

Nursing & Residential Care

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Title: Understanding and reducing refusals of personal care in dementia

Abstract 100-150 words

Refusals of assistance with personal care in dementia can be a major source of distress for both the person with dementia and their caregivers. Tamara Backhouse examines the issue and considers ways of minimising refusals of care.

Key words – 5-6

Dementia, Personal Care, Refusals, Resistance, Activities of Daily Living

Key points 4- 6

- Refusals of care are common in advanced dementia
- Refusals of care are distinct since they always occur within an interaction
- Refusals of care can have serious consequences such as poor hygiene and neglect or leading to controlled restraint
- Person centred care, modifying caregiver approach, adapting to the person's preferences, minimising the care task, eliminating underlying issues and altering the environment may reduce refusals

- Research evidence suggests playing recorded music during care; person centred bathing techniques and talking to the person in a non-patronising way can work to reduce refusals of care in dementia.

Reflective questions

- What are potential causes of refusals of care in dementia?
- What can you do to reduce the likelihood of refusals of care?
- How can you adapt your approach to reduce refusals of care?

Understanding and reducing refusals of personal care in dementia

There are over 50 million people living with dementia worldwide (Prince et al, 2015), with numbers in the United Kingdom (UK) expected to be over one million by 2021 (Prince et al, 2014). People with dementia (PWD) often develop extensive needs for assistance with their personal care (Prince et al, 2015). These needs are often substantial compared to those of people with different conditions (Prince et al, 2015). Assistance with personal care can be defined as any 'physical support given to the person in connection with eating or drinking ..., toileting ..., washing or bathing, dressing, oral care or the care of the skin, hair or nails' (Health and Social Care Act, 2008, Part 1 General).

Dementia symptoms can include memory loss; reduced understanding and cognition; changes in behaviour, and difficulties with communication, visuospatial abilities, and completing activities of daily living (Robinson, Tang and Taylor, 2015; Doung, Patel and Chang, 2017). These symptoms can complicate personal care interactions in dementia.

What are refusals of care?

Refusals of care have been defined as 'deliberate acts invoked from the caregiving encounter that were either verbal or physical and were thought to be meaningful responses of the care recipients to their perceived environment, such as a threat, or disability and were means of communicating needs,

conflict, rejection, or an unwilling acceptance of an interaction between a caregiver and a care recipient' (Spigelmyer, Hupcey and Kitko, 2018, p11). Refusals of care, sometimes termed 'resistance-to-care', 'resistiveness', 'noncompliance' or 'rejection of care', are distinct from other behaviours, which can be common in dementia such as agitation (Choi et al, 2017; Volicer, Bass and Luther, 2007). This is because they always occur within personal care interactions and are not a general state or symptom happening when the person is alone (Fauth et al, 2016; Volicer, Bass and Luther, 2007). People living with dementia may refuse care at the start of the interaction or at any point during it. Refusals may be verbal or physical and can be along a continuum of mild to extreme (Volicer and Hurley, 2015). Refusal actions can include the person turning or pulling away from the caregiver, grabbing objects or the caregiver, hitting, kicking, verbally declining, becoming upset, being verbally aggressive, ignoring offers of assistance, or stiffening their body or jaw (Volicer and Hurley, 2015).

Prevalence

Refusals of care are common in dementia, particularly in the advanced stages (Ishii, Streim, and Saliba, 2012). They can occur in care home, hospital (Featherstone, Northcott and Bridges, 2019) and family settings (Fauth, Femia and Zarit, 2016). Prevalence data for refusals differs depending on how refusals are defined and recorded; on the care environment, and the presentation, stages and subtypes of the dementias (Ishii, Steim and Saliba, 2012). In the United States (USA), refusals were estimated to occur in 12% of residents in residential care per week (Gruber-Baldini, 2004), and have been reported in 17% (Volicer, Bass and Luther, 2007) and 28% (Galik et al, 2017) of nursing home residents (USA).

Causes

There are multiple factors that can lead to refusals of care:

- **Health:** such as delusions, apathy, hallucinations, psychosis, depression, pain, or other comorbidities (Galindo-Garre, Volicer and van der Steen, 2015; Ishii, Streim, and Saliba, 2012).
- **Environmental:** such as the temperature of the room, noise levels, poor lighting, or being in unfamiliar surroundings (Rader et al, 2006; Social Care Institute for Excellence, 2015).

- **Personal:** such as unmet needs, irritability, the actions not aligning with previous routines, difficulty communicating, usual likes and dislikes, embarrassment, the conviction that care is not needed, or not understanding the caregivers' intentions (Volicer, Bass and Luther, 2007; Spigelmyer, Hupcey and Kitko, 2018).
- **Caregiver approach:** such as using simple speech in soft or high-pitched tones, talking slowly, or using repetition (elderspeak), negative instruction or statements, or being too abrupt, loud or quick (Galindo-Garre, Volicer and van der Steen, 2015; Belzil and Vezina, 2015).

Consequences

In the UK, 10% of care home managers caring for PwD reported that they found refusals of care difficult to manage (Backhouse et al. 2014). Refusals of care can have serious consequences, if assistance with care is not provided the person may have poor hygiene. This could threaten their dignity, lead to urine burns, pressure ulcers and/or infections. Long-term failure to provide personal care could be viewed as an act of omission (Care and support statutory guidance, 2018). Conversely, if care is attempted against the person's will this may lead to conflict, anxiety and distress for both caregiver and PwD (Spigelmyer, Hupcey and Kitko, 2018). Restraint or forced care may be resorted to by caregivers, and crisis points may be reached (Watts, Jackman and Howarth, 2019; Backhouse et al, 2018^a; Backhouse et al, 2018^b, Spigelmyer, Hupcey and Kitko, 2018; Ishii, Streim and Saliba, 2012; Edvardsson et al, 2008; Volicer et al, 2009; Ayalon et al 2006). Prolonged refusals may lead to considerable distress and anxiety, and contribute to caregiver burden (Fauth, Femia and Zarit, 2016; Ishii, Streim and Saliba, 2012).

Legislative Frameworks and Safeguarding

Legislative frameworks are in place that are relevant for refusals of care. Prolonged refusals of care can be difficult for care-home staff to negotiate, since failure to provide necessary personal care could be viewed as an act of omission. Conversely, engaging in distressing personal care encounters with a PwD could be detrimental to their psychological and emotional welfare. Both scenarios are

undesirable. Safeguarding guidance and policies to prevent neglect and abuse should be adhered to (The Care Act, 2014; Care and support statutory guidance, 2018).

Before assisting a person with their personal care, consent should be gained. Where a person refuses this should be respected, however if a person lacks the mental capacity to make this decision the Mental Capacity Act (2005) provides guidance (Mental Capacity Act, 2005). To assess capacity, staff need to determine if there is an impairment of, or disturbance in the functioning of a person's mind or brain. A diagnosis of dementia means that there is. In this case, the question becomes 'is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?' To evaluate this, there are four aspects to assess. The person will be assessed as not having capacity if they cannot do one or more of these things (Mental Capacity Act, 2005):

- 1) Understand the information about the decision
- 2) Retain the information long enough to make the decision
- 3) Weigh up the information about the decision
- 4) Communicate their decision by any means

Assessors should start from an assumption that the person has capacity; do everything possible to enable the person to make the decision them self, and understand that decisions that appear unwise do not mean the person does not have capacity. Capacity can fluctuate, therefore decisions about capacity should be time and decision specific (Mental Capacity Act, 2005).

If a person is assessed as lacking the capacity to make a decision, a Best Interests decision can be made on their behalf such as, about holding the person so that necessary assistance with care can be provided or using medication to pacify the person (Social Care Institute for Excellence, 2017). If significant decisions such as resorting to complete care against a person's will need to be made, a Best Interests meeting should take place (Watts, Jackman and Howarth, 2019; Mental Capacity Act, 2005). Decision makers should: take into account all relevant aspects; involve the person as much as possible; consider the person's past and present beliefs, wishes and values; weigh up pros and cons; consult

widely, and record the decision making process (Mental Capacity Act, 2005). The decision needs to have the person's best interests at the forefront and any resulting actions must be the least restrictive and proportionate to the harm being averted (Mental Capacity Act, 2005).

Deprivation of Liberty Safeguards (DoLS) (applicable for England and Wales only) permit care homes and hospitals to request authorisation from a local authority to use restraint and restrictions that deprive a person of their liberty. DoLS cover the use of continuous supervision and control of a person and/or situations where the person is not free to leave. However, frequent or repeated use of sedative medication or physical restraint to manage behaviour and allow personal care to take place may be part of this (Social Care Institute for Excellence, 2019). Any deprivations have to be in the person's best interests. The amendment to the Mental Capacity Act (Mental Capacity (Amendment) Act 2019) means that Deprivation of Liberty Safeguards (DoLS) are due to be replaced by Liberty Protection Safeguards (LPS) by the end of 2020 (Social Care Institute for Excellence, 2019).

Person Centred Care

The best strategy is to prevent refusals of care occurring in the first place. Person centred care has great potential to do this. The concept of person centred care became apparent in the late 1990's through Tom Kitwood's groundbreaking work (Kitwood, 1997). Kitwood advocated a person centred approach, which involves seeing the person as an individual first rather than a person with a diagnosis of dementia. He argued that undermining a PwD's personhood (recognition of the value of the person), which can happen through seventeen means such as, imposition (forcing or overriding), ignoring (carrying on as if the person is not there), withholding (refusing to meet an obvious need), banishment (excluding a person), and treachery (use of deception to manipulate) should not occur. Instead, focus should centre on improving PwDs' experiences by prioritising each person's psychological needs of attachment, identity, inclusion, comfort, occupation, and predominantly, love. This positive person work approach is key in maintaining the personhood of each PwD (Kitwood, 1997).

Professor Dawn Brooker has developed Kitwood's work. She defines the contemporary person centred care approach as a culture having four elements: Valuing people, providing Individualised care, recognising the Personal perspectives of PwD and generating supportive Social environments. These, together make the VIPS Framework, which has been widely used to improve person centred practice for PwD (Brooker and Latham, 2016). The Care Fit for VIPS online toolkit aimed at a variety of services such as care homes, day care and home care is free to access and simple to use (Care Fit for VIPS, 2020).

In relation to refusals of care, using a person centred approach to understand the 'person' with dementia better has immense potential in care staff's management of refusal behaviours. Creating a supportive atmosphere where the person is valued and interactions are non-threatening can build feelings of security and trust. Personal care within this safe space is likely to be more acceptable to the person and therefore progress more smoothly. This approach may reduce instances of refusals occurring or stop any refusal behaviours that do occur from escalating.

National Institute for Health and Care Excellence (NICE) Dementia Guideline Advice

Dementia guidelines from the National Institute for Health and Care Excellence 2018 include a section on 'agitation, aggression, distress and psychosis', but not refusals of care specifically. However, the advice could be useful for refusals of care, which can involve, or be caused by, the PwD feeling distressed, aggressive or agitated. The guidance (NICE, 2018) recommends looking for information to explain why the behaviours are occurring and then treating their clinical or environmental cause. Suggestions include using an observational assessment to detect underlying pain, or checking for delirium or inappropriate care. Non-pharmacological interventions are to be used as first line treatments, with antipsychotic medications prescribed only to those in severe anguish or whom may harm themselves or others (NICE, 2018).

Advice from Charities and Other Organisations

Advice is publically available from many charities and other organisations (for example, Alzheimer's Society Factsheets UK, 2019; Alzheimer's Association USA, 2019; Social Care Institute for Excellence UK, 2015; Alzheimer's Society Canada, 2018). Box 1 shows some of the key advice for caregivers available from these sources. These ideas may be useful due to the underlying person centred care focus with actions such as reassuring the person, generating trust and reducing their embarrassment, which could make the person feel less threatened. The practical focus, such as preparing the environment and making sure there is enough time for the care interaction may assist caregivers to be more organised and calm, which could in turn be less worrying for the PwD.

Asking yourself the question, 'does this care action really need to take place today?' may be useful. Other strategies such as, trying again later, using a different approach, different person, or different time of day, or only attempting to assist with the minimum of what needs to be done at the time may work (Backhouse et al 2018a). Overall, thinking around the situation, trying different approaches, and adapting to the person may be the best courses of action.

Box 1: Ideas for Caregivers from Organisations:

- be calm
- be flexible
- communicate with the person
- generate trust
- reassure the person
- involve the person as much as possible
- reduce the person's fear and embarrassment
- adapt to the person's preferences
- try to help with care at a later time
- maintain the person's general health
- control any pain
- prepare the environment for the task
- make areas safe
- check room and water temperatures
- obtain any necessary equipment
- create a soothing atmosphere
- distract the person
- have enough time for the care activity
- use familiar toiletries and routines
- seek help and support if needed

Scientific Evidence

The scientific evidence has focussed on non-pharmacological interventions to reduce refusals of care (see Box 2). In 2014, a best evidence review (Konno et al, 2014) examined the research for non-pharmacological interventions to reduce refusals in nursing home settings. They found some evidence that educational programmes for staff, which focussed on towel bathing or person-centred showering or bathing reduced refusals for this care activity. There was low quality evidence that playing recorded music during showers, baths or mealtimes reduced refusals of care (Konno et al, 2014). Abilities-focussed approaches, where staff work to maximise the person's current abilities, during morning care had mixed results in reducing refusals. Konno et al (2014) concluded that the available evidence is weak, but person centred non-pharmacological interventions could have a place in reducing refusals of care in dementia (Konno et al, 2014).

Box 2: Non-pharmacological Interventions for Refusals of Care

No evidence of effectiveness

- Aromatherapy

Possibly promising - very limited/mixed evidence

- Distraction techniques
- Abilities-focussed approaches

Low/Moderate evidence

- Communication techniques
- Person centred bathing modifications (towel bath or shower)
- Playing music during care

Limited low quality evidence showing that using pleasant images (for example, of puppies) to distract PwD during care may reduce refusals (Chou 2016). Communication strategies such as reducing the use of simple speech in soft or high-pitched tones, talking slowly, or using repetition (elderspeak) can reduce refusals of care (Williams et al 2017). There is no evidence that aromatherapy with essential oils is effective for specifically reducing refusals (Grey and Clair 2002), with one study noting more

refusals of care potentially due to the stimulus of the oils (Bowles et al 2002). More widely, aromatherapy has inconsistent effects on agitation and behavioural symptoms (Forrester et al, 2014).

Limitations of the research include the variety of care tasks under study, small studies, varied designs, and differences in measuring refusals of care and in the evaluations of the interventions (Konno et al, 2014). Most interventional research has taken place in long-term care settings. There has been no research specifically examining non-pharmacological interventions for refusals of care in dementia in hospital settings, with home-care workers, in the UK context or in non-western countries (Konno et al, 2014).

Conclusion

Refusals of care are prevalent in dementia in long-term care settings, hospitals and family homes. They can be distressing for PwD and their caregivers. Professionals and carers should work towards preventing refusals of care to reduce difficult situations and negative consequences such as poor hygiene or distress. Due to the variety of causes, different care activities in which they can occur, and multiple ways people refuse assistance there is no one way to best prevent or manage refusals. It is likely that a holistic approach would be beneficial: using a person centred care approach; knowing the person, their likes, dislikes and routines; taking into consideration the care needed, environment, person's preferences, underlying health issues, caregiver approach and communication style. Measures taken, if successful, should help to reduce distress for all concerned, improve care delivery, and help to maintain the personhood of the PwD. More research needs to take place to assess the effectiveness the identified strategies and non-pharmacological interventions.

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