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Caregivers' perspectives on good care for nursing home residents with Korsakoff syndrome

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Abstract

Background: In the Netherlands, people with severe cognitive deficits due to Korsakoff syndrome are generally admitted to a specialized nursing home. Professional caregivers experience that these residents are often not aware of their deficits, and consequently, their willingness to accept care is relatively low. However, these residents need permanent support when performing daily tasks due to severe cognitive deficits. The combination of objective care needs and low subjective responsiveness makes caring for people with Korsakoff syndrome a complex undertaking. It is unknown how professional caregivers deal with this complex task and how they manage the associated ethical challenges.

Objectives: The aim of this study was to explore the professional caregivers' perspectives on good care for residents with Korsakoff syndrome.

Methods: A qualitative study design was used. Data were collected via semi-structured interviews. The Framework Method was used for the thematic analyses of the interview data.

Participants and research context: Five specialized nursing homes participated in this study. Twelve professional caregivers, including nurses, nursing assistants, and support workers, were selected based on the ability to provide rich information on the study topics and to capture a variety of demographic and professional characteristics.

Ethical considerations: The institutional review board of the VU University Medical Center Amsterdam approved the research protocol. The study was conducted in accordance with the ethical principles for medical research involving human subjects.

Findings: Three perspectives on good care emerged: (1) making daily life a joint effort, (2) being steadfast, and (3) treating with respect.

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Discussion and conclusion: Professional caregivers try to achieve responsiveness in people with Korsakoff syndrome in three different ways. These perspectives reflect fundamentally different views on the care relationship and the autonomy of the resident. By elucidating the three perspectives, we hope to promote the practitioners' reflection on their own ideas about good care for people with Korsakoff syndrome.

Keywords
Alcohol-related cognitive disorder, empirical approaches, good care, Korsakoff syndrome, nursing home, professional caregiver, qualitative research

Introduction

Korsakoff syndrome (KS) is characterized by severe memory impairments and executive dysfunction and is often accompanied by confabulations (Table 1).[1–10] In daily life, these deficits often manifest themselves in apathy and a lack of motivation to take care and find something to do with the day.[9,11] To put it simply, people with KS are difficult to budge. Other problems that complicate the care for people with KS are psychiatric disorders and neuropsychiatric symptoms.[12–16]

What makes it even more difficult for professional caregivers working with people with KS is that these people are often unaware of their deficits.[1,17–21] They do not understand why they would need any help: "they do not believe they have a problem."[18] In line with this, in a recent study among people with KS residing in a nursing home, 70% were shown to be overestimating their functional capacities.[22] As a consequence, professional caregivers experience in daily practice that residents' willingness to accept care is relatively low and that providing care is challenging and exhausting. The combination of objective care needs and a low subjective responsiveness thus makes caring for people with KS a complex undertaking,[23] and it is often quite a battle for caregivers to be able to provide a minimum of care.

Common among most definitions of care is their inherently development-oriented or conservative nature. The objective of care is to develop and foster, or at least to maintain and conserve, something, such as a certain level of functioning or dignity. This is also how the concept functions in ethical theory, and in particular in the so-called "ethic of care" and related approaches. Tronto[24] (p. 103) describes care as "everything we do in order to maintain, continue and repair our world," and Agich[25] states that the essence of long-term care is to support people in (re)gaining a meaningful way of life with which they can identify themselves.

Background

These abstract definitions of care attempt to render the essence of care and its objective, but do not reflect its complexity in practice. At least they do not apply to the care for people with KS where the central challenge is to realize their responsiveness to the care offered to them in answer to their objective care needs. It is as yet unknown how professional caregivers deal with this complex charge in practice and how they manage the ethical challenges it brings. Due to the lack of scientific knowledge about the care for people with KS, professional caregivers often have to find their own way through trial and error without clear guidelines.

In recent years, several initiatives have been taken to improve the care for people with KS. Potentially promising interventions are errorless learning[26–28] and the empathic directive approach.[29] This study aims to contribute to this emerging research field by interviewing professional caregivers who have many years of experience in caregiving for people with KS. What support do they believe these people with KS need? What do they want to mean to them in their daily lives? How do they see their relationship with the

Table 1. Characteristics of Korsakoff syndrome.

Characteristics of Korsakoff syndrome

Cognitive deficits

Severe memory dysfunction:

- *Episodic, semantic memory impairment*: memory, related to personally experienced events specific to time and place, and to facts, is affected
- *Anterograde amnesia*: the inability to create new memories
- *Retrograde amnesia with temporal gradient*: the inability to recall events that occurred, or information that was learned, in the past with disproportionate loss of more recent memories
- *Preserved procedural memory or implicit learning*: learning of verbal, motor, and other cognitive skills without awareness

Executive dysfunction:

- Severe problems in planning and task organization
- Achronogenesis: inability to order memories in the appropriate temporal sequence
- Lack of illness insight
- Confabulations: false or erroneous memories arising involuntary

Neuropsychiatric symptoms

- Irritability
- Agitation/aggression
- Disinhibition
- Apathy

Affective impairments

- Flattened affect
- Anxiety

residents? More specifically, how do they deal with trade-offs between respecting resident's autonomy, on the one hand, and motivating them to accept care, on the other? Or to put it more obtrusive, how do they navigate between the two extremes of leaving the resident to their fate, on the one hand, and forcing them to accept their care, on the other?

In the Netherlands, people with severe cognitive deficits due to KS are generally admitted to a specialized nursing home. Through years of experience, these nursing homes have developed practical expertise in the long-term care for KS residents. To elucidate this knowledge, we conducted a qualitative interview study among professional caregivers working in these specialized homes. Our main question was: What are the opinions of professional caregivers on good care for nursing home residents with KS? We defined good care as the ideals that care professionals, based on their practical knowledge and experiences, pursue in the care of people with KS and how they attempt to realize this.

Objectives

The aim of this study was to elucidate the practical knowledge on good care for people with KS acquired in specialized nursing homes and to make this knowledge accessible for reflection.

Methods

Study design

This study used a qualitative design to make an in-depth understanding of the experiences, views, opinions, and beliefs of professional caregivers of people with KS possible.[30] Data were collected via semi-structured interviews as this method supported the caregivers to stay focused on the topics of this study but also allowed them to bring up new ideas during the interview.

Research team

The research team consisted of seven members. The interviewer (T.J.) was a psychologist-in-training who was in the process of preparing his master's thesis and had no relationships with participants. He had received the usual training offered to psychology students and was supervised by the leader of this research project (M.F.D.). The leader of the project is a psychologist and an experienced qualitative researcher (PhD). The other members of the research team were I.G. (PhD student, elderly care physician), K.J.J. (PhD, epidemiologist, health scientist, and researcher), R.B.V. (PhD, elderly care physician, and researcher), E.M.L.V. (PhD, registered nurse, nurse scientist, and associate lecturer), and C.M.P.M.H. (PhD, elderly care physician, and professor of elderly care medicine and geriatric ethics).

Setting and selection of participants

In the Netherlands, there are about 30 nursing homes providing specialized care to people with KS. Five of these nursing homes were selected to take part in this study. These homes had also participated in a large, quantitative, descriptive study on the functional status and quality of life of people with KS.[15,16] Their size varied from 20 to 138 places per nursing home. Three nursing homes were located in rural areas and two were urban.

The first author made initial contact with the nursing home management and invited them to take part in the study. All of them agreed to participate. Next, the nursing home managers were asked to inform their professional caregivers and to distribute invitation letters to them. All professional caregivers who were directly involved in the care of residents with KS were eligible for inclusion and were asked to participate. In consultation with the nursing home managers, participants who were willing to participate were selected based on (1) their ability to provide rich information on the topics of this study and (2) to capture a variety of demographic (age and gender) and professional (profession, working experience, and employment status) characteristics in the study sample in order to achieve a maximum of opinions on good care. All participants worked exclusively with people with KS and performed similar activities. No participant dropped out during the study.

Data collection

Twelve participating professional caregivers were interviewed between April 2016 and July 2016. The interviews took place in the nursing home where the participant worked. The interviews were audio-recorded and lasted between 60 and 90 min (mean, 80 min). Only the participant and the interviewer were present during the interview.

The topic list was developed by the research team based on clinical practice and research of the literature. The topics involved positive and negative experiences in daily practice, coping with stressful situations and challenging behavior, opinions about residents' competency in everyday tasks, ways to handle residents' dysfunctioning, and opinions about the patient–caregiver relationship. These topics were always discussed with reference to actual cases presented by the interviewees themselves. An interview guide was developed outlining the topics and protocol used to guide the interview. The interview guide was then tested in one pilot interview and underwent a minor revision. The interview started with some questions about the demographic and professional characteristics of the participants.

Data analysis

The Framework Method was used for the thematic analyses of the interview data.[31] This method provides clear steps to follow and produces highly structured outputs of summarized data. It is therefore useful in multi-disciplinary research teams and in particular when not all members have experience of qualitative data analysis.[31] During a systematic and methodical process, a set of codes are grouped into categories around similar and interrelated ideas or concepts. Next, codes and categories are arranged in an analytical framework.

In conclusion, the framework method involves seven stages: (1) transcription, (2) familiarization with the interview, (3) coding, (4) developing an analytical framework, (5) applying the analytical framework, (6) charting data into the framework matrix, and (7) interpreting the data. First, the interviews were anonymized and transcribed verbatim in Dutch (T.J.). After familiarization with the transcripts by reading and re-reading the text, impressions, ideas, and early interpretations of each interview were noted down and discussed. In developing the analytical framework, we made use of five main categories that could structure the data (T.J. and M.F.D.): (1) restraint versus self-direction in general, and more specifically with regard to (2) remaining in bed; (3) use of alcohol, cigarettes, and food; (4) verbal aggression, sexual disinhibition, and annoying behavior; and (5) views on personal contact. Next, the analytical framework was applied and chartered by (1) analyzing all the interviews systematically according the five main categories and (2) categorizing the analyzed citations according to these categories (M.F.D.). Initially, data interpretation of this framework resulted in two perspectives on good care for residents with KS. After classifying respondents conform to these perspectives, a third perspective on good care was identified (M.F.D.). Finally, the findings were presented to the other members of the research team (I.G., C.M.P.M.H., K.J.J., R.B.V., and E.M.L.V). Through group discussion, the results were further clarified, interpreted, and verified.

Ethical considerations

The institutional review board of the VU University Medical Center Amsterdam approved the research protocol and deemed it not to be subject to the Dutch Medical Research Involving Human Subjects Act (2014.259/A2016.040). All participants provided informed consent before starting the interview. By signing the form, the participants allowed the authors to record the interview and to use the data anonymously.

Results

Characteristics of participants

The mean age of the 12 participants was 40 years (range, 20–53 years), and 8 of them were female (Table 2). Participants included four support workers, three nursing assistants, and two nurses. Three participants were trained as both nursing assistant and support worker. They had on average 20 years of work experience in a nursing home (range, 5–35 years), and 10 years with KS residents (range, 3–25 years). They worked on average 29 h per week (range, 16–36 h).

Three perspectives of professional caregivers on good care for people with KS

It emerged that three perspectives on good care for people with KS exist among professional caregivers (Table 3): (1) making daily life a joint effort, (2) being steadfast, and (3) treating with respect.

Making daily life a joint effort. In this perspective on good care, a KS resident is described as someone who needs help in all facets of his daily life, whether it is his personal care or the way he spends his day or

Table 2. Characteristics of participants ($N = 12$).

	Demographic characteristics		Professional characteristics				Nursing home
Respondent	Age (years)	Gender	Profession	Working experience in nursing home (years)	Working experience with KS residents (years)	Number of working hours per week	Location
R1-NH1[a]	40	Female	Vocational support worker	22	20	24	Rural
R2-NH3	30	Female	Certified nursing assistant/vocational support worker	13	11	24	Rural
R3-NH2	28	Female	Certified nursing assistant	12	5	30	Urban
R4-NH2	49	Female	Certified nursing assistant/vocational support worker	32	7	36	Urban
R5-NH3	40	Female	Certified nursing assistant/vocational support worker	13	4	24	Rural
R6-NH3	44	Female	Bachelor support worker	12	8	32	Rural
R7-NH3	53	Male	Nursing assistant	35	25	36	Rural
R8-NH5	42	Female	Certified nursing assistant	20	8	28	Urban
R9-NH1	37	Male	Vocational support worker	15	8	28	Rural
R10-NH1	20	Male	Vocational support worker	5	3	32	Rural
R11-NH4	49	Male	Licensed nurse	31	15	32	Rural
R12-NH4	44	Female	Licensed nurse	26	8	16	Rural

KS: Korsakoff syndrome.

[a] NH-1, 138 places; NH-2, 31 places; NH-3, 80 places; NH-4, 48 places; NH-5, 20 places.

Table 3. Perspectives of professional caregivers on good care for people with KS.

	Making daily life a joint effort	Being steadfast	Treating with respect
View on the resident	Someone who needs help in daily life	Someone who pushes boundaries	Someone like "you and me"
Care aim	To make sure that the resident has a pleasant day	To get the resident where you want him	To respect the resident's wishes and feelings as much as possible
Perception of duty	To help, complement, take over	To be consistent in the limitation of intolerable behavior	To properly weigh respect versus intervention
Care domain	All facets of daily life	ADL, medication, cigarettes	ADL, medication, cigarettes
Relationship with resident	Carrying along, having fun together	Keeping a distance	Engaging in dialogue

KS: Korsakoff syndrome; ADL: Activities of Daily Living.

maintains his relationships. The professional caregivers holding this perspective think that they should help the resident with KS in all these facets.

They want to do so by "repairing the rifts" in the lives of people with KS. Their goal is not to help them find their way to do it themselves, but rather to compensate for these absent skills and to carry the residents along:

> and Christmas was great fun one year . . . [. . .] . . . his daughter would arrive and so I thought it might be fun to give each other presents . . . so I say, you know what, just come down here with her, I have a car . . . then we can go into town together . . . [. . .] . . . there is a Christmas market . . . we go there by the end of the day . . . we sit down somewhere . . . drink coffee and cola . . . with that girl too . . . we will make sure that we'll have some presents . . . he wasn't able to think of anything, so I bought those presents for that daughter . . . well, then we just sat down somewhere . . . really nice . . . Christmas spirit . . . she took a lot of photos, that daughter . . . well, that is so extremely valuable . . . (R7)

> if ever a friend sent a woman [KS resident] a postcard . . . then I asked . . . gosh . . . would you like to get back into contact with her . . . yes . . . well, then we will go look her up . . . the address . . . google . . . and then we tried to retrieve the address to send a postcard back . . . and then include the question of, gosh, would you like to pay me a visit someday . . . (R1)

The help may also take the form of a kindness among friends, such as helping a resident move or bringing someone the TV guide for years on end. The latter was also to help create a relationship of trust:

> he just wanted the TV guide . . . [. . .] That I say, mate, I will bring you one . . . and always before he could ask . . . I had the guide . . . [. . .] and then something else . . . deodorant . . . aftershave . . . I really brought him all this . . . [. . .] I had done everything as promised . . . and then he felt something like, how nice, someone . . . does respect me even if I ask just little things . . . so because of that silly TV guide . . . [. . .] I still do it . . . I have gained so much trust from this man . . . (R7)

The goal is to give people the best life possible—a good experience, a nice day. If this goal is achieved, the professional caregivers themselves are also pleased. In that sense, there is little distance between the residents and the caregivers. In this perspective on good care, the residents are people for whom their professional caregivers are willing to go the extra mile and with whom they can have fun too:

> that was great fun to do . . . and [. . .] to see . . . how much satisfaction it gave them . . . [. . .] for instance, we were going to wrap Easter eggs for a hotel, for Easter . . . well, we were doing so in the living room . . . [. . .] . . . and now and then took a chocolate ourselves . . . and the fact that they did so for another company, they were pleased as punch . . . [. . .] when the weather was nice, for instance . . . then we quit at three in the afternoon . . . and then we went outside to do some things fun . . . and then we agreed . . . we will work another 2 hours after dinner . . . [. . .] that sounded fine to them . . . (R11)

This is not to say that they have an equally good relationship with everyone, but it is typical that the relationship between the professional caregiver and the resident is not problematized. Some matches are simply better than others.

The fact that they have to restrain the resident's freedom in his own (or cohabitants') interest sometimes is not problematized either. If someone has not had a shower for a year, you cannot provide proper care. In these cases, they have no scruples about seeking a court order to have the resident admitted to a psychiatric hospital under the Dutch Psychiatric Hospitals (Compulsory Admissions) Act:

> we once had a client . . . he arrived here from another ward and that man hadn't showered for a year . . . and allowed no contact . . . and . . . well, I do struggle with something like that . . . that you should let it go . . . that you

> should have to accept that . . . [. . .] we then applied for authorization from the court . . . and he was carried off by police and ambulance to a closed psychogeriatric ward . . . and there, he was sort of . . . reset, as it were . . . and now he has returned to us and he really is a very, very pleasant man . . . (R2)

Being steadfast. In this perspective on good care, the resident with KS is described as someone who tends to push the limits of whatever is permissible. This is someone who does not want to get up in the morning, does not want to take a shower, and who is challenging in his behavior. Good care primarily means that as a caregiver you do not run away from such situations, but that you remain firm and show who is the boss:

> but you just have to show that you are a bit . . . the boss . . . so to speak . . . for if you don't . . . they won't do anything . . . they then just do whatever they want. (R3)

Giving in to an off-day is no option in this approach. People with KS need structure. It is important for them to be approached in the same manner every day, so they know what they are expected to do and do not continuously feel like a failure. Being steadfast, in other words, provides safety and helps to establish patterns:

> we have a resident, for instance . . . who washes on fixed shower days . . . and if he has skipped just one day . . . [. . .] it is without question that he won't shower the following day either . . . for if you truly have him stick to the routine and shower him, say, every Wednesday and Friday. Then that man knows . . . and then it won't be an issue . . . but if you miss it once . . . he thinks . . . forget it, I won't do it. (R3)

> those are simply agreements that must provide her with a bit of structure and safety . . . and she always tries to wriggle her way out of it. (R12)

Another argument here is that the resident should experience that his conduct is not without consequences. Many battles are avoided by making it perfectly clear that bargaining is futile: "only when I show them that I won't accept it, they will accept that there is no get-away."

> I had it for a while during meals . . . I then simply tell someone to leave the table . . . and later . . . I do always go and talk to them . . . [. . .] this one knew perfectly well what she was doing . . . and later I went to talk to her and I made my boundaries very clear . . . She tried twice . . . and I have not had to deal with it ever since . . . because they remember: oh, that's right, you don't accept it . . . (R9, on sexually disinhibited behavior)

You can almost see and hear the battle with the resident to "get them where you want them" (R3) in these quotes. One respondent (R10), who explicitly refers to caring for people with KS as a battle, even speaks with awe about his "opponents": they flawlessly feel what they can get away with and with whom. Another respondent also said that "they are certainly not stupid" (R9).

In order to be able to properly wage this fight, it is important for these professional caregivers to retain their distance from the residents. The caregiver should not be tempted to think that he has a special bond with a resident, as that would make him vulnerable:

> Because it will work against you . . . The trust, for instance . . . if I'd had the illusion that I had built something special . . . another colleague comes along who has more to offer him at that moment . . . then I am nowhere . . . I assume I would be hugely offended . . . for I was the one who built that relationship of trust . . . or if something unexpected happens and they are suddenly cross with me . . . or they won't come out of bed, whereas they usually did when they were in my charge . . . [. . .] then you would feel hurt . . . then you would no longer be able to do your job objectively . . . (R9)

The distance can actually be felt in the way the respondents with this perspective on good care talk about their residents. They do not bring specific people—with whom they battled or had fun—to life, but just give general descriptions of KS patients. The statement that "they are like obstinate teenagers" (R4) implies a clear "we" (the professional caregivers) versus "they" (the residents).

Treating with respect. In this perspective on good care, the KS resident is described as someone who wants to be treated with respect and with equality. The professional caregivers are continuously asking themselves how best to act in a certain situation without disrespecting the resident and save him from the negative consequences of his behavior at the same time. They consider the advantages and disadvantages of their actions and recognize the dilemmas they have to face:

> it was far from open-and-shut to me . . . [. . .] I'd then asked myself if it was right . . . [. . .] if she wouldn't, she wouldn't have enough cigarettes for the rest of the week . . . and then [. . .] she would be completely stressed . . . she just didn't have much to spend . . . so . . . [. . .] we had to steer her in this . . . only . . . she felt belittled by us . . . yes, perhaps that is how it comes across . . . [. . .] I couldn't get her get rid of that feeling . . . and I couldn't fully justify it to her either . . . I couldn't fully justify it to myself . . . that I thought . . . yes, it does come across as belittling . . . I'm actually forcing you to . . . to do that . . . (R5)

This example shows that the respondent can imagine that the resident felt belittled by the professional caregiver; she believes that she would have felt the same way. In this perspective on good care, the "us and them" is far less prominent than in perspective 2; the resident with KS rather is a human with feelings similar to those of the professional caregivers:

> Then I imagine, as it were, that he would be me, that the fridge would be locked and that I would have to ask my husband to make me a sandwich, for instance. That is of course . . . That would be awful . . . (R1)

The strive toward a certain equality in the relationship is also expressed in the professional caregiver's ability to admit that the resident is right. The caregiver is not superior to the resident and is not always right:

> yes, you come here in the mornings . . . and then you sit down in your hen house . . . then you have that change-of-shift report [. . .] and then you rush around in the ward . . . and it might be even 10 o'clock before you all finally open your mouths . . . and then I think, yes, you could actually be right . . . (R8, quoting a resident)

The professional caregiver also takes the resident with KS seriously in the sense that they do enter into dialogue, discuss their considerations, and, to a certain extent, share their feelings:

> I went to sit with him, and he said . . . well, I have won . . . [Court authorization was rejected] so I said, well, yes . . . I don't know if you should see it that way . . . but take it from me that I find it very difficult . . . I find it very difficult to let go of you . . . because I'm afraid, it's going the wrong way . . . (R8)

The professional caregivers' list of duties in this perspective is still limited to the provision of care (Activities of Daily Living (ADL), medication, cigarettes) as it is in perspective 2. However, unlike that perspective, this one places values like humaneness, a good atmosphere, and self-worth in the foreground; the respondents with this perspective on good care do not describe the provision of care as a battle:

> I think it is a good thing [. . .] that there are rules and that structure is provided, for these people do need them, because they will get used to them, but I also believe that you should be a bit lenient about them. There is nothing wrong with being humane, that is what I think. (R1)

> to support someone in such a way that they stay as independent as possible . . . and . . . especially . . . keep their dignity . . . that's what I believe to be the main thing . . . yes. (R6)

Discussion

This study aimed at elucidating the practical knowledge and experiences of professional caregivers on good care for people with KS acquired in specialized nursing homes and making this knowledge accessible for reflection. The results of this study showed that caregivers have different perspectives on good care for these residents: (1) making daily life a joint effort, (2) being steadfast, and (3) treating with respect. The first perspective entails that the professional caregivers consider it to be their main task to ensure that the residents have the best life possible; it is more important for something to *succeed* than for the resident to have managed it all *by themselves*. The second perspective on good care is that it primarily means that professional caregivers are consistent in limiting intolerable behavior (such as self-neglect, aggression, and sexually disinhibited behavior). The third perspective stresses that professional caregivers should take residents seriously and, insofar as possible, treat them as they themselves would like to be treated.

The perspectives described all three issues that are relevant to the care of vulnerable people who are no longer able to look after their own interests. The first issue concerns the way in which the professional caregivers relate to their residents, the *care relationship*. Care—in the context of institutional long-term care—is an intersubjective process in which the caregiver and the care recipient cannot treat each other as strangers, but in which it is pivotal to realize a good balance between distance and involvement. The first (*making daily life a joint effort*) and third (*treating with respect*) perspective represent two ways for such a balance to be found, either by making some of the day together or by entering into dialogue with the resident, and placing yourself in his position. For these professional caregivers, personal contact is a competence that they use to achieve their professional goals. This is clearly different for the professional caregivers who hold the second perspective (*being steadfast*). They can only provide good care if they maintain a "professional" distance from the resident; only then will they succeed in limiting the resident and not being hurt themselves. In this perspective, personal contact involves the risk that the resident will gain control over the caregiver or that the latter begins counting on a relationship of trust that will never materialize: "you don't build anything."

Another related aspect of the care relationship is the degree of equality between the professional caregiver and the care recipient. With regard to this aspect, the dividing line is slightly different. In the first perspective (*making daily life a joint effort*), the professional caregiver may well engage with the resident, but only in the role of support worker who sees shortfalls, makes up for missing competences, and have the residents tag along, more or less from his own ideas of a "good life.." There is no discussion about this role. When it comes to the dimension of equality, the first perspective is more akin to the second (*steadfast*) than to the third (*equal*) perspective. In both the first and second perspectives, the professional caregivers know what is good for the resident and experience a duty of care in realizing it. In the third perspective, equality is high on the agenda. The professional caregivers consider the resident to be someone with a voice that needs to be heard. And if that truly is impossible, they are aware of what it means to the resident to be deprived of control.

This touches on the second major issue in the care for vulnerable people, namely the view on the *autonomy* of the residents in terms of independence and free choice. As Thomson[19] (p. 89) put it, "The challenge is to allow them some 'independence' in the 'cared-for' setting, while at the same time meeting their needs and keeping them safe." The three perspectives described here differ greatly in the extent to which they allow for an autonomy in this sense. Inherent in the third (*equal*) perspective is that intervention in the resident's freedom of choice and action is to be kept to a minimum; after all, one would not want that for oneself either (R1: "Suppose I had to ask my husband to make me a sandwich. That would be awful . . . "). This perspective more or less corresponds to what Agich[25] (p. 48) describes as parentalism, that is, "the situation in which an affectively concerned caregiver strives to enhance the well-being, including the autonomy, of another dependent individual." In other words, the professional caregiver places themselves in the position of the other, but at the same time realizes that the other person is limited in their functioning as an independent agent and, therefore, needs protection. In this perspective, the caregiver allows for free choice wherever possible, but takes over responsibility—sometimes with pain and difficulty—wherever needed.

Inherent in the second (*steadfast*) perspective is that intervention in the resident's freedom of choice and action is the *raison d'être* of care. Representatives of this perspective hope that coercion can be prevented through a consistent and structuring approach: "urge to prevent coercion." Ethically, this perspective can best be described as paternalism: "the interference with a person's liberty of action is justified by reasons referring to welfare, good, happiness, needs, interests or values."[32] The good that the paternalizer is aiming for is not only the safety of the person with KS, but also the actual prevention of coercion. In the perspective of the caregiver, this is realized by being steadfast. At the same time, this perspective is motivated by the importance of self-protection on the part of the professional caregiver in order not to be defeated by his work.

There seems to be a split on this point in the first (*daily life*) perspective. Whereas the relevant respondents said that they wanted to do everything to give the resident a pleasant day and offer them positive experiences, they did not seem to be too concerned about the application of coercion. Unlike their counterparts that held the second and third perspectives, these professional caregivers were prepared to take on a resident's *entire* life. The fact that this could compromise the resident's freedom becomes clear when he refuses to be helped despite all his caregiver's personal efforts. If all else fails, recourse is made to coercive measures without too many scruples. In this perspective, independence or free choice is not an actual guiding principle; the main thing—from the perspective of these highly involved professional caregivers—is a good life for the resident. This perspective is paternalistic too—and in a strong sense—but is also motivated by an intention to promote a good human life, just as people with autonomy can live it. It is thus more in line with a positive conception of autonomy as opposed to negative autonomy. While negative autonomy is the prevailing concept of autonomy in biomedical ethics and implies that caregivers minimize interference and respect free choice of the person they care for, a positive conception of autonomy on the other hand refers to offering support and creating conditions for someone to actively shape his life and identify with fundamental values.[33] Thus, promoting positive autonomy as a goal of care can consist in supporting a person in developing his values or in offering him valuable experiences that contribute to a good human life. In view of the fundamental and irreparable dependence of people with KS, this is an infinite task for the caregiver. However, a risk of the positive approach to autonomy is that it might involve an authoritarian stance, resulting in a denial of liberty.[26,33] The apparent ease with how professional caregivers think about coercion in the first perspective might be an example of this risk.

Given the fundamental differences in the relationship with the resident and the views on autonomy, it does not seem plausible that professional caregivers working with people with KS can draw elements from the three perspectives as they please. By elucidating the three perspectives on good care explicit and establishing links with related ethical notions, we hope to make practitioners sensitive to these differences and allow them to reflect on them. What do they believe to be the purpose of the care for KS residents? What significance does personal involvement and equality have to them in the often very long-term and intensive care relationships? What importance do they attach to ethical principles such as parentalism and (positive and negative) autonomy?

In addition, the personality of the professional caregiver might also play a considerable role. Some have a greater need for personal contact and make it a focal point within the care relationship, whereas others feel the need for self-protection and, therefore, keep a greater distance. This also applies to the residents, for that matter; they all have their own preferences too. While it is pleasant for one resident to have an enthusiastic caregiver who enjoys the personal contact with their residents, it can be more preferable for another to be treated with more distance, whereas the third feels most at home with a caregiver who considers their feelings.

Strengths and limitations

This study is the first study that provides in-depth insights about the perspectives of professional caregivers on good care for people with KS living in a nursing home. Another strength is that the respondents were working in specialized nursing homes and had years of experience in the care for KS residents enabling them to provide rich information on the topics of this study. They knew what they were talking about. The most important limitation of this study is that the perspectives are only based on a limited sample of professional caregivers. Due to the selection of these caregivers who are working with people with KS solely and specifically in specialized nursing homes, it is unknown whether their counterparts working in general nursing homes may have different perspectives on good care for this patient population. Therefore, the results are not generalizable to these settings.

Conclusion

This qualitative study describes three perspectives among current professional caregivers on good care for nursing home residents with KS: making the residents' daily life a joint effort (and enjoying it together), being steadfast (and keep distance from the residents), and treating the residents with respect (and explore their feelings). These perspectives reflect fundamentally different views on the care relationship and the autonomy of the resident. By elucidating these perspectives, we hope to promote practitioners' reflection, for example, in the form of peer support meetings or moral case deliberation. This may also reveal to what extent it is possible to adopt and acquire perspectives. Further research informed by care ethical literature on the place of coercion in care relations and how this relates to autonomy in residents with KS is recommended.[34,35]

Conflict of interest

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