is how we treat each other	
Just be kind	Christina: *What is important to you here at the hospital?* Ms. Hansen: *That people are nice. That is very important. That makes you feel comfortable everywhere.* *A little friendliness, a little kindness. Even if they are overworked, I mean, we were also overworked, but nobody dared to be so cheeky with patients, you know? They make jokes about them. They snapped at them.* [Ms. Wagner] *But above all, of course, it's important that they don't react so aggressively. They can also say, of course, be glad that you're getting anything at all to eat here at all, as was the case with these ladies. (laughs). 'No, this "What do you want again?" No, no, no, no.'* [Dr. Fischer]
Unprejudiced	*That is crucial. I also emphasised that at the beginning. That you're not treated like a fool. 'Oh, another one of those fools, no.'* [Dr. Baumgartner] *And I want to be positioned in such a way that no one says, look, there's that stupid old lady again.* [Ms. Schmidtmeier]
Being taken seriously	*But friendly and—if you have something, they listen to you, that's also important, rather than saying, oh, what's he doing there again, don't sit down, we'll come back tonight, then we can talk again or something. It's not like that. So when you're approached or when I speak to them, something is said straight away and it's said in a civil manner. That's also important, isn't it?* [Mr. Nörenberg]
Open and honest	*Above all, you always have to be honest and say what you think.* [Ms. Hansen] *And also not to hide anything or say, oh, you can't do that, but to talk about it [dementia] quite openly.* [Dr. Fischer]
I'm contributing too	*And if you are—very nice, then the other person is also nice. That's very important.*[Ms. Hansen] And if someone comes across as stupid, he just comes across as stupid once and then I've finished them off. No, I don't put up with that. [Ms. Zimmermann]
Someone cares about ME	
Acknowledging me	*What is important to me is that they—how should I express myself, that they ask how I am [. . .]* [Ms. Schimanski]
Responding to me personally	*But here's jam and honey, which I don't like, damn. I'm absolutely sick of it.* [Ms. Wagner] *About the past. Yes, I've given up. If I said I would like to talk about the past, they're not interested in that, today, the present time is decisive, not what happened a hundred years ago, nonsense like that. They're not interested in what happened a hundred years ago. That's what they say then.* [Mr. Berg] *[. . .] oh, how nice it would be to hit a few balls here now, nobody says, come on, so get that out of your head, you know you're not allowed to play golf. It's bad for you.* [Dr. Baumgartner]
Doing something good for me	*I found that [good], that a lot of—nurses—- signalled, so you can tell us what you would like or tell us if you want something and they went to a lot of trouble.* [Dr. Fischer]
No hully gully! I want professional care	
Professional care of the acute disease	*I can't say anything negative, so no nonsense, but rather it's really well done and organised.* [Mr. Nörenberger] *They're in a hurry. They close it [. . .], pick up the tray and go out. That's it. Yes, and the next one is coming again. Or they forget something. Yes. Most of them forget something, yes (laughing). One comes, the other goes. One injects, the other distributes.* [Ms. Wagner] *So they [the staff] come straight away, ask what's wrong, listen to it. Depending on what it is, they decide that someone comes with medication or something like that [. . .] that's not the case with me now, but that's how it is, you can count on it going on sensibly. So I'm quite sure of that.* [Mr. Nörenberger] *Yesterday, for example, she was supposed to come back at four o'clock. But she never turned up.* [Ms. Kretschmar]
Professional care of my dementia	*Then I tried to reconstruct it [previous day's situation], [. . .] I asked the ladies, I said, can you tell me again who was there, I've got ten euros [he has ten euros but does not know where they came from], well, it's only ten euros, but I don't want to keep it. And then they said, oh, that's rubbish, so in that sense, what's the point and, they didn't make any effort at all, so to speak.* [Dr. Fischer] *Clearly, the understanding that they understand that I—can't say everything the way I would like to and that you respond to it.[. . .] So, if they were to say, 'What are you talking about or why aren't you talking?' if you can't think of the word, 'That doesn't exist' or something like that, right.* [Dr. Fischer] *Yes, why am I restless? That's the first question, why.* [Mr. Nörenberger]
Focusing on my goals	
Getting well	*The most important thing. That you come home healthy.* [Mr. Nörenberger]
Back home quickly as possible	*[. . .] I would love to leave this hospital again and, above all, move back into my old arbour.* [Ms. Schmidtmeier] *That everything stays the way it was [is important].* [Ms. Müller]
Getting back on my feet	*I did gymnastics once, twice, for example today, [. . .] And once I went cycling. Yes, that was it [. . .] I would actually like to do more so that I can get walking.* [Ms. Kretschmar] *I'm just happy if I can use my leg again, that would be the most important thing, and that I could walk again, yes.* [Ms. Schimanski]
LOOK! I've still got capabilities	
My capabilities	*You have to think that I'm already so old, I'm no longer young, but—people are totally shocked that I can still walk like this at this age. [. . .] Even with walking, I can, nobody can fool me there. So, yes, from the older people, when they said, 'Gosh, if only we could walk like you'.* [Mr. Berg] *But since I'm actually a chiropodist and beautician and all that, I thought, no, you can't have done anything wrong and then things went on.* [Ms. Grothe]

(continued)

Table 3. Continued

Subthemes	Example interview quote
I have it in my own hands	*And then I also make an effort to walk in the corridor. Or walk here and have a look there instead of lying down.* [Ms. Keller]
Empowering instead of restricting	*Well, I would like it to be like it has always been, I was a commercial clerk and I would also like, let's say, that we are positioned in such a way that a) I can organise my things myself first, unless it is mutually agreed that we somehow find something together, that is another matter, but that I realise myself that you're alive again.* [Ms. Schmidtmeier] *[. . .] I asked them to call my wife again. 'Why should we call your wife now?' I said I wanted to speak to my wife, because I have it in my head that we actually want to go on holiday in three days'.[. . .] And they thought that was quite—'Why should we call again?'* [Dr. Fischer] *[With the angel shirt] They wanted to do me something special, something particularly good. 'And you have to wear this' [. . .] And I thought, okay, come on, just put it on. [. . .] That was also someone who thought they had to show off, if I say you're getting this, then you have to take it, right?* [Ms. Schmidtmeier] *[. . .] And—then, after that, I wasn't allowed to go out.—The suspicion of [. . .] memory impairment which is clearly still the case today, I have an impaired memory and—I always had very nice conversations with the trout [. . .] When I was allowed to go out. I wasn't allowed to go out at all afterwards because they were worried. [. . .] because they're afraid I won't find my way back. This fear is unfounded. I maintain.* [Dr. Baumgartner]
Skipping Groundhog Day	
Always the same	*But there's [not] so much to do, [. . .] when I sit here sometimes, I talk to the walls.* [Mr. Berg] *This is my everyday life, where we are sitting here now. Day in, day out. It's inevitable that you slowly start to feel stupid in your head. You can't help it.* [Ms. Schmidtmeier] *[. . .] the usual thing you do every day. We get the first tablet at half past six in the morning, which I also took at home. Then they ask: 'Do you want to be washed? Do you want to be washed?'. First they drive me out to the washbasin and then I wash myself. [. . .] Then they dress me. Because it's only half past seven, I say I'll stay in the room. At 8 o'clock I go and have breakfast and then I take the City Gazette.* [Ms. Kretschmar]
Options to pass the time	*Oh, I can get through the [day]. I sleep a lot. I read a lot, sleep a lot. I don't switch on the TV at all.* [Ms. Kretschmar] *Lie here and watch a bit of television. [. . .] Walk back and forth here from time to time.* [Ms. Keller]
Highlights bring joy	*And somehow going outside a bit and seeing what it's like outside. I was only with this therapist once for ten minutes, riding a bike, at the monitor. That was very interesting, it's nice [. . .] I said, man, what a beautiful landscape that was. You saw something different, right? Everything is missing. And always the same thing here.* [Ms. Wagner] *[. . .] but what I enjoyed most was, do you know the hospital? There's one, a fish pond, and there are water lilies in the fish pond. And you can talk to them. And they're not dangerous.* [Dr. Baumgartner]
A bit of both: mingle and single	
Being with others – It's a match	*Doesn't have to be hours of serious conversation, but something nice—something light.* [Ms. Keller] *Have some fun. [. . .] And then they themselves are happy about it because they realise that he's OK. But in the same way, I can say that they are okay too.* [Mr. Nörenberger] *I'm happy when I see someone, when someone comes in here and we chat, I think that's really nice.* [Ms. Hansen]
Being alone—Retreats	Christina: *And what's it like for you to be alone in your room?* Ms Falk*: Oh, I don't mind that either.* Christina: *Do you prefer to be alone in your room?* Ms. Falk: *Yes. I have my peace and quiet.* *That would be nice* [to get together with other people]*, yes. But I also like to be alone.* [Ms. Roggenkamp]
Recognising what relatives mean to me	
From big part to no part	*That's the most important thing for me when our little darling comes, as I have a very lovely daughter-in-law. She is such a treasure.* [Ms. Schimanski] *Christina: What is important to you here at the hospital?* *Ms. Müller: That I see my husband.* *That's, no, that's really reassuring too, yes. Because especially when you're, let's say, ill or something happens, then you want to be together.* [To her husband] *Well, I want to be with you until the last minute. If I'm the one, you'll do it anyway.* [Ms. Zimmermann] *I still don't know how this is going to continue. I don't know. Then I first have to find out who is responsible for such things. Because I'm all alone, all by myself. I don't have a single adult relative on my father's or mother's side. And now I have to do it all on my own.* [Ms. Wagner]
Different ways of support	*I always had a thick top thing [duvet] for covering up. Now I come in here this morning, I see it from a distance and here it is* [points to his bed]*. And it was like this, you can already see how thick this thing is. And there's the son, he went there to the 'authorities'. 'No, no, that's clear, we'll sort it all out nicely.'* [Mr. Berg] *My son, he gave me some* [magazines] *and so on. And my son, he cares, he's coming back today too. He's very special, it's particularly important for him that I recognise everything around here*. [Ms. Grothe]
I'm worried about them	*And then the son had to prepare the food every day and had to go shopping. It was also so unpleasant for me that the boy still had to go to the shops.* [Mr. Berg]
It isn't worth speaking about	
Food and drinks	*Oh, you know what? It doesn't matter at all. I don't care, it all tastes good and I don't care at all. Yesterday it was such a big portion, [. . .] I don't like pasta anyway. I didn't eat the pasta at all, then I had some vegetables and then two pieces of meat. [. . .] And that's what I ate. That was all. It'll be fine, it'll be fine. I'm just happy if I could use my leg, that would be the most important thing [. . .].* [Ms. Schimanski]
Physical environment	Ms. Nörenberger [wife]*: So he was in another hospital a few years ago for a urological problem. We also had a, he had a nice room there, also in the new building. It was all great, but the staff, they didn't even say hello. As a visitor, you could walk the whole corridor and it was a long way to his room. They came towards you, not one of them even said hello. And I found that so unpleasant and these people here, they all said hello.* Mr. Nörenberger: *All of them. And, yes, and that's the most important thing, not.*

It isn't worth speaking about

Other aspects, such as the physical environment, technology or food and drink are *not worth speaking about* and were not the focus of the participants' interview statements unless they were related to the characteristics described above. Nevertheless, the environment is perceived as positive if it is friendly, bright, clean and well-maintained or offered benefits, e.g. a lounge or a private ward 'like a hotel'. However, these aspects are not decisive and meaningful for the participants but rather are *nice to have* compared to aspects such as the social environment.

Discussion

We identified eight characteristics of a DFH from the perspective of people with dementia and contributed to its conceptualisation. From their perspective, a DFH is characterised by *more than what's necessary*, i.e. a pleasant interaction, someone who cares, professional care, recognition of individual capabilities and goals, variety, opportunities to be alone or socialise, and consideration of the individual role of relatives. Moreover, our findings show that people with dementia can adapt to hospital circumstances and do not expect special services, environments or VIP status. In contrast, their expectations of a DFH represent aspects of humanity and person-centred care. Other studies confirm aspects, e.g. kindness, listening, being seen as an individual person and responding personally, are important to people with dementia in hospitals [29, 30].

The DFH characteristics identified here are in line with the principles of dementia-friendly initiatives focusing on strengthening autonomy, enabling participation in society, and reducing stigmatisation [16, 17] and show how this can be operationalised in hospitals. In particular, our results show that people with dementia fear and experience public-stigma in hospitals, which is reflected in discrimination, denial of capabilities, restrictions on their self-determination and lack of involvement. This represents a paradox as early detection of cognitive impairment is recommended [31, 32] and is an important component of a DFH, according to dementia experts [33] and the literature [10]. However, information about a dementia diagnosis seems to lead to stigmatisation rather than empowerment and support of people with dementia. Other studies confirm stigmatisation of people with dementia by healthcare professionals [29, 34–36]. Such experiences can lead to selective disclosure of the diagnosis [37] and can hinder help-seeking and access to healthcare [35]. To counter this paradox, strategies and interventions must be developed to empower people with dementia and reduce stigmatisation in hospitals.

In contrast to the findings in the literature [10, 11] and by dementia experts [33, 38], the physical environment has less priority for people with dementia unless it has an impact on other DFH characteristics that are meaningful to them, e.g. self-determination through restrictions on leaving the ward or common areas for socialising. One explanation for this may be related to the different perspectives and priorities of healthcare professionals, who focus on reducing challenging behaviour and patient safety [39, 40]. A study by Digby and Bloomer [41] confirms that the environment is less important to people with dementia. However, a study by Hung, Phinney [3] shows contrary results and indicates that the environment is associated with aspects such as respecting patients' rights, safety, social interaction and independence. Accordingly, it seems that in the study by Hung, Phinney [3], the physical environment is important due to these underlying aspects, as in our study.

Our results illustrate different perspectives on DFHs and suggest that the perspective of people with dementia differs from the perspective of healthcare professionals. This emphasises the importance of involving people with lived experience in the development of healthcare services. Additionally, we can confirm Hung, Phinney [3] experiences that people with dementia in hospitals enjoy participating in research and feel valued when their voice is heard. Furthermore, our study confirms that people with dementia can be more than just participants in interviews. They can be meaningfully involved in and enrich healthcare research [42].

Limitations

Our study has several limitations that need to be considered. The participants were recruited by dementia experts and healthcare professionals, which might have affected the sample [15]. Despite our efforts to obtain a heterogeneous sample, we did not succeed in recruiting young people with dementia and achieving diversity regarding migration backgrounds. Furthermore, none of the participants had a higher degree of care than three. Nevertheless, for many of the participants, a higher degree of care was applied for from the long-term care insurance during hospitalisation, which suggests that the degree of care hitherto did not correspond to their current condition. Although we were able to achieve heterogeneity in the severity of dementia, our sample does not represent all types of dementia, e.g. frontotemporal dementia or Lewy body dementia. Notably, many of the participants had unspecified dementia. Most of these aspects, such as age, migration background and dementia type, were addressed by the people with dementia included in the participatory group. Additionally, we only included people with a dementia diagnosis (at least unspecified dementia). This might also have influenced the sample, as the dementia diagnosis is often not recorded or not diagnosed prior to hospitalisation in Germany [9, 43]. Moreover, it needs to be considered that the interviews were conducted in Germany, so the results may differ from the experiences and opinions of people with dementia in other countries because of cultural norms, the understanding of ageing, care of people with dementia and hospital systems and structures.

Further limitations may result from the location of data collection. Although it was beneficial to interview people with dementia during their hospitalisation, this also means that interruptions or limited privacy, e.g. could have influenced the interviews [15]. In the dyadic interviews, the relatives may have influenced the people with dementia. Nevertheless, it is important to involve people with dementia in research under their own conditions; they may otherwise not participate in research, which could lead to greater bias. To minimise possible bias, the dyadic interviews were analysed at the end of the analyses. These interviews did not produce any new themes and confirmed the previous analysis.

Conclusion

For the development of a DFH, it is important to include all perspectives, especially those of people with dementia because only they have the lived experience. Our results differ from the findings in the literature [10] and from the perspective of professional dementia experts [33], which indicates different views. For people with dementia, a DFH is characterised by *more than what's necessary*, i.e. a pleasant interaction, someone who cares, professional care, recognition of individual capabilities and goals, variety, opportunities to be alone or socialise, and consideration of the individual role of relatives. Our findings are important for the concept of a DFH to develop meaningful interventions for people with dementia.

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Abbreviations: DFH(s): dementia-friendly hospital(s)
DEMfriendlyHospital study: Characteristics of dementia-friendly hospital study.

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