Introduction

People with dementia sometimes develop behaviours in the course of their illness that do not always correspond to the expected behaviour of their environment. These "non-compliant" behaviours trigger different reactions in their environment.

This depends on the context in which the behaviour with dementia occurs. Are we dealing with the home environment or are the persons in acute, day or long-term care?

The real environment makes demands on people with dementia that do not always match their experienced reality. The resulting actions and reactions of people with dementia are often perceived as challenging by the environment.

This challenging behaviour of people with dementia often presents caregivers with unsolvable tasks.

Therefore, it is absolutely necessary to understand the reasons for the challenging behaviour of people with dementia in order to be able to react adequately.

Clarification of terms

Accompanying people with dementia can often be very challenging for caregivers. This is especially true when aggression, an increased urge to move, considerable orientation problems, a high degree of danger to others and oneself or other behaviours occur. Behavioural patterns of persons with dementia-related changes are often described as "disturbing" with a natural-scientific-medical focus and a nursing focus based on it.

In the more recent gerontological literature, the term "behavioural disturbances" is included. This term has a negative connotation. Behaviourally conspicuous is a person who disregards the norm shaped by his or her environment; as a result, he or she stands out to the social environment.

In 1995, the International Psychogeriatric Society defined the value-free term Behavioural and Psychological Symptoms of Dementia (BPSD). This subsumes symptoms of disturbed perception, thoughts, moods or behaviour that are common in persons with dementia-related changes. According to Finkel, the group of these behavioural symptoms includes: physical aggression, shouting, agitation (e.g. walking around, gathering, swearing, shadowing, sexual inhibition).

In English, the terms difficult, behavioural distur bance, disruptive behaviour, dysfunctional behaviour, disordered behaviour, inappropriate, problematic behaviour and non-cognitive symptoms are used to describe behaviours that are considered problematic in nursing interactions.

The terms imply an intrinsic origin of the behaviour, i.e. caused by the person with dementia themselves. Environmental influences as triggers are less taken into consideration here.

The term "challenging behaviour" is used by representatives of social psychological schools and is taken from social pedagogy. This term does not imply a negative meaning or attribution, but the cause of the phenomenon results from an interpersonal context that is subject to change.

The term makes it clear that it is up to the interpretation of the interaction partner of the person with dementia change "whether a behaviour is perceived as challenging and not primarily up to the person with the disease himself".

Agitation

Cohen-Mansfield uses the term "agitation" synonymously with challenging behaviour. Agitation is thus defined as "inappropriate verbal, linguistic or motor activity that cannot be explained by clear needs or confusion per se". Cohen-Mansfield's interpretation of the term focuses more on displayed aggressive behaviour. The American psychiatrist distinguishes four categories:

- physically aggressive behaviour (e.g. hitting),
- physically non-aggressive behaviour (e.g. aimless wandering),
- verbally aggressive behaviour (shouting) and
- verbally non-aggressive behaviour (e.g. refusal).

Agitation is interpreted as a form of communication when there is a loss of control of the situation. The person showing aggressive behaviour may appear to have lost contact with reality as perceived by carers. He may show emotional reactions that do not appear to others to be appropriate behaviours in his current situation. This definition is based on the person showing the phenomenon and ignores interaction processes between interaction partners.

Apathy

Forms of passive behaviour, e.g. apathy, social withdrawal, depressive behaviour, occur daily in persons with dementia-related changes and are described as resistant to interventions. Intervention concepts, e.g. reality orientation training or basal stimulation, focus primarily on promoting cognitive resources and delaying identity. Restrained and calm patients challenge the attention of caregivers less and are experienced as less stressful for this reason.

Explanatory approaches

Behaviour is often a form of communication for people with dementia. This form of non-verbal communication is manifested by agitation, restlessness, aggression and belligerence and can often be interpreted as an expression of unmet needs such as pain, hunger, thirst or urination. Repetitive vocalisation or changes in tone, pressure or rapidity of speech can be a sign of unmet needs, even if it is meaningless vocalisation.

Thus, carers should not see mentioned behaviours merely as symptoms of dementia or as a consequence of the neurological disease process, but try to look at and interpret the meaning at the level of interaction.

Radzey assumes that the occurrence of challenging behaviour is only partly due to impairments in cognitive abilities and life activities and that answers are to be drawn more from the dynamics of the dementia process. The author argues that the occurrence of the phenomenon is due to an interaction of neurologically determined, life-world and care environment-specific factors.

In her essay "Perspectives of an Institution-Based Research Nurse", Norberg raises the question of whether challenging behaviour should be assessed as meaningless behaviour or more as legitimate reactions to a stressful situation that is perceived as disturbing. The phenomenon should therefore always be interpreted ambiguously on different levels.

Theunissen assumes that the phenomenon should be interpreted as a "survival strategy" of cognitively impaired persons.

Based on these approaches, "challenging behaviour" can have different causes:

- be a medically identifiable symptom of a dementia-related illness (e.g. Pick's disease),
- be a desperate expression of self-determination, when an elderly person cannot realise their own will or wishes in any other way,
- a means of communication,
- a reaction to psychosocial deprivation, e.g. due to a lack of care,
- be an appeal, cry for help, message or signalling behaviour to the environment to draw attention to psychological or physical needs,
- a creative adaptation to a home or hospital environment that is difficult for the elderly to tolerate and becomes more incomprehensible to them, and it can be
- be misunderstood as an assault, insult, defilement or embarrassment towards carers on the relational level.

These forms of communication always become visible when the conspicuous behaviour is not suppressed by the administration of psychotropic drugs. The use of sedatives to immobilise and restrain chronically confused elderly people in cases of self-endangerment ethically contradicts the approaches of person-centred care, validating conversation and biography work. The spectrum of manifestations of challenging behaviour can vary between individuals; the forms depend on the state of mind and the reaction patterns of those affected.

Framework of conditions

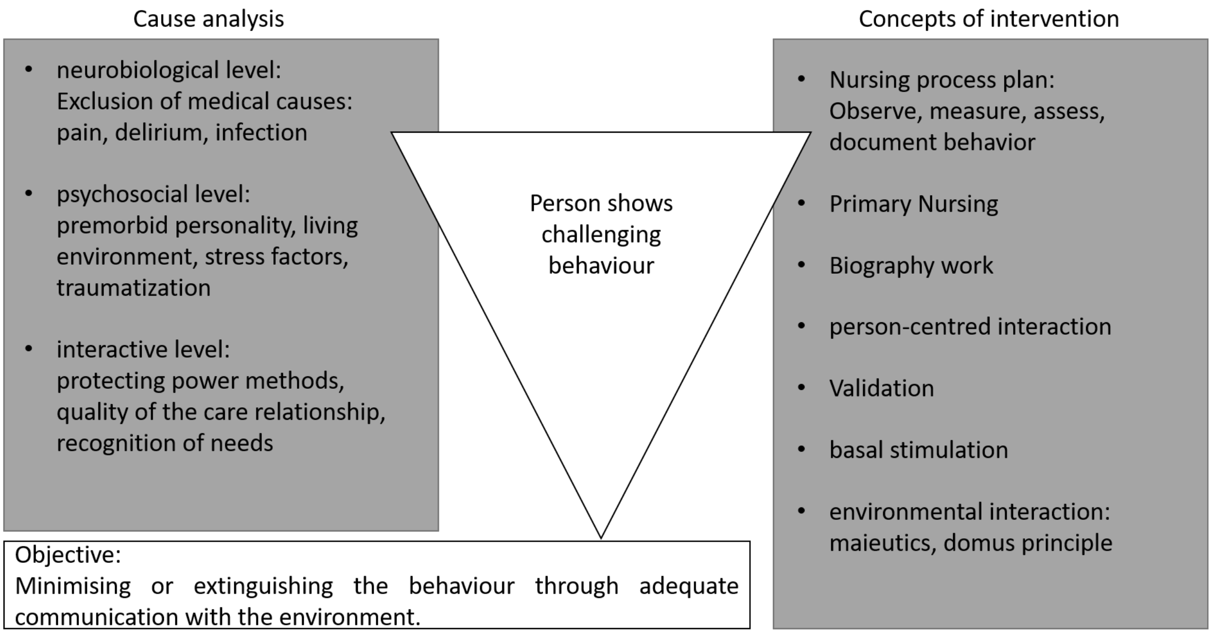

Abbildung 1 Framework of conditions

Challenging behaviour is understood here as the reaction of the person with dementia to an increasingly unfamiliar and unpredictable environment in which they no longer succeed in establishing contact with other people and being understood, and in which they feel powerless. In this way, the surrounding people are challenged to consider aspects of relationship design and milieu as important modifiable factors influencing behaviour.

The most significant causes of challenging behaviour in persons with dementia at the interactive level include:

- Use of protective power methods (e.g. Fixation, administration of psychotropic drugs for immobilisation, detractions),
- Quality of the caring relationship,
- the ability of carers to interpret the psychological and physical needs of the person concerned.

Interaction processes can be negatively influenced by caregivers and their behaviour, i.e. they have the possibility to refuse to be a person and can exclude persons with dementia from this; as a reaction to this, persons affected can react in a challenging way.

Protective power methods

The professional nursing relationship, especially with patients with cognitive disabilities, is based on an imbalance. Because the problematic behaviour of those affected is usually not the subject of a case-related and general culture of reflection and dialogue in the facilities, there is a danger that one-sided interests, e.g. those of the nurses themselves to calm the patient down as quickly as possible, will be enforced.

The aim of the protective use of power is solely to protect the person with dementia, neither to punish nor to blame or condemn them. Protective use of power assumes that patients who exhibit agitated behaviour may act in ways that are self-injurious or injurious to others. Ignorance of power protective actions that carers perform include a lack of awareness of the consequences of the caring action and ignorance of how to satisfy the psychological and physical needs of the agitated elderly without hurting themselves or others.

Poorly trained carers are more likely to use protective power methods when dealing with the affected person because they are less able to respond to challenging behaviours of the affected person with dementia-specific interactions.

Fixation

Fixation (movement restrictive measure) is one of the most controversial physical restrictive interventions in dealing with challenging behaviour in persons with dementia-related changes. It involves the use of trunk and limb restraints that prevent voluntary changes in position, e.g. standing up and walking, and that cannot be removed independently by the person. If other movement restrictions, e.g. bed restraints, are taken into account, more than 80 % of patients with dementia-related changes in care institutions are affected.

Kong critically points out that agitated behaviour in patients with dementia-related changes is more prevalent when caregivers resort to restraints.

Psychopharmaceuticals

Carers who advocate the administration of psychotropic drugs usually assume that care is based purely on biomedical parameters. The administration of psychotropic drugs prescribed by a doctor often does not have the desired effect of immobilising an agitated person with dementia.

Although prescribing the medication, usually neuroleptics, is a medical task, the constantly present nurses play a key role in recognising psychopharmacological side effects (rigidity, urinary retention, constipation, delirium), which can lead to psychomotor agitation and a risk of falling. Burnout-stricken nurses and nurses without (geronto)psychiatric nursing skills are more likely to advocate sedation medication with neuroleptics. The administration of these drugs promotes pathological regression. Drive, among other things, is inhibited by the administration of medication. Many psychotropic drugs exacerbate pre-existing memory disorders through their anticholinergic component. They can lead to acute states of confusion and pronounced disturbances of the vegetative system, which are easily overlooked due to the lack of communicative ability of those affected.

Personal detractions

Certain behaviour patterns of nurses can provoke aggressive reactions in patients. In American literature, this is referred to as "battered nurse syndrome". The nurses are characterised by disrespectful-commanding behaviour, are intolerant and use "personal detractions". Detractions are subtle forms of belittling and disparaging the elderly that are embedded in everyday interactions and may reveal negative feelings such as hostility, irritation, dislike or contempt. Detractions are used to enforce care.

Detractions are used to enforce care measures. Detractions are used by caregivers in a highly destructive way, especially for cooperation with chronically confused patients. Different actions and perceptions can mutually influence the behaviour of the interaction partners. It is not only the elderly person who reacts to actions with a certain behaviour, but the carer herself.

If a person with dementia change constantly receives detractions in subtle ways, they begin to doubt the sincerity of the caregiver and become suspicious, they react with feelings of insecurity, fear, apathy, aggression and may behave defiantly towards caregivers.

Since those affected have a distinct sense for moods and feelings with their non-verbal communication parts as well as for double messages, personal detractions can have a more or less subtle effect on the dementia process. According to Kitwood, personal detractions are usually not an expression of bad intentions, but rather occur out of helplessness, excessive demands, little knowledge about dementia-related illnesses and a lack of reflection on one's own limits. Kitwood points out that personal detractions are well-intentioned but misguided attempts to fill the interactive void in the interaction process.

Quality of the nursing relationship

The carers who have little psychosocial and professional skills to deal with people with dementia are more likely to feel helpless in a challenging situation. They will feel feelings of frustration, anger and defensiveness towards the patient. These emotions can lead to a less empathetic and caring attitude on the part of the caregiver in follow-up contacts and can accordingly reinforce challenging behaviour on the part of the patient.

From an attitude of carers that does not recognise the personhood of people with dementia and is characterised by detraction, it can be deduced that the dementia-related change can have an impact on carers' behaviour. One's own powerlessness is difficult to bear.

The high demand for perfectionism in everyday nursing care, which greatly restricts people with dementia, means that they are even less able to bring their world of experience into line with reality. This, together with the lack of nursing knowledge about person-centred care, triggers fear and resistance in carers, which in turn can lead to reactions and have a negative impact on the caring relationship.

Identifying needs

According to Kitwood, the most significant psychological needs of patients with dementia changes are love, attachment, comfort, identity, employment and inclusion in the social community. Patients who completely lose their cognitive abilities in the course of the dementia process are little to no longer able to meet these needs autonomously. For example, it is not possible for the patient in the advanced stage to postpone psychological needs.

When dealing with challenging patients, it is not always possible to work according to a plan in direct care, because the old person's self-will and his psychological and physical needs, which are not easy to interpret, make dealing with him a resistance and demand all attention in order to achieve a satisfactory care outcome. In the advanced dementia process, the verbal ability to speak can be lost. Those affected then communicate their needs to the carers mainly through facial expressions, gestures, vocalisations, crying, laughing or stereotyped movements.

If a need is not recognised or interpreted as such by the carer for a long time, the affected person demands more attention: frequent ringing, repetitive calling, tendencies to run away, etc. The caregiver then has to take care of the affected person. It is striking that carers only ever intervene when the challenging behaviour has already occurred.

It becomes clear that the current behaviour and well-being of the person with dementia and the behaviour of the carer are interrelated. This reciprocal relationship is illustrated graphically and explained below.

Conflict of needs

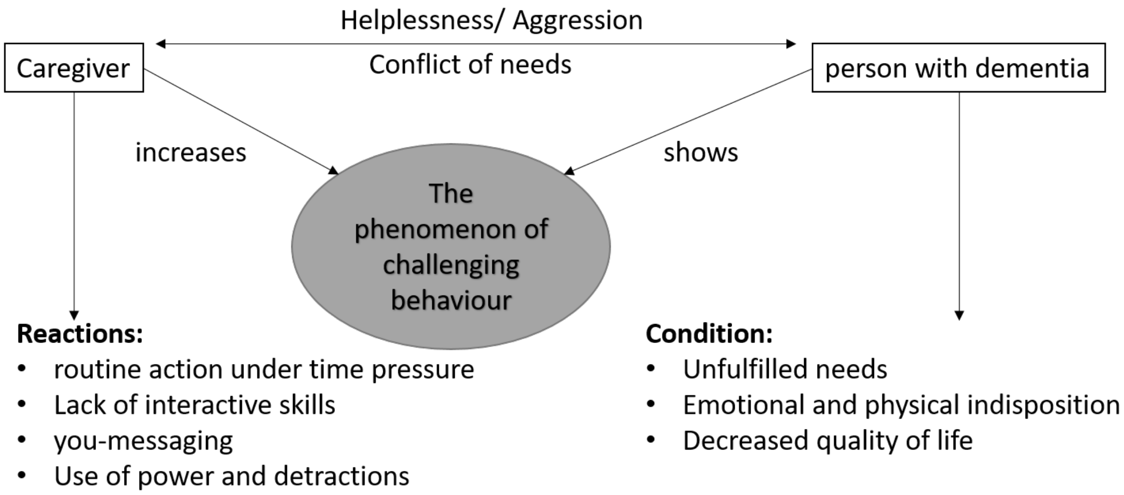

Abbildung 2 Challenging behaviour as a conflict of needs. The situation of the patient with dementia and that of the carer are mutually dependent.

The situation of the Patient with Dementia

A person with dementia change is a sensitive person. In addition to the loss of cognition, there is the trauma of being separated from many familiar things (e.g. the family), of having lost personal possessions, the fear of having to live indefinitely in a place that is foreign to them.

The physical ageing process again brings the danger of being helplessly at the mercy of others. This creates the danger of trauma reactivation, triggered by "flashbacks", e.g. during personal hygiene. For this reason, much of what she communicates is accompanied by feelings: Love, pride, hate, fear, anger, disappointment, sadness. The person in the advanced dementia process, especially with additional motor and sensory impairment, has a limited behavioural repertoire in the ability to express and interact.

For this reason, psychological and physical needs, e.g. attention, occupation, dislikes and feelings, wanting to leave, etc., can only be communicated to others with difficulty. As one's own neediness plays a greater role again in old age anyway, regressive processes (feelings of guilt and shame) push more strongly into consciousness.

The situation of caregivers

The carer has the need to provide optimal care and to have her work recognised by the person in need of care. In contact with the person concerned, she often reacts under time pressure, unconsciously with routine actions, due to insufficient interactive skills as well as with "you" messages, possibly feels emotionally or physically uncomfortable herself, uses protective power methods to achieve her own needs, e.g. the result of a care measure, within a certain time window.

Under these conditions, she cannot sensitively observe and perceive non-verbal signals as expressions of the person's needs. A cognitively impaired patient perceives these body signals more intensely and reacts much more sensitively to discrepancies between what is said and the accompanying signals: a raised index finger, folded arms, fists on the hips or hands hidden behind the back can trigger aggressive behaviour in the cognitively impaired patient, while an open palm and approving nod while listening may clear up the situation.

A conflict of needs occurs with similar reactions on both sides of the interaction partners involved. If the carer cannot empathise with the situation of a patient with dementia, the patient feels, due to sensitive "antennae", that he or she has not been understood and reacts in the further course of the interaction with inadequate behaviour, just like the carer herself.

For the caring relationship, this conflict of needs is the "actual moment of truth". It is therefore a matter of appreciating the psychological and physical needs of both partners in the interaction.

Challenging situations for people with migration experience

People with a migration background experience a double foreignness as affected persons and as relatives: On the one hand, there is the change into another culture and on the other hand, there is the incision that arises from dementia. A modern western way of living and working collides with the traditional values of people with migration experience. This familial and cultural alienation is intensified by dementia.

Conflicts, experiences of powerlessness in the everyday life of those affected and their relatives, experiences of frustration in the relationships between people with a migration background and autochthonous service providers play a significant role.

Already due to dementia, an alienation from everyday practical ways of living and understanding occurs. With the loss of the national language learned over many years, the verbal ability to communicate is now also severely impaired.

Non-verbal expressions such as body language or voice pitch are very much culturally influenced. Thus, different cultural/ethnic backgrounds cause misunderstandings in non-verbal communication as well.

It can therefore be seen that the conflict of needs described above in connection with the care of people with dementia and migration experience can increase to a considerable extent due to the clash of cultures. In fact, we cannot speak of only two cultures here. The person with dementia and migration experience is confronted with many unknown cultures in the inpatient setting, represented by different generations with different ethnic backgrounds that meet in an inpatient facility.

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