Emotional experience in patients with advanced Alzheimer's disease from the perspective of families, professional caregivers, physicians, and scientists

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Objectives: The objective of this qualitative study was to gain insight into families’ and professionals’ understanding of the emotional experience in patients with advanced Alzheimer’s disease.
Method: A total of ten focus group interviews were carried out with 63 participants (relatives n=20; caregivers n=17; physicians n=12; scientists n=14) recruited using purposive sampling strategies. Each focus group was audiotaped, transcribed and analysed using the method of structured qualitative content analysis.
Results: Study findings show that for all groups with the exception of relatives, emotionality is one of the most important characteristics retained despite the illness. Indicators are patient's continued ability to produce emotional signals, be responsive to others, and retain emotional information despite memory loss. In the spectrum of emotions, professional caregivers emphasize positive emotional states more strongly than physicians or scientists. In contrast, relatives emphasize the loss of emotional experience. Critical indicators denying subjective emotional experience are impairment of (autobiographical) memory (especially the non-recognition of relatives), the reduction of means of verbal expression with simultaneous uncertainty in interpreting nonverbal expression as well as the perceived discrepancy between present emotional experience and behaviour and that of the premorbid personality.
Conclusion: When relatives anchor on the premorbid personality, the perceived discontinuity of emotional reactions to stimuli triggering an emotional response in contrast to their own expectations gives rise to an extremely ambiguous situation. Training programmes should be developed for families to help them comprehend and respond to nonverbal emotional expression.

Keywords: Alzheimer’s disease; psychological and social aspects; caregivers; focus groups; emotions

Introduction

Dementia is on the rise worldwide. Germany is among the nine Global Burden of Disease (GBD) regions with the highest number of dementia patients (1.6 million) (Prince, Wimo, Guerchet, Ali, Wu, & Prina, 2015). Some two-thirds of all dementia cases can be classified as Alzheimer's disease (AD), a progressive neurodegenerative disease characterized by impairment of a number of higher cortical cognitive and affective functions. Experimental studies have identified deficits in emotion processing, in particular in the recognition of others' emotional states (McLellan, Dalrymple-Alford, & Porter, 2008; Klein-Koerkamp, Beaudoin, Baciu, & Hot, 2012). However, studies have also shown that options for nonverbal interaction as well as socio-emotional competencies are still in place, even in later stages of the disease (Maki, Yoshida, Yamaguchi & Yamaguchi, 2013; Bucks & Radford, 2004; Sabat & Collins, 1999). Since the ability to express oneself verbally diminishes in line with the progression of AD, emotions play an important role in communication. Emotional expressions can provide information about a person's state or about their attitude towards a situation, and they can prompt others to perform certain actions (Scherer, 1990; Russell & Fernandez-Dols, 1997). Perception and appropriate interpretation are a basic prerequisite for the AD patients’ remaining emotional capacities to actually unfold (Athlin & Norberg, 1987). Misinterpretations can cause interaction partners to fail to pay attention to a behaviour or to overlook important information and communication cues. Caregivers' beliefs about whether Alzheimer's patients are still capable of communicating, even at later stages, influence their own efforts to communicate with the patient (Scholl & Sabat, 2008; Ekman, Norberg, Viitanen, and Winblad, 1991). Subjectively perceived emotional contact is particularly important for caregivers, however. The more limited the patient's capability is assumed to be, the greater the risk that caregivers will distance themselves from the patient and consider their own actions to be meaningless (Akerlund & Norberg, 1990). However, perceiving and interpreting emotional experience is difficult. Studies on emotional responsiveness show that as AD progresses, emotional expression changes; facial expressions diminish and are not always coherent with the AD patients' emotional experience. Video analyses of facial expressions of final-stage Alzheimer's patients show that complex emotions are not recognizable, but rather only fragments of emotional facial expressions such as joy, surprise, sadness or anger (Asplund, Norberg, Adolfsson & Waxman, 1991; Jansson, Norberg, Sandman, Athlin & Asplund, 1993). In many cases, the disease is accompanied by neuropsychiatric symptoms, in particular, apathy, which lead to a great impairment of emotional responsiveness and in general, reduce the frequency of the facial expression of emotions and their specificity and congruence with the stimulus (Seidl, Lueken, Thomann, Kruse, & Schröder, 2012).

The time and extent of this loss of abilities differ from individual to individual. The illness progresses dynamically and the remaining abilities are represented differently depending on social context (Kitwood, 1997). Considerable significance should therefore be attributed to the interaction partners with whom the patient communicates in each specific situation. Studies have identified differences between professional caregivers and relatives in the attribution of symptoms, their frequency of occurrence and causes (Cohen-Mansfield, Golander & Heinik, 2013; Donnelly, 2005), their cognitive capacity (Burns, Nichols, Graney, Martindale-Adams & Lummus, 2006), and their convictions as to the causes leading to crises in dementia (Toot, Hoe, Ledgerd, Burnell, Devine & Orrell, 2013). Differences among professional groups (physicians, psychologists, and professional caregivers) with respect to symptoms, the identification of symptoms, the presumed aetiology, and options for intervention for challenging behaviour are described in the study conducted by Cohen-Mansfield, Jensen, Resnick & Norris (2012). However, only sparse research exists on the perception and interpretation of emotional experience comparing different interaction partners.

Method

Design

In a qualitative study, four different groups were investigated: relatives, professional caregivers, physicians, and scientists. These groups represent nearly all individuals in contact with patients with middle- to late-stage Alzheimer's disease. A focus group design was selected for the study (Willig & Stainton-Rogers, 2008; Ryan, Gandha, Culbertson & Carlson, 2014). We preferred to use focus groups rather than individual interviews, since the inherent group dynamics of the focus group format allows the deeper significance of a topic to be explored and access to implicit (tacit) knowledge to be gained (Morgan, 2012).

Sample and recruiting

Three focus groups each with relatives and caregivers and two focus groups each with physicians and scientists were carried out in the state of North Rhine-Westphalia, Germany. A total of 63 participants – 20 relatives, 17 professional caregivers, 12 physicians and 14 scientists – took part in separate focus groups. Relatives, professional caregivers, and physicians were recruited regionally via networks such as Alzheimer's societies, medical specialists' initiatives, and an advertisement in a regional newspaper. Scientists were recruited Germany-wide based on the results of screening of research programmes on dementia. The participants were selected according to the principle of 'purposive sampling' (Flick, 2014). Table 1 presents the inclusion and exclusion criteria for the participants.

[Table 1 near here]

The focus groups with relatives were composed of relatives caring for the patients themselves (50%) or who had contact to care home-resident patients at least twice a week (50%). Eight relatives were spouses of a patient (40%), while seven were children (35%) of a patient or the patient's children's spouses (20%). One participant was a patient's niece. Seventy-five per cent of the participants were over 55 years old (Table 2).

[Table 2 near here]

In the focus groups with the professional caregivers, 13 participants (76%) had more than 10 years of professional experience in caring for patients with Alzheimer's disease (Table 2). Ten of the participants were certified geriatric caregivers, 6 were nurses, and one participant had both qualifications (geriatric caregiver and nurse). Two of the 17 participants had acquired additional qualifications in caring for dementia patients. Among the 17 professional caregivers, 11 worked in (partially) residential care facilities. These included nearly equal numbers of caregivers from facilities specializing in dementia treatment (45%), as well as those from facilities not specializing in dementia (55%). Three participants each worked for an out-patient care service and for hospital-based acute care of dementia patients. Apart from one male participant, all caregivers were women.

The focus groups with physicians comprised both physicians in private practice (50%) and physicians working at (gerontopsychiatric) hospitals (50%). Nine of the 12 physicians (75%) had over 10 years of experience in the medical care of patients with Alzheimer's (Table 2). Five of the six physicians in private practice also offered their medical services at care homes or dementia group homes. The participants included neurologists, psychiatrists, general medicine specialists, and internists. All physicians were older than 36.

The participating scientists came from clinical research (36%) and health services research (64%). All of the scientists were involved in relevant research projects in which personal contact with the patient is a component of the research. The disciplines of medicine, psychology, and gerontology were represented. The group of scientists included both senior scientists (50%) and early career researchers (50%).

Procedure

A semi-structured guide tested on a pilot focus group with five professional caregivers served as the framework for the discussion in all focus groups. The interview guide comprised key questions and additional questions. The key questions were visualized in order to stimulate thinking and argumentation. The participants were asked the following questions: 'How does the world of feelings of the Alzheimer's patients present itself to you?'; 'In your view, how does the emotional experience of patients with Alzheimer's disease differ from the emotional experience of healthy individuals?'; and 'Are there situations in which you think it is possible to successfully communicate with the patient even if they have advanced Alzheimer's disease?' The participants were encouraged to explain the reasons for their particular view and to substantiate it based on situational or case descriptions. A list of additional questions served to obtain more detailed information on relevant items. The participants were asked to name indicators they used to make their assessment, as well as uncertainties they may have, and the role of contextual factors that in their experience have an impact on the extent to which the emotions of Alzheimer's patients are perceived.

All focus groups were facilitated by the author in a neutral role. A 'funnel design' was used (Morgan, 1998). In each group, one research assistant noted (nonverbal) information on the interaction among the participants, such as when participants supported the comments of other participants. Each focus group lasted around 2.5 hours and was audiotaped and transcribed with the consent of the participants.

Analysis

All transcripts were evaluated by means of qualitative content analysis (Hsieh & Shannon, 2005) and framework analysis (Ritchie, Spencer & O'Connor, 2003). Deductive and inductive categorization were combined using the software MAXQDA. For quality assurance, two raters (the author and an additional rater from the research team) were deployed. There was good inter-rater reliability (Cohen's kappa = 0.84).

In the first step, both raters read all transcripts independently of each other, wrote brief summaries of what had been discussed, and made comments on the text passages that appeared relevant to them for the comparison between the various stakeholder groups.

In the second step, main thematic categories were developed deductively based on the guide. One focus group each from each of the four stakeholder groups was rated by the two raters independently of each other, the results discussed and the preliminary categories modified and added to. The entire material was then rated based on the main categories.

In the third step, the inductive development of subcategories was carried out. In several rounds of discussion, the entire category system was broken down and the entire material then rated independent of each other.

The analytical assessment was performed on this basis. To this end, case overviews and thematic essays were developed for specific subcategories in order to identify differences and commonalities between the groups of participants.

Results

The results of the study show that scientists, physicians, and professional caregivers reach similar findings when attributing emotional experience; however the explanations are characterized by various focuses and nuances. The assessments by the group of relatives deviated significantly from the assessments of the other groups.

The perspective of the scientists, physicians, and professional caregivers

The members of professions dealing with dementia agreed that while in the course of the disease emotional experience is increasingly influenced by the disease symptoms, this experience was retained right into the advanced stage of the disease. The indicators for this are social interactions in which the patients enter into an emotional relationship with their environment. This comprises not only emotional responsiveness that at times continues to express a situation-appropriate reaction, but also the capacity to perceive and distinguish mood and emotional mind-set during interpersonal contact based on individuals' intonation, volume, facial expressions, or gestures.

Based on the patients' behaviour during care and their observation of the group dynamics among the patients, professional caregivers deduce a high level of emotional sensitivity on the part of the patients. This interpretation includes the notion that while patients do not notice that they have been verbally deceived due to their deficient memory capacity, when it comes to emotional contact, e.g. touching, they are able to differentiate sincere attention from insincere attention. The professional caregivers interpret this characteristic as a means of compensation for cognitive deficits, which suggests a new quality compared to healthy individuals.

> I sense that this world of feelings is very well-developed and – perhaps it's a lame comparison – not unlike the way blind people concentrate much more on their sense of hearing and use it much more than we do. And that's exactly what my

> feeling is with people who are changed by dementia. They know immediately if I am not being authentic. (professional caregiver #30)

In contrast, physicians and scientists assume that both for the search for intimacy and contact, as well as the intuitive ability to receive emotional signals from others involve a fundamental capacity to regulate relationships and emotional ties already in place during childhood.

> This distinctive search for intimacy, protection, this desire to retain close ties, and to sense how close another person is to you and where you feel safe and secure, even up to and including in the late stages of the disease. (physician #38)

> Of course, one thing that is essential for survival very early on is the ability to recognize whether the person sitting across from me is on my side or not. This is instilled very early on. When it comes to dementia, we also say, 'First in, last out'. So I think that this is an ability that definitely is retained for a very long time. Meaning on a very fundamental, emotional level; not a taking of perspectives in the cognitive sense, but the regulation of ties and relationships on an emotional level. (scientist #62)

However, both groups emphasize that the ability to reflect on the emotional state of others is already lost in the middle stage of the disease. While professional caregivers are uncertain as to whether impulses for help that they observe among patients towards other patients and that appear to them as pity or as 'caring about others' are in fact an expression of a still-intact ability to understand the emotional states of others, scientists also describe this behaviour, but emphasize the loss of ability for cognitive perspective-taking.

> I think they also notice when someone else is crying. The problem is therefore rather that we would think about why the person is crying and what we can do to help the person. And that's something they can no longer do. But they can offer comfort and give them a hug. (scientist #60)

All three groups assumed that patients are able to perceive sympathy and antipathy up to and including the advanced stages of the disease.

It is professional caregivers who are confounded by the fact that on the one hand, patients appear to forget aggressive behaviour on the part of a fellow patient fairly quickly, but on the other hand, based on facial expressions, gestures, eye movement and even fundamental physiological reactions, they observe that patients react individually and specifically to people with whom they have relationships. Depending on the person the patient interacts with, physical intimacy is permitted or rejected, and the patient shows more or less intense responsiveness and the presence or absence of negative emotional states such as restlessness. These observations lead to the conclusion that despite the cognitive deficit of no longer being able to remember events, they are still able to recognize individuals by means of nonverbal signals and connect both positive and negative emotions with certain individuals.

Scientists and physicians agree with the hypothesis of a familiarity-based recognition that allows a certain continuity in relating to others beyond the conscious recall of individuals or earlier events that they experienced together with these individuals. However, there is uncertainty with respect to the stimuli that can 'trigger' this type of tie.

While all three groups claimed that patients also experience emotions in the advanced stages of AD, they have different opinions on the extent to which it is possible to correctly interpret the patients' emotional experience in contact with them, with scientists the most sceptical. They emphasized that facial expressions are not a reliable indicator of how late-stage Alzheimer's patients feel. While physicians share this scepticism, they also believe that if there were more time available for patients during medical and nursing care at care homes, it would be possible to better understand patients' emotional utterances. At the same time, physicians also describe the difficulty expressed by scientists of being able to distinguish whether the particular emotional utterance should be attributed to the disease symptoms or to the situational circumstances. The frequent existence of a comorbidity makes interpretation more difficult. In contrast, professional caregivers are much more optimistic with regard to the possibilities of recognizing how Alzheimer's patients feel. They consider it to be possible in principle to interpret nonverbal signals even in late-stage Alzheimer's patients. Positive facial expressions in particular, such as a smile, are always interpreted as 'feeling well'. Since psychosocial factors are considered to be the primary trigger of emotional utterances, professional caregivers also assume that it is not only possible to recognize what patients feel, but also what their emotional utterances are related to. From their view, this can be concluded from familiarity with their biography, meticulous observation or their own empathy towards the patient.

> But I think these are the sensory channels that mature because they are no longer able to make themselves understood verbally, meaning through language. I of course have to be very sensitive myself in order to perceive this. I always say that it's a different language. But I'm learning to understand it. (professional caregiver #29)

The professional caregivers particularly emphasized the emotions with positive valence in the range of emotions. In later stages, in which the patient's awareness of the disease is lost, the professional caregivers assess the patient's emotional experience as more positive than in stages of the disease in which the patient is still fighting against himself or herself, cognizant that his or her own cognitive abilities will be lost. In the later stage of AD, patients then display humour, are again able to accept physical contact, and their mood can then be more easily positively influenced by external stimulation and activation, the professional caregivers reported. Anxiety, which the physicians and scientists describe as a typical emotion influencing all stages of AD, was mentioned very rarely.

The relatives' perspective

In contrast to the members of professional groups concerned with dementia, the relatives are convinced that the increasing loss of both cognitive capacity and the possibilities of verbal expression is also associated with a loss of emotional experience.

Relatives experience that as the disease progresses, jointly shared memories fade. For the relatives, these memories are not simply facts forgotten by the patient. They are rather part of their shared biography in which these memories are emotionally anchored. From the perspective of the relatives, the items that the patient can no longer remember also no longer have any emotional significance for the patient.

> (...) the way I see it, this world of feelings keeps getting smaller somehow, and is restricted to a minimum. (...) my mother-in-law always had a close connection to her children. (...) She was always a 'feelings' person: my family, my children, my grandchildren. That's all gone. If we look at picture and if I say, 'That's your daughter and your grandson'. 'Hmmm'. That's all that's left. (...) Then I think, my God, that's her life, the family; the things she experienced with them, and it's all gone. If I put myself in her place and imagine losing everything, this connection, the feelings, the love for my family. (...) It's all no longer important, not there anymore, and even when her brother died, a tear rolled down her cheek (...) and that was it. And I thought, God, no. (daughter-in-law #10).

The overall loss of the capacity for emotional experience is attributed to the impairment of the patient's autobiographical memory. For the patients' children in particular, the critical indicator is the failure to recognize the relative. If the patient is no longer able to recall the relative’s name, nonverbal expressions such as smiling or gestures that appear to be emotional devotion on the part of the patient are mistrusted. This is particularly true when communication on the verbal level is no longer possible.

> I think that she doesn't have any feelings any more at all, or she isn't able to express them anymore. (..) My mother doesn't even notice when I come or go. For instance, when I arrive, I say hello and touch her arm, 'Hello Mother. I'm here'. Then she says, sometimes: 'That's nice'. (...) And a minute later, a nurse from the nursing staff comes in and says, 'Oh, Mrs. G. Your son is here'. 'I don't have any children!' (son #5)

For all relatives, the benchmark of comparison for perceiving and interpreting the patient's world of feeling is the formerly healthy person. When stimuli that used to trigger emotions fail to stimulate affective responses or they trigger reactions that are inappropriate for the situation and untypical for the formerly healthy person, relatives are disconcerted or they assume that the patient's emotional experience is completely gone as a result of the disease. Relatives are most likely to assume a subjective experience quality when they can create an apparent congruency between the formerly healthy person and the person now affected by AD.

> She loves music. She was a very good singer, a soprano, and that is reflected again. Meaning that when classic radio is on, and that's quite often the case at home, she feels very well. (husband #11)

Many of the relatives feel helpless when confronted with the patient's reactions and find it confusing when the patient does not react as expected. This confusion is a burden for the relatives.

> I tried looking at pictures. That worked for a while, but that doesn't really help her anymore. So you really don't know at all what you should do now, what will be good for her or what doesn't help. Because sometimes exactly the opposite happens. (daughter #12)

In the range of emotions, the loss of emotions most frequently lamented are those emotions that characterized the patient's personality, on the one hand, and those that shaped the interaction with the relatives, on the other. The loss of modesty is felt to be particularly painful and – if they occur among patients – reactions such as aggressive behaviour that are otherwise not typical for the patient. The perceived inability to experience positive feelings is also painful, such as happiness in the presence of family members who expressed an emotional connection to the patient when he or she was still in a healthy state.

The perceived changes in the patient's emotional experience cause the family members to believe that they will also lose the ability to maintain (emotional) contact with the patient.

> After a certain time I do ask: 'So how do you feel? How are you? What are you thinking about?' because he doesn't communicate anymore. It's so strange now, and our contact, it's starting to fade. And when he's lying in bed in the evening, he takes the cover (...) I always think that he wants to be completely wrapped up. And then when I take his hand when it's time to say good night, he also holds onto my hand very firmly, for a long time. But there isn't much more than that. (wife #15)

With this interpretation, family members rely solely on communication patterns from the past. It is based on the conviction that 'successful' communication is possible only on a verbal level and only if it can be safely assumed that messages will be encoded or decoded 'correctly'. If the 'linguistic codes' created and employed together in the course of the relationship with the family member while he or she was still healthy can no longer be called up, it is concluded that reciprocal communication is no longer possible. Other means of expression, such as emotional nonverbal options, are barely noticed as a means of communication.

Discussion

Summary of results

This was the first study that aimed to compare how relatives, professional caregivers, physicians, and scientists perceive and interpret the emotional experience of patients with Alzheimer's disease. Study findings show that for all groups with the exception of relatives, emotionality is one of the most important characteristics retained despite the illness. Indicators are the patient's continued ability to produce emotional signals, be responsive to others, and retain emotional information despite memory loss. Based on an array of behaviours, a long-lasting capacity for regulating a fundamental emotional relationship and binding emotional ties has been assumed. This is consistent with Bowlby's (1969) 'attachment theory' which Browne & Shlosberg (2006) used to explain the 'parent fixation' of Alzheimer's patients.

The comparison between the professional groups demonstrates that in the spectrum of emotions, professional caregivers emphasize positive emotional states more strongly than physicians or scientists and are markedly more optimistic about recognizing a patient’s emotional state and accurately interpreting its causes. Professional caregivers ascribe especially great significance to psychosocial influence factors. This includes particularly their own caregiving contribution: the assumed emotional experience is viewed as feedback on the success of their own caregiving actions. Their own influencing potential is not critically examined.

The assessments of the group of relatives deviated significantly from those of the other groups. Consistent with the findings of Harmer & Orrell (2008), the present study demonstrates that relatives tend to focus on the loss of abilities rather than to perceive them as retained resources that they value and foster.

While relatives also describe situations in which emotional utterances occur, they express doubt about a fundamental subjective quality of experience. This is especially apparent in their attribution of positive emotions, which in the patient's healthy state could be reliably interpreted as an expression of valuation of events. The perceived discontinuity of emotional responses to emotion-triggering stimuli contrary to their own expectations or a changed emotional expression (facial expressions, behaviour) compared to the formerly healthy person constitute highly ambiguous situations for relatives, and they make the integration of their probabilistic and evaluative orientations more difficult (Babrow, 1992). The uncertainty of not being able to categorize observations and the fact that the patient behaves differently to their expectations is experienced as distressing.

Future research

The results of this study suggest that there are psychological mechanisms leading to biased judgements both in professional caregivers and relatives.

Professional caregivers are too optimistic that patients can experience emotional states despite their dementia and too quickly assume that the patient's satisfaction and well-being are the result of their own caregiving. The success of their own activities is evaluated in particular based on the patient's facial expression, an indicator that the scientists consider to have only limited validity. However, as long as the patient remains capable of having an emotional relationship with his or her environment, the caregiver's own caregiving can be considered to be significant, leading in turn to individual self-affirmation. Athlin, Norberg & Asplund (1990) also reported how important it was to caregivers to be able to establish emotional contact to the patient. The findings of our study show the other side of the coin, however. Attributions that feed self-affirmation could impair critical reflection about one's own interpretations of the patient's behaviour (Ross & Anderson, 1982).

The relatives underestimate the patient’s sentience. The results of the present study indicate that relatives especially focus on characteristics and abilities with which they can recognize the patient's premorbid personality, albeit only rudimentarily. As assumed by Cohen-Mansfield, Golander & Heinik (2013) with regard to the perception of challenging behaviour, the results therefore suggest a distortion of judgement due to the 'premorbid personality' anchor (Tversky & Kahneman, 1974). Additionally, the present results give rise to the question as to whether the generalized attribution of perceived emotional deficits to the disease is not actually a coping strategy for dealing with insecurity (Monat, Averill & Lazarus, 1972). Reinterpretations are part of such a coping process, employed in particular when control of a situation seems or is impossible.

This study provides indications for this kind of coping strategy. In the shared reflection in the focus groups, the participants' own interpretations were carefully reconsidered. In so doing, relatives revealed their uncertainty about whether they understood the patients' behaviour correctly and shared their concern that the patients sense and are aware of more than they think they are. The results of Harris, Adams, Zubatsky & White (2011) also show uncertainty on the part of the relatives as the disease progresses. The spouses participating in that study were uncertain as to the effects of disease on the quality of their relationship. They registered that it was increasingly difficult to behave in their relationship similarly to the way they had behaved in the past. The generalization of the loss of abilities observed in the present study may counteract the stressful situation of uncertainty.

Further research is necessary in order to investigate the hypotheses that the biased judgements ascertained as part of this study ensue from self-serving attributions among professional caregivers, on the one hand, and from coping strategies among relatives, on the other hand.

Implications for practice

Emotional competences and nonverbal utterances of Alzheimer’s patients can take on a communicative function particularly when, at later stages of the disease, verbal capabilities are impaired. It is even more significant for communication partners to neither underestimate nor overestimate the patients' remaining abilities.

While the psychosocial perspective is significant as an alternative concept to a purely biologistic interpretation of the design in clinical practice, in interaction with motivational factors, it is also accompanied by the risk of contributing to distorted perception (Eggers, Ekman & Norberg, 2013). Self-serving attributions made by professional caregivers can lead to an overinterpretation of nonverbal utterances of Alzheimer's patients, i.e. too much is read into the apparently emotional behaviour and in so doing, caregivers underestimate the influence of dementia-related disturbances, such as deficits in emotional regulation. Underestimates of pathological influence factors as well as overestimates of one’s own influence on the disease were also shown in caring for patients with aggressive behaviour (Karger 2015). As a consequence, there is a danger of belated consideration of medical intervention.

If the patients are cared for at home by their relatives, coping strategies for stress management may lead to a blanket attribution of patient behaviour to the disease’s own dynamics. Emotion-oriented approaches in care indicate that they can influence not only the patients' emotional well-being, but can also play a major role in influencing the extent and course of the disease (Finnema, Dröes, Ribbe & van Tilburg, 2000). Against this backdrop, blanketing the loss of emotional experience harbours the danger of overlooking situative and interpersonal factors of a patient’s emotional states so that remaining resources cannot be developed.

Limitations

The results of the professional groups concerned with dementia cannot necessarily be transferred to professional caregivers with more limited training. As the study performed by Kada, Nygaard, Mukesh & Geitung (2009) showed, there is a correlation between a positive attitude towards Alzheimer's patients and the level of specialized training. It can also be assumed that physicians and scientists who rarely have direct contact with Alzheimer's patients may assess the situation differently. Further research is required in order to compare how different groups perceive and interpret typical characteristics of Alzheimer's dementia.

Conclusions

This explorative qualitative study permitted insights to be gained into families’ and professionals’ understanding of emotional experience in patients with advanced Alzheimer’s disease. For relatives, it is especially difficult to correctly attribute nonverbal signals and emotional utterances. Family members are frequently only able to fall back upon their own subjective observations and, at best, their discussions with other relatives or professional caregivers. The results of the study clearly illustrate the need to develop training programmes for families to improve comprehension of and ways to respond to nonverbal emotional expression. Furthermore, there is a need for good training programmes for professional caregivers that particularly convey the interdependency between pathological processes and external psychosocial and institutional factors influencing Alzheimer's disease. Such programmes can counteract the risk of professional caregivers overestimating the patients' remaining abilities, of overwhelming the patients, or of working away at goals that cannot be achieved (Tarrier, Barrowclough, Ward, Donaldson, Burns & Gregg, 2002).

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Table 1. Inclusion and exclusion criteria for the participants

Participants	Inclusion	Exclusion
Relatives	• The diagnosis 'Alzheimer's dementia' confirmed by a physician. • Patient's need for care • Close relative • Primary caregiver or at least twice-weekly visit to the patient at a care home.	• Other dementias, unclear diagnosis • Patient still lives independently
Caregivers	• Training as geriatric caregiver or nurse • Full-time paid work in nursing care with a focus on Alzheimer's dementia	• Care assistant • Volunteer
Physicians	• Specialists and general medicine specialists • Medical care of Alzheimer's patients at least once a week	• Physicians at university hospitals
Scientists	• Current participation in a research project on diagnosis, therapy or care of Alzheimer's patients • At least two scientific publications on the topic in the past two years	• No personal contact to Alzheimer's patients in the context of the research

Table 2. Sociodemographic variables of the participants

Note: Years of professional experience for relatives not meaningful and omitted

	Relatives, %	Professional caregivers, %	Physicians, %	Scientists, %
Sex				
female	55.5	94.1	66.7	78.6
male	45.0	5.9	33.3	21.4
Age				
< 35	0	23.5	0	21.0
36–45	5.0	29.4	33.3	35.7
46–55	20.0	29.4	33.3	28.6
56–65	35.0	17.6	33.3	14.3
66–75	30.0	/	/	/
76–85	10.0	/	/	/
Professional experience				
1–5 years		11.8	16.7	50.0
6–10 years		11.8	8.3	21.4
11–15 years		41.2	41.7	7.1
16–19 years		0	0	7.1
20–30 years		23.5	16.7	7.1
>30 years		11.8	16.7	7.1