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# The kind assailant: how dementia patients view their carers

## REFLECTIONS

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#### **A day on the wards**

It is another day on the ward with many tasks to complete. I am a final year medical student who is working hard to be an effective member of the team on a care of the elderly ward. As I work attentively and swiftly to complete the morning jobs, a nurse interjects. She explains that she needs to give a patient an antibiotic, but their IV access is no longer functioning. However, realising that this patient needs their medication I decide to reprioritise. I proceed to the clinical room; assemble all required equipment for the insertion of a cannula and attend to the patient. The patient appears confused and although I try my best to obtain informed consent for the procedure, all I receive is a nod. An inquisitive one at best. Upon reflection, I know that I must proceed as it is in the patient's best interest.

As I start to insert the needle the patient grimaces and clearly looks uncomfortable. I apologise as I failed to insert the cannula. I decide to try again, and I receive the same puzzled look when asking for consent. I proceed once more and unfortunately; it is unsuccessful again. The patient appears uncomfortable and agitated. I apologise and stop. This bewildered patient is subjected to pain and while it seems justifiable, there is little I could do to reassure the patient.

Unfortunately, this was only the start of my patient's problems. The following week their fluid intake diminished, and the blood tests confirmed dehydration. At the same time one of the patients in the bay developed influenza. As such, the bay was "isolated". All staff members were required to wear an apron, face mask and gloves to enter the bay. This is required to prevent spread of a potentially lethal infection. If this wasn't enough, three patients then refused medications, two others refused blood tests and one patient declined cannulation - despite being counselled that it was required for an imminent CT scan. It felt like the

whole bay was rebelling.

Understandably, any confused individual, unsure of their surroundings and potentially unaware of what is taking place would feel distressed and overwhelmed, if they are suddenly approached with masked individuals with needles.

### **What barriers exist in communication with patients who have cognitive impairment?**

These two encounters encouraged me to think about the difficulties in communicating with patients that have cognitive impairment. During early stages of disease patients with dementia suffer from anomia, literal and neologistic errors, and impairment in comprehension. The level of deterioration in the comprehension and expression of language is closely associated to the global severity of dementia. Rousseaux et al. have also shown that such patients tend to end conversations in requests rather than assertions, which can have implications in obtaining consent as well as understanding patient's preferences. (1) Additionally, the impairment affects both the receiving and relaying aspects of communication.

Research carried out by Machiels et al. (2017) has shown that there is a paucity of healthcare professionals with good skillset in communicating with cognitively impaired patients. (2) Complicating factors like heavy workload are present and this limits availability to attend to their patients. For instance, nurses have consistently raised concerns over large volumes of paperwork that have this effect. Additionally, difficulties experienced in communicating with patients have often led to observed reduction in patient-carer interactions and care. This is largely attributed to elevated levels of stress that healthcare professionals experience while managing patients with cognitive impairment. (3) Patients with Lewy body dementia often struggle with fluctuating cognition that primarily affects executive function and attention. Thus, patients lack the ability to follow commands or understand what others try to tell them, which increases frustration for the patients and healthcare professionals. (4)

Symptoms of dementia are influenced by the interplay of biological, social and psychological factors. These patients are less able to cope with the stresses that can arise from day to day changes in care and interactions with new members of the healthcare team. In addition, when such stress is recognized, it is often ignored or managed by reassuring the patient. However, this only serves to distract the patients from the stressful experiences rather than addressing them. (5) In my experience, this was seen in the instances when patient

ask about if their spouses were visiting soon. The usual reply from caring staff being "I am sure they will show up", even if no visit was planned for that day.

Additionally, patients with dementia are more likely to show neuropsychiatric and behavioural symptoms during a period of transition; such as a hospital admission. This is particularly troublesome as the patients often have little preparation for this. Swift changes of environment are often psychologically demanding for the patients with cognitive impairment. (6)

Cognitive impairment often leads to anxiety, apathy, irritability and sorrow, which increase the risk of depression and exacerbate behavioural changes. The risk of these changes significantly increase as the severity of the underlying condition worsens. According to Wragg et al. up to 50% of all patients with Alzheimer's disease suffer from depression while the frequency of delirium with visual and auditory hallucinations vary between 10-73%. (7) During these periods of high level of impairment, communication is very difficult and drug therapy is often prescribed. However, often they have little role in treating the patient and rather, it is for the benefit of other patients and staff. (8)

It is generally accepted that healthcare professionals tend to have less confidence in recognising symptoms of depression, or even pain, while treating patients with cognitive impairment. This is attributed to patient's limited ability to vocalise such symptoms. As a result, there is growing concern that the methods of communication used are inadequate in addressing concerns of patients with cognitive impairment. Therefore, greater knowledge and experience is required to ensure that the level of communication is appropriate, and this level is dependent on the condition of the patient. (9)

### **What can healthcare professionals do to improve communication with patients who have cognitive impairment?**

NICE guidelines encourage delivering patient-centred care in which the human value of the patient, their individuality and relationship with others are respected. (10) This communication is effective due to these following reasons:

- By respecting the human value of the patient, the severity of their cognitive impairment does not lead to less care or negligence. In fact, it promotes care delivery in which communication is appropriate and considerate of the level of impairment.
- Allowing patients to communicate their understanding of the disease while appreciating that their personality and previous experiences helped shape that understanding.

- Healthcare professionals should work as part of a team that include family and carers to build relationships that promote patient's well-being. (10)

Healthcare professionals should avoid modifying their speech and language using assumptions based on the outer appearance of patients and age. Communication is often stereotyped when healthcare professionals interact with older patients, as a result of presumed or imagined deficits. Subsequently, patients face staff who use high pitch sound, diminutive naming, simple vocabulary, exaggerated intonations and exaggerated praise. All of these can lead to reduced sense of personal control and withdrawal from activities. Equally, over-accommodating of patients' needs might lead to a negative effect on communication. For example, Savundranayagam et al. showed that elaboration and repetition was helpful in aiding understanding, but short sentences can often be interpreted as directive and conveying negative messages. (11)

Patients with cognitive impairment require adaptable communication that takes into account their personal history and communication strengths. It should promote the individuality that makes care more relevant and communication more successful. Stereotyped forms of communication may be perceived as patronising and often lead to a breakdown of trust and resistance to care. (12)

Communication is not a simple process and a successful clinician is able to adapt to different situations and is alert to the varying needs of different patients. However, it can be difficult on occasions to ascertain what the patient might specifically require. During such cases, family members and carers can provide an insight to the patients need. As such, it is important that good relationships are built and maintained with carers and family members to ensure optimal care is provided. (13)

Effective communication is a crucial aspect of care as it allows clinicians to facilitate appropriate treatments. Equally, it helps patients understand their therapy and improve concordance. Many patients can have similar presentations and diagnoses, but patients' experiences of these are rarely identical. Subsequently, we should all listen and be able to adapt to communication needs. By appreciating the personal aspects of patients' care, we can optimise our communication – this is especially vital when caring for patients with cognitive impairment.

My experience as a student have helped me appreciate

communication challenges that can present while caring for patients. Understanding disease process and their effect on patients is crucial, however, good communication skills are essential and the key factor in delivering personalised care.

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