

Creating relationships with persons with moderate to severe dementia

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Abstract

The study describes how relationships are created with persons with moderate to severe dementia. The material comprises 24 video sequences of Relational Time (RT) sessions, 24 interviews with persons with dementia and eight interviews with professional caregivers. The study method was Constructivist Grounded Theory. The categories of 'Assigning time', 'Establishing security and trust' and 'Communicating equality' were strategies for arriving at the core category, 'Opening up', which was the process that led to creating relationships. Both parties had to contribute to create a relationship; the professional caregiver controlled the process, but the person with dementia permitted the caregiver's overtures and opened up, thus making the relationship possible. Interpersonal relationships are significant to enhancing the well-being of persons with dementia. Small measures like RT that do not require major resources can open paths to creating relationships.

Keywords

dementia, relationship, relational time, well-being

Introduction

Person-centred care is considered a prerequisite for providing successful dementia care (Kitwood, 1997; NHS & SCIE, 2006; Swedish National Board of Health and Welfare, 2010). An essential element of person-centred care is that the caregiver *attempts to establish a relationship with the person with dementia* (National Board of Health and Welfare, 2010, p. 21). The relationship between the caregiver and the person with dementia is crucial to person-centred care because interpersonal relationships are

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considered essential to successful care outcomes (Davies & Nolan, 2008; McCormack, 2004). Creating relationships with persons with dementia can, however, often be perceived as arduous, due to lack of understanding about how relationships are established (Adams, 2008; Allan & Killick, 2008; Dewing, 2004; Ericsson, Hellström, & Kjellström, 2011).

The ability to create and maintain relationships is critical to the person with dementia's sense of identity and feelings of personhood (Tester, Hubbard, Downs, MacDonald, & Murphy, 2004). Since the person with dementia's capacity to create and maintain relationships declines successively due to cognitive deficits, the caregiver's confirmation of the person with dementia is critical to his or her sense of being somebody – a person (Brooker, 2004; Davies & Nolan, 2008; Edvardsson, Winblad, & Sandman, 2008; Malloy & Hadjistavropoulos, 2004). Confirmation from others is the foundation for developing a relationship with the person with dementia (Harman & Clare, 2006; Malloy & Hadjistavropoulos, 2004; Penrod et al., 2007; Sabat, 2002).

Persons with dementia want relationships with other people and are capable of having them, even when the dementia is advanced, but others must take the initiative to create and maintain the relationship (Penrod et al., 2007). Hellström, Nolan, & Lundh (2005) describe how a married couple maintain couplehood, despite the wife's far advanced dementia. Both parties describe the relationship as entirely possible and meaningful, but it required initiative on the part of the husband to maintain it. Another study showed that relationships are meaningful to persons with severe dementia. When asked what they enjoyed, they mentioned activities such as coffee 'klatches', a pastime that involves interaction and often a relationship with another person (Cahill & Diaz-Ponce, 2011).

Norbergh, Helin, Dahl, Hellzén, & Asplund (2006) studied professional caregivers' attitudes towards persons with dementia and identified negative attitudes towards persons with communication deficits and behavioural disorders as relational barriers. In these cases, professional caregivers often avoided creating a relationship beyond interaction in the course of basic nursing. McCallion, Toseland, Lacey, & Banks (1999) have shown, however, that professional caregivers can be trained to interact more with persons with moderate to severe dementia in order to facilitate relationships.

Relationship-centred care, considered an evolution of person-centred care, further reinforces the importance of the relationship between the person who receives care and the caregiver (Davies & Nolan, 2008; Nolan, Ryan, Enderby, & Reid, 2002; Ryan, Nolan, Reid & Enderby, 2008). Davies & Nolan (2008) argue that in order to be person-centred dementia care must be relationship-centred. Existing research emphasizes the importance of relationships (Nolan, Davies, Brown, Keady, & Nolan, 2004; Ryan, Nolan, Reid, & Enderby, 2008). There is a need, however, to increase understanding of how relationships are established with persons with dementia, particularly with persons in more advanced stages of dementia. The aim of this study is therefore to increase understanding of how relationships can be created with persons with moderate to severe dementia.

Method

Context

The study was carried out at six residential units for persons with dementia in southern Sweden where a method called 'Relational Time' (RT) is used. RT is defined here as: *A time of interaction with the person with dementia (one-to-one). A way of activating/stimulating the person with dementia that begins with the unique person's interests, wishes and capacity and*

where focus is on the person. In this study, RT was used as an instrument to enable study of how relationships with persons with dementia are created. The aim of RT is to enhance activation and encourage interaction with the person with dementia. RT is included in the day-to-day schedule so that all residents in the dementia unit will benefit from the method, which must be provided with continuity, at least once a week, by a caregiver who knows the person well. RT is documented in order to record activities that persons with dementia are prevented by forgetfulness from relating themselves. Other professional caregivers and relatives can also refer to the documentation and give each other suggestions for suitable activities/occupations that promote interaction with the person (Ericsson, 2006).

Procedure

How a relationship is created may be seen as a social process, which was studied here on the basis of Charmaz's (2006) Constructivist Grounded Theory (GT). For this study, RT sessions ($n=24$) were videotaped for 20–61 minutes and the person with dementia was interviewed immediately after the taping. The professional caregiver was interviewed later. In order to retain what Charmaz (2006) calls the 'natural context', RT took place in the usual, for the person with dementia, familiar environment and an undisturbed place with only the caregiver and the person with dementia present. The interviews with the person with dementia lasted 2–13 minutes and were conducted in the setting where the RT session had taken place. The questions were brief *here and now* questions with a concrete connection to the activity that had taken place. The persons with dementia were videotaped and interviewed on three occasions, except for two persons, one of whom was interviewed once and the other twice. All but one of the professional caregivers involved in the RT sessions were interviewed once. Prior to the interview, the interviewer (IH) viewed the videotape in which the professional caregiver was involved. The interviews with caregivers lasted 19–31 minutes and consisted of open-ended questions (Polit, Beck, & Hungler, 2001). When an interview triggered new questions, these were asked of the next respondent in accordance with the method (Charmaz, 2006; Glaser & Strauss, 1967;). The interviews were transcribed verbatim and the video-recordings were written out in the form of field notes, comparable to the notes taken by a participant observer (Fangen, 1995).

Participants

The dementia nurse or the division manager contacted potential participants. Nine persons with dementia participated in the study, eight women and one man, ranging in age from 75 to 97. They had been residents of the unit for three months to seven years. All had a diagnosis of some type of dementia. The stage of dementia was established according to the Functional Assessment Staging Test (FAST) (Reisberg, 1988), wherein the stage of dementia was assessed on a scale of 1–7, where a higher figure denotes lower functional capacity. The participants' scores on the FAST scale varied from 5–7 (FAST 5 = n_2 ; FAST 6c = n_2 ; FAST 6d = n_3 ; FAST 7a = n_1 ; FAST 7b = n_1). The professional caregivers, all women, had been providing care to persons with dementia for 2–16 years.

Ethical considerations

Regional Ethical Review Board (reg.no.2010/30-31) reviewed the study from an ethics standpoint. Before the study commenced, everyone involved was informed in writing and orally about the aim of the study, that participation was voluntary and that confidentiality would be maintained. Thereafter, oral information was provided on an ongoing basis before each study occasion. Relatives gave oral consent to ask the person with dementia whether they were willing to participate in videotaping of RT and to be interviewed. The persons with dementia gave oral consent to participating before every videotaping session, since due to memory deficits, consent given on one occasion cannot be deemed to apply to a later occasion (Hellström, Nolan, Nordenfelt, & Lundh, 2007). The professional caregivers also gave oral consent to the videotaping and individual interviews.

Data analysis

Initial analysis commenced as data were collected. The interviews and videotapes were subject to constant comparison (Charmaz, 2006; Glaser & Strauss, 1967). All material was coded based on Charmaz's (2006) recommended structure as follows: a) initial coding in which text sequences were given substantive code names; b) focused or selective coding in which substantive codes were grouped and given more abstract category names ('theoretical coding'); and c) identification of relationships between categories and sub-categories in theoretical integration (Charmaz, 2006). The core category, 'Opening up', which explains the process, emerged during theoretical coding.

Results

The 'Opening up' process was necessary to establish the relationship with the person with dementia. The strategies for reaching the core category, 'Opening up', are the categories of 'Assigning time', 'Establishing security and trust' and 'Communicating equality', which are all interrelated. The process took place when the person with dementia and the caregiver met for a 'Relational Time' session (RT). Both parties' participation was necessary to establish the relationship, but the caregiver had the greatest responsibility and guided the process. The contribution of the person with dementia was to be open to and permit the caregiver's overtures. How the caregiver controlled the process determined whether the person opened up to the caregiver's overtures.

Assigning time

One strategy used was 'Assigning time', which the caregivers believed was a way to pay attention to the person with dementia. The person was assigned time by the caregiver, but also indirectly by the organization.

Caregiver (CG): . . . we used to do it [RT] when we had extra time. But now we make it [RT] a first priority . . . and that the other comes . . . it's more allowed. And it's been decided by the management and the bosses that this is a priority . . .

'Assigning time' was clearly signalled to the person with dementia through the caregiver's express statement: *This is your time now*. No signs that the caregivers were stressed or

expressed lack of time could be observed in any of the RT sequences. It was important, according to the caregivers, that time was set aside for RT in the day-to-day schedule: ‘... if you’ve set the time aside... you listen, you know... you are there.’ The persons with dementia perceived that caregivers were genuinely relaxed and focused on them during RT, for which they expressed appreciation.

Interviewer (**I**): ... and those times are worthwhile?

Person with dementia (**PWD**): Yes, they are worthwhile [conviction in the tone of voice], they are. She is so, she is so calm... otherwise she is run off her feet, but when she is here then... [laughs].

It seemed, despite assurances from caregivers that time had been assigned for them, that the persons with dementia still felt unsure that caregivers truly had time for RT.

Video sequence (**VS**): In the midst of an ongoing activity, the person suddenly asks: ‘Do you really have time for this?’ And then answers her own question: ‘No, you don’t have much time, do you?’ The caregiver chuckles and says that she’ll try to manage, since she knows the person enjoys it. The person with dementia remarks that this is good, and then starts telling her story to the caregiver again, who listens intently.

The persons with dementia sought to confirm whether there was really time for RT, which could be interpreted as arising from fear of losing out on the session. There may have been a need to check whether there was any point to opening up to a relationship that might quickly be broken off again. In the interviews, the persons with dementia expressed that there were a lot of people who had to share the caregiver’s attention.

Feelings of significance

‘Feelings of significance’ was a dimension of ‘assigning time’. The persons with dementia interpreted and expressed verbally that they felt like someone important when time was assigned to them. Incidental chat while the caregiver performed other tasks was not of the same quality as the one-to-one sessions.

I: ... these sessions with a caregiver, you think, ... are?

PWD: Oh, it’s so nice [emphasis] because ... they don’t have time, they usually don’t have time, it’s only when we eat and they are there and say a few words ... when they come in and ... make the bed and so forth ... No, I’m not complaining about them, I’m not.

I: It was interesting what you said about how when they are doing something and talking at the same time, that’s not really the same thing, is it?

PWD: No, it isn’t ... like when you sitting there just the two of you ... that’s different ... oh, yes ...

The person with dementia was interpreted to have ‘Feelings of significance’ when the caregiver truly became intimate and personal. This lent a feeling of deep fellowship, a feeling that was compared to earlier friendships:

PWD: There’s something that makes it fun, that it’s only one person, I think.

I: What is so good about it when there is just the two of you, do you think, when you are with one member of staff like that?

PWD: It is a little more personal somehow, don't you think? Yes, I think it is. I think it's almost as if we had gone to school together, so that, it comes from so deep inside.

I: Do you mean it's almost like when you had friends at school?

PWD: [becomes obviously happy about my suggestion] Yes, that's what I mean, really close like that. Oh yes, they are really, truly love partners here [laughs].

In the interviews, the persons with dementia expressed that the most important thing was the caregiver's presence and attention during RT, not that anything was achieved.

Establishing security and trust

The category 'Establishing security and trust' involved the caregiver's approaching the person in a non-threatening way and taking pains to provide a sense of security and trust by constantly adjusting to the person. In some cases, it seemed as if this was done when contact was first made. The caregiver's suggestion to do something together could trigger statements from the person with dementia like: 'You're so nice', to which the caregiver answered: 'It's great that we can be together like this'. The goal seemed to be to establish security and trust, a goal that could be observed sooner or later, but the process was sometimes more prolonged. The reason for a varied or more prolonged process was interpreted as serious intellectual deficits in the person with dementia. Conditions that promoted the process were when the caregiver demonstrated responsiveness, made time, repeated information and adapted her approach and how she treated the person when she picked up signals that the person was annoyed. The task sometimes seemed difficult due to the person's severe deficits, as revealed in the following example:

VS: The woman sits with her eyes closed and seems unresponsive to the caregiver's overtures. On one occasion, the woman looks up at the caregiver and asks, 'cold?' and then closes her eyes again. The caregiver picks up the subject of 'the weather', which she interprets the woman to have initiated, and offers to go on a walk with her later that day. The woman looks at her again and nods in reply. Hope can be seen in the caregiver's expression that she has got through to the person, but silence falls again and the woman closes her eyes tightly. The caregiver admires the woman's hair and gently caresses her head. She then begins to ask intellectual questions about the woman's life. There is no response. The woman sits in her wheelchair, eyes closed, head averted from the caregiver, who continues asking the woman questions in various ways. Only when the caregiver begins to tell the person about an everyday activity that had been done does the woman look up and seem to follow the narrative. After a great deal of effort with various topics, the caregiver suggests that the woman might want to lie down and rest for a while, which she agrees to. While the caregiver helps the woman to bed, a dialogue that is both verbal and non-verbal ensues. The woman hugs the caregiver, and the caregiver thanks her. **CG:** 'Are you a little chilly?' **PWD:** 'Yes, I am sometimes'. **CG:** 'Well, I will have to share my warmth with you'. The woman agrees. It can be heard in the caregiver's statements when she is chatting with the woman, without receiving any verbal answers, that the caregiver nonetheless perceives that she is being answered. One suddenly hears the woman say, in a clear voice: 'It's such a pleasure every time you come!' The caregiver answers: 'It's such a pleasure to be here'.

The example describes a prolonged process. Under certain circumstances, the person with dementia expressed withdrawal from the caregiver, when the caregiver asked intellectual questions, for example. The caregiver was, however, responsive to the expressions and changed her strategy, which was interpreted as leading to the establishment of security

and trust. After RT, the person with dementia was asked how it felt, whereupon she answered with conviction: 'It feels lovely!'

Approaching

'Approaching' was a dimension of 'Establishing security and trust', which involved the caregivers first observing the person to determine whether the time was right to approach or make contact. The categories 'Creating an inviting environment' and "Sense of self-determination' were significant to approaching the person.

According to the caregivers, one cannot ignore that there are two parties involved in the approach, but they still felt that the caregiver was mainly responsible for ensuring that the approach was a positive experience. Caregivers emphasized the importance of personal commitment to RT, but expressed the opinion that not all caregivers are committed. The situation could feel uncomfortable for some people, which was thought to depend on the caregivers' capacity and willingness to approach persons with dementia. Caregivers interpreted honesty and sincerity as prerequisites to approaching persons with dementia.

CG:...I'm sure some people think this is hard, the RT...Not everyone is cut out to...neither...oh, how should I put it...talk or give...people are very different. And it has to be really hard for them...After all, it's...maybe a little hard for, and..... you have to let go...and you have to open up too. Even... if a person like them [person with dementia] feels like...go out and go for a walk...or whatever...you feel, well...vibes if you don't think it's fun. So not everyone can do it, I don't think so.

The person with dementia also described the approach as a privilege not all caregivers were granted.

I: But you can talk to the girls?

PWD: Oh yes, I think so...

I:...and that's fun?

PWD: Sure, as long as they want to talk to you, but a lot of them don't want to.

Creating an inviting setting. 'Creating an inviting setting' had to do with the caregiver's efforts to make the setting warmer and more welcoming, something interpreted as significant to approaching the person. Drinks and snacks were usually offered, with the drinks served in pretty glasses. The person might also be offered coffee, fruit or other sweets. Candles were lit and the person was sometimes invited to move to a special room decorated in a seashore theme and with an extra heat source.

VS: 'Let's go in here', the caregiver says. 'Oh, it's so nice here', the woman exclaims as they enter the room. 'Yes, it's lovely', the caregiver agrees. They each take a seat in armchairs placed close together. The woman meets the caregiver's eyes, giving what is interpreted as a look of tenderness and mutual understanding.

The person with dementia gave spontaneous verbal expression of liking the room and was interpreted as also giving non-verbal expression of feelings of security and trust in the caregiver by means of, for example, looks of tenderness and mutual understanding.

Sense of self-determination. Instilling a 'Sense of self-determination' was part of the approach, in which the caregiver considered and showed respect for the person's signs or verbal expressions of willingness or unwillingness to participate in RT. **CG:** '...it's more

like: May I come in and bother you a little bit?' The person was asked what they wanted and their wishes were respected, and although the activity was suggested by the caregiver, the suggestion corresponded to the person's wishes, interests and remaining capacities. When the caregiver asked for the person's permission to disturb them, this was interpreted as helping the person with dementia feel a sense of self-determination. The persons with dementia also stated that there were times when they did not want to participate in RT, when for instance they were not feeling well or felt a need to be alone for a while. Even when they were unwilling to participate, the perception was that the caregiver respected their wishes.

I: But do you like it when somebody comes to see you like this?

PWD: Oh, yes, of course, it's great fun, but... you can't be feeling too bad, because it's no fun then... If you're feeling well... but if you... feel bad, it's no fun... but that's not fun for anybody.

There were also RT sequences in which the person expressed a desire to stop an ongoing activity and the caregiver responded immediately, acting in accordance with the person's wishes.

VS: Right in the middle of the activity, the woman wants to stop and go home. The caregiver immediately complies with her wishes and shows by her actions that she intends to stop. One can hear the caregiver trying, calmly and quietly, to allay the woman's anxiety while slowly starting to wrap up the activity. She does not contradict the woman, but instead offers her dinner which the woman rejects at first. The caregiver quietly comments that it is raining, which leads the woman to remark that the rain makes it hard to go outside. The caregiver turns up the volume on the CD player. It can be interpreted, based on the woman's expression and that she sings along with the verses, that she likes the music. The caregiver also offers the woman a drink in a pretty glass and snacks that are on the table. The woman asks where all this came from and the caregiver tells her that her husband brought it. After a few minutes, the woman expresses gratitude and looks very contented, sitting there in her armchair.

It was interpreted that the caregiver's rapid response to the person's wish to end the activity gave the person a sense of self-determination. This in turn seemed to lead to a sense of security and trust, which was interpreted as contributing to the person changing her mind about wanting to go home.

The persons with dementia sometimes expressed something also interpreted as a form of self-determination, which involved yielding decisions to someone else. In the interviews, they expressed that it was good if the caregiver took the initiative and suggested activities, since they could not remember and thus were unable to state interests and wishes. They were interpreted as feeling content, satisfied and secure in yielding decisions to the caregiver. It sometimes seemed difficult for the persons with dementia to understand what was being offered them. It was therefore interpreted as essential to participation that the caregiver suggested the activity while reminding the person of previous occasions when he or she had been involved in the activity, and that the caregiver prompted the activity.

VS: The caregiver comes into the room and announces that now they are going to talk about old sayings. The caregiver has to repeat the information because the woman does not hear the first time, and she adds words when in the repetition, as one usually does. The woman says that she doesn't know how, but the caregiver encourages her by saying: 'Oh my, of course you do, you did a great job last time'. It seems as if the caregiver is referring to the preceding occasion to help

the woman understand she has done this before and, in so doing, give her the confidence and courage to agree to the activity. The woman is still hesitant, but the caregiver goes on: 'You were so good at it and it was so much fun last time'. After the caregiver has arranged seating, lit candles, put on background music and served snacks, she began the activity, which seemed immediately to appeal to the woman.

The person expressed non-understanding of what was being offered and was therefore hesitant about participating, but when the activity was eventually started, the person showed signs of content.

Communicating equality

'Communicating equality' represents the caregiver's various attempts to communicate to the person with dementia a sense of being an equal. This was interpreted as significant to encouraging the person to open up and thus make a relationship possible. To help the person feel like an equal, the caregiver might suggest an activity that involved cooperation between the parties. Verbal reinforcement of equality between them, and the use of items with similar exterior attributes were interpreted as conducive to the sense of equality.

VS: The caregiver suggests that they should put on aprons to bake. She then puts on an apron before tying an apron around the woman's waist, saying that now they are the same. The woman and the caregiver observe one another and agree that now they look lovely. Once the cake has, with their combined efforts, been put in the oven and they have cleaned up the mess together, the woman remarks that they are 'good girls', to which the caregiver immediately agrees with conviction in her tone.

Conditions for 'communicating equality' were interpreted as improved when caregivers placed herself very close to the person, at the same level and in a position that made eye contact possible. Caregivers sometimes placed themselves at a slightly lower level. This placement was interpreted as a deliberate strategy by the caregiver that contributed to the person's self-perception as an equal.

When the caregiver paid no notice to the person's deficits, this was interpreted as an effective strategy for encouraging the person to feel like an equal. When the person with dementia could not manage a task, the caregiver might say: 'I couldn't do it either; that was hard' or 'I didn't understand that either'. The caregiver's uniform was mentioned as an example of something that kept the parties from being entirely equal. CG: 'I go in as a friend. I'm wearing a uniform, but still...you are... a fellow human being'. Although caregivers expressed the view that equality could never be perfect they were interpreted as believing that it was entirely possible for the person with dementia to feel like an equal.

Feeling like a contributor

'Feeling like a contributor' was a dimension of 'Communicating equality'. Caregivers believed that the persons with dementia wanted to participate and that by participating, they perceived themselves as contributors. CG: 'They really want to help or want to feel like they are a part of things. So, it's not just about you coming up with something to do. They have to be involved'. The persons with dementia were observed to contribute something, such as knowledge and life experience, in nearly all RT sequences. They expressed verbally

and non-verbally what could be interpreted as pride in having been able to contribute. The persons with dementia were interpreted as contributing by responding to the caregiver's friendly actions, for instance. An example of this was the woman who had had her own nails painted and then, after carefully selecting a nail polish, wanted to paint the caregiver's nails.

Expressing concern for the caregiver was another way to contribute. For the persons with dementia, it was interpreted as important to them to reinforce verbal expressions of appreciation by, for example, touching or hugging the caregiver.

VS: The woman gives the caregiver, who is sitting close to her, what is interpreted as a tender glance, and asks with a sympathetic tone whether the staff have had a rough day. The caregiver answers that things have been a little quieter today. The woman turns towards the caregiver and tries to hug her while saying: 'You're not working too hard, are you, darling?' The caregiver moves away a little, so the woman ends up embracing the caregiver's arm. 'Oh no', says the caregiver, 'we get to rest sometimes too'.

In the situation described, however, it can be interpreted that the person's sense of contribution was stymied when the caregiver was not ready just then to accept the hug.

Opening up

'Opening up' involved the persons with dementia availability for the caregivers' overtures as a consequence of 'Assigning time', 'Establishing security and trust' and 'Communicating equality'. Differences in degree of 'Opening up' were, however, interpreted to exist between the various video sequences, which seemed to depend on how well the caregivers succeeded with their strategies for attaining the intended goal. The person with dementia expressed awareness of their inability to remember and hold a conversation, but expressed the view that the one-to-one time (RT) helped them have the courage to try anyway.

PWD: Oh, I like (one-to-one) better... than a lot of them... then I don't really want to say anything.

I: These times when you meet one-to-one, how do you feel about those times? How do you feel then?

PWD: Oh, I get happy, it feels like a relief, and then you get things out that you have inside, you have the courage to tell other people... then you get it out...

I: mmm... yes, I see... And you have the courage to say these things when you are together one-to-one?

PWD: Yes, I do... I trust her completely...

I: So, these times are important to you?

PWD: Very [emphasis] important...

At the caregiver's prompting, the person often began telling parts of her life story. It seemed as if trust in the perceived relationship of equals had the effect that even persons interpreted as having significant language deficits had the courage to talk. There were times when the narrative was suspended, but this did not seem to worry either party. Calmly and quietly, the caregiver, usually interpreted as having good knowledge of the person's life story, suggested a possible continuation of the story. Although her suggestion was not always right, the person with dementia was observed to continue the story after a brief pause.

On one occasion when the person with dementia was worried about being able to manage a step in an activity, the caregiver encouraged the person to try with the words: CG: 'Of course you can, I'm right here'. The person was interpreted as feeling trust that the caregiver would intervene if necessary and hence had the courage to try the step, and succeeded.

'Opening up' involved reciprocity, which involved the caregivers in also extending trust and becoming more open. Clear interest could often be observed in the persons with dementia when caregivers shared something about themselves. PWD: 'Yes, and they might talk about their concerns, and I about mine... a dialogue, you know...'. It was interpreted, however, that professionalism was maintained through the process. The person with dementia expressed the view that the caregiver: '...is very personal without being nosy... it's nice'. The caregivers interpreted this experience of letting go as, for themselves and the person with dementia, a shared experience, which was interpreted as reciprocity during the session. I: If I understand you right, you have also felt a sense of calm during this time? CG: 'Oh yes. It... gives me as much as it gives the person who gets it [RT]. It actually does'.

Prominent findings

The caregivers created relationships with persons with dementia by initiating and controlling the process. To make the person with dementia receptive to the caregiver's overtures, the caregiver first demonstrated that they had time for the person (assigning time), which gave the person a feeling of significance. It was also important that the caregiver established a sense of security and trust in the person with dementia. The approach to the person was important in making this perception possible. To facilitate the approach, an inviting setting was arranged and efforts were made to help the person feel a sense of self-determination, including that found in wanting and being permitted to yield decisions. Efforts were also made so that persons with dementia would perceive themselves as equals; that the persons felt they were contributing and allowed to contribute was an important aspect here. These strategies led to the person with dementia to open up, which was the prerequisite for creating the relationship.

Discussion

Discussion of results

The results showed how relationships with persons with dementia were created in the context of the Relational Time method. At first glance, the professional caregiver's assignment of time and guidance of the process in order to create a relationship with the person may be understood as an example of what Kitwood (1997) and Brooker (2007) describe as malignant social psychology, which involves exerting power over a person in a position of dependency. Providing care to persons with dementia is complex and it requires caregivers to be aware of the risks inherent in the position of power they automatically occupy in relation to the person who is dependent upon care (Kitwood, 1997). The caregivers' overtures and guidance of the process were probably necessary due to the functional deficits of the persons with dementia. Brooker (2007), however, argues that the person's dependency on the caregiver's overtures, help and support requires constant self-examination by the caregiver: the caregiver must examine and manage the imbalance of power in order to avoid infantilizing the person.

The person's uncertainty as to whether the professional caregiver had time probably did not promote creating a relationship and may be one of the main reasons it sometimes took quite some time for a relationship to be established. Davies & Nolan (2008) state that it takes time to establish relationships and time is at a premium in modern, pressurized working environments (Hall & Kiesners, 2005), but some scholars contend that care outcomes are not solely dependent upon caregiver resources. The professional caregiver's attitudes and flexibility also play a role (Cohen-Mansfield & Bester, 2006; Kontos & Naglie, 2007), an opinion shared by the caregivers in this study. It was, however, clear that the persons with dementia were not unaffected by the constant reminders that time was short, which is consistent with the understanding that lucidity exists despite far advanced dementia (Cahill & Diaz-Ponce, 2011; Hughes, 2008; Kontos, 2004). Doubt about whether the caregivers had time for RT may have been, and could be, the greatest barrier to creating relationships in the care setting. The core category of 'Opening up' was interpreted as that which Buber (1958) describes as essential to the relationship. Buber (1958) speaks of the 'encounter' in which one is open or available for the other, but also discusses the vulnerability inherent in opening up to the other, since there is risk of rejection. Rejection is probably something that occurs relatively often in the day-to-day care setting, since so many people are in urgent need of the caregivers' attention. Accordingly, assigning time for RT was most likely significant to creating the relationship, although the most important thing might have been that caregivers showed through body language that they had the time, rather than verbally expressing that they had time. These prerequisites are consistent with that which Buber (1958) identifies as fundamental to the human *I and Thou* encounter, where the deep relationship is established – the encounter that demands openness, presence, closeness and interest from both parties (Buber, 1958).

In the one-to-one RT session with the caregiver, the persons with dementia dared to try, for example, to tell a story even when cognitive capacity was impaired. Occasional errors were overlooked by caregivers, which was probably a strategy for preventing feelings of frustration in the persons with dementia. There was, however, a belief that such overlooking of mistakes might have been perceived as exaggerated. Kitwood (1997) and Brooker (2007) categorize exaggerated praise as infantilization. There is reason to believe that exaggerated disregard of things an adult person should normally know about and be capable of might have been perceived as infantilization. Studies have shown that lucidity is often greater than what might be expected based on the person's deficits (Ericsson, Malmberg, Langworth, Haglund, & Almborg, 2011; Hughes, 2008; Kontos & Naglie, 2007; Zingmark, Sandman & Norberg, 2002).

According to this and earlier studies (Malloy & Hadjistavropoulos, 2004; Nolan, Davies, Brown, Keady, & Nolan, 2004), a sense of security and trust has proven important to creating a relationship. A prerequisite for establishing security and trust was that the persons with dementia had a sense of self-determination, although aspects of the results indicated that it may be equally important to be allowed to yield decisions to someone else. The question is whether the sense of self-determination was not more a matter of having one's wishes respected and not being directly contradicted than of being allowed to decide things for oneself. Confirmation is always highly significant in caring for persons with dementia (Edvardsson, Winblad, & Sandman, 2008). The caregiver's efforts with the woman who wanted to go home, for example, probably led to a greater sense of security and trust, which was probably more important than actually being able to act on the original expressed wish to go home. Malloy & Hadjistavropoulos (2004) talk with reference to

Heidegger, about being 'transparent', where the caregiver facilitates, rather than prescribing limits, and provides support when the person's capacities are inadequate or where autonomy could lead to harm or violation of personhood. Self-determination may not always be the best or most secure situation. When caregivers were transparent, the persons with dementia did not notice that it was the caregivers who were 'in charge' and therefore felt liberated and self-determining, in line with Malloy & Hadjistavropoulos (2004).

The professional caregivers and the persons with dementia mentioned that not all caregivers were willing or able to establish relationships. Kitwood (1997) and Brooker (2007) posit that caring for persons with dementia demands closeness and warmth and that closeness is essential to creating a relationship (Buber, 1958). Since the relationship is considered significant (Davies & Nolan, 2008; McCormack, 2004; Nolan, Davies, Brown, Keady, & Nolan, 2004), it may be important to consider the relevance of the perception that not all caregivers have the capacity or sensitivity required to establish relationships with persons with dementia. It is likely that professional caregivers may find it difficult to get as close to the person as they need to in order to create a relationship. Basting (2003) argues that dementia itself can be frightening, often due to inadequate understanding of the disease. Norbergh, Helin, Dahl, Hellzén, & Asplund (2006) showed that there was a lack of interaction due to language difficulties. The persons with dementia communication deficit may explain why one-to-one situations may feel uncomfortable for caregivers. Kitwood (1997) argues, however, that if caregivers are given the opportunity to process what engenders feelings of discomfort, the approach that is so important to establishing a relationship may be made possible. Research has shown that education and training can improve caregivers' skills at providing care to persons with dementia (Kontos & Naglie, 2007; McCallion, Toseland, Lacey, & Banks, 1999;), which might also apply to creating relationships. Experience working with RT for some time may have helped the caregivers in this study improve their skills at creating relationships with persons with dementia. The fact that capacities believed lost often emerge when a relationship has been established (Normann, Asplund, Karlsson, Sandman, & Norberg, 2006; Zingmark, Dandman, & Norberg, 2002) may have been the reason that caregivers, who had thought it not worth the effort to try and approach persons with dementia in such a way that relationships were established, suddenly discovered that capacities exist that do make it worthwhile. It is conceivable that such a discovery may have changed the caregivers' views of both the person and the dementing illness and thus made them more inclined to prioritize one-to-one interaction, as in RT, which they have learnt by experience facilitates the creation of relationships.

There is every reason to believe that the sense of well-being perceived during RT was linked to the relationship that had been created. The person with dementia's deficits, however, impede the maintenance of the relationship and make it frail and short-lived, particularly when the person has severe dementia (Malloy & Hadjistavropoulos, 2004; Penrod et al., 2007). For this reason, it is likely that the deep relationship that engenders well-being must be recreated in every encounter with the person with dementia. For the persons with dementia who participated in this study to feel episodes of well-being, it was probably important that they were given opportunities for the one-to-one interaction offered in RT. There is, however, always risk that a method like RT, introduced to improve care, will be performed mechanically and not fulfil the original aim of creating a relationship. This mechanization would hopefully be revealed when the positive effect of the 'encounter'

(Buber, 1958) – the relationship – fails to materialize and thus also the feelings of well-being expressed by both parties in the study.

Discussion of method

The investigator (IE) was in the field intermittently for two months to perform repeated videotapings and interviews with persons with dementia. It was important to interview the persons with dementia on repeated occasions because they were generally fatigued after the videotaping and unable to maintain focus and concentration on what they had been involved in, that is, the purpose of the interview. Charmaz (2006) argues that it is important to have a prolonged engagement in the field (Creswell, 2007) and to perform repeated interviews to obtain in-depth information (Charmaz, 2006). The interviews were held immediately after RT in order to capture the person's perceptions of the session. Experiences that trigger positive or negative feelings may remain in the person's consciousness for some time after the experience (Engström, Marmstål Hammar, Williams, & Götell, 2011). Despite this, there was risk that the information might be insufficient to achieve saturation in the material (Charmaz, 2006) because the interviews were brief. This was compensated for by means of the repeated interviews. The briefer interviews often yielded more concentrated information than the longer interviews, in which the person with dementia's concentration on the subject successively waned.

Both authors (IE and IH) who conducted the interviews have experience of working with, and interviewing persons with dementia and caregivers. Various stages of dementia and the difficulties several persons with dementia had expressing themselves clearly in words required follow-up questions to verify what the person was perceived to be saying both verbally and non-verbally, since the risk of over-interpretation is always present. The capacity to express oneself in words may be lost while the capacity to understand may be intact (Hughes, 2008), which makes it possible to verify the information given (Ericsson, Aronsson, Cedersund, Hugoson, Jonsson, & Wärnberg Gerdin, 2009). There was also risk of posing leading questions, but it was significant that the questions were direct, short and concrete due to the diminished capacity for abstract thinking common in dementia (Allan & Killick, 2008).

The investigators (IE, IH) had a preunderstanding that could increase the risk of over-interpretation. The co-author (SK) did not participate in data collection and had no previous experience in the field of study and thus acted as a peer debriefer (Creswell, 2007), which is considered to reduce the risk of over-interpretation. Pre-understanding is, however, not only a drawback, as it also facilitates notice and identification of important information that might otherwise have been missed (Charmaz, 2006). The interviews with caregivers were conducted by co-author IH, who had no experience of RT, which was thought to reduce the risk of experience-based influence on how questions were asked and that respondents might give the answers they believed were expected (Glaser & Strauss, 1967). Triangulation (Charmaz, 2006; Creswell, 2007) was applied to further enhance reliability through the involvement of all authors in the analysis, the use of multiple sources of data and several interviewers.

Conclusion

Caregivers can establish relationships with persons with moderate to severe dementia. The most important factors in creating relationships are: that the caregiver takes the

initiative and demonstrates that time is available; that the person with dementia feels a sense of security and trust and feels like an equal, and thus dares to open up to a relationship. In a simple and straightforward way, the results of this study give caregivers an understanding of the factors that influence how relationships with persons with dementia are established. It is likely that creating relationships may also be a path to understanding the practical application of person-centred care. When a relationship has been established with the person with dementia, caregivers are given the response so sorely needed to feel that their work is meaningful, while persons with dementia feel a sense of well-being through the confirmation of their personhood.

Greater awareness of the significance of relationships in caring for persons with dementia is needed in organizations and among caregivers. Understanding needs to be increased that small measures, such as the RT method, that do not require significant resources can open paths to attaining the goal of creating relationships with persons with dementia to enhance their sense of well-being.

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