

Aphasia can put patients' sense of self and relationship-building skills at risk. Nurses must recognise how aphasia affects patients' whole lives to provide high-quality care

# Improving support for patients with aphasia

## In this article...

- › The effect of aphasia on fundamental needs
- › Effective communication strategies
- › How to deliver compassionate care

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**Abstract** Thompson J, McKeever M (2014) Improving support for patients with aphasia. *Nursing Times*; 110: 25, 18-20. Effective communication is fundamental to holistic care and positive outcomes for patients affected by aphasia. However, when patients are unable to communicate verbally, the standard of nurse-patient interaction is often poor. In a summary of our recent discussion paper, we use the theory of human-scale development as a framework to discuss the impact of aphasia on health and wellbeing. We suggest strategies to improve nurse-patient communication and quality of life for patients with aphasia.

Aphasia is the loss of the ability to understand or formulate language. It is caused by brain dysfunction, most commonly as a result of stroke. People with aphasia may find it difficult to speak, read, write, remember words or understand what others have said.

Good nurse-patient communication is central to clinical assessment, health promotion and patient autonomy. Patients' health outcomes are improved when nurses use communication to express concern and commitment and, in return, invite trust and human connection.

Although communication involves verbal, non-verbal and graphic abilities, nurses' communication strategies tend to focus on speech and do not always exploit alternative non-verbal methods. This results in an inability to engage effectively with patients affected by aphasia, which in turn leads to discrimination in stroke

services and poor long-term outcomes (O'Halloran et al, 2008).

## Theory of human scale development

If nurses are to use communication as a therapeutic tool, they must understand the devastating impact aphasia has on quality of life. According to the theory of human-scale development, quality of life depends upon the satisfaction of nine fundamental human needs (Fig 1). Most of these needs are concerned with the psychological and social issues associated with the sense of self and relationships. If an activity involved in satisfying multiple needs (such as speech) is removed, the impact on life quality is devastating.

Patients with aphasia often complain that health professionals focus on physiological stroke events rather than aphasia experiences. In an autobiographical account, a patient tells a health professional: "I have aphasia", only to be informed: "You mean you had a stroke" (Liechty and Heinzekehr, 2007). When health professionals focus on biomedical brain damage, they may neglect to recognise the psychosocial impact of aphasia.

## Impact of aphasia on the self

People require freedom and creativity to construct a sense of self (Rogers, 1967). Language is at the core of this construction. Without language, this process becomes difficult, as the individual cannot inform the world who he or she is, or understand who others are.

Aphasia makes it difficult for the functional mind to be perceived by others. This may lead to an assumption that language loss is the same as cognition loss or lack of

## 5 key points

- 1** Patients with aphasia experience problems in using language correctly
- 2** The most common cause of aphasia is stroke
- 3** The theory of human scale development proposes nine fundamental human needs
- 4** Many of these needs are compromised if patients cannot communicate
- 5** Nursing practice should take into account the impact of aphasia on patients' lives

capacity. With capacity hidden, an individual is transformed from a person to a mere physical presence and often viewed as a burden with little social value.

Nurses caring for people with aphasia control conversations and focus dialogue on their own nursing task goals, while patients rarely open discussions and have little influence over topics. This unbalanced communication results in a further reduction of the self and a denial of patients' rights to participate in their own care or control their own future.

It is essential that nurses get to know the patient as a person, then empower that person to regain the creativity, confidence and freedom required to control their life.

### Use of family

Where aphasia impedes direct verbal interaction between nurse and patient, family and friends can be a valuable source of information and support.

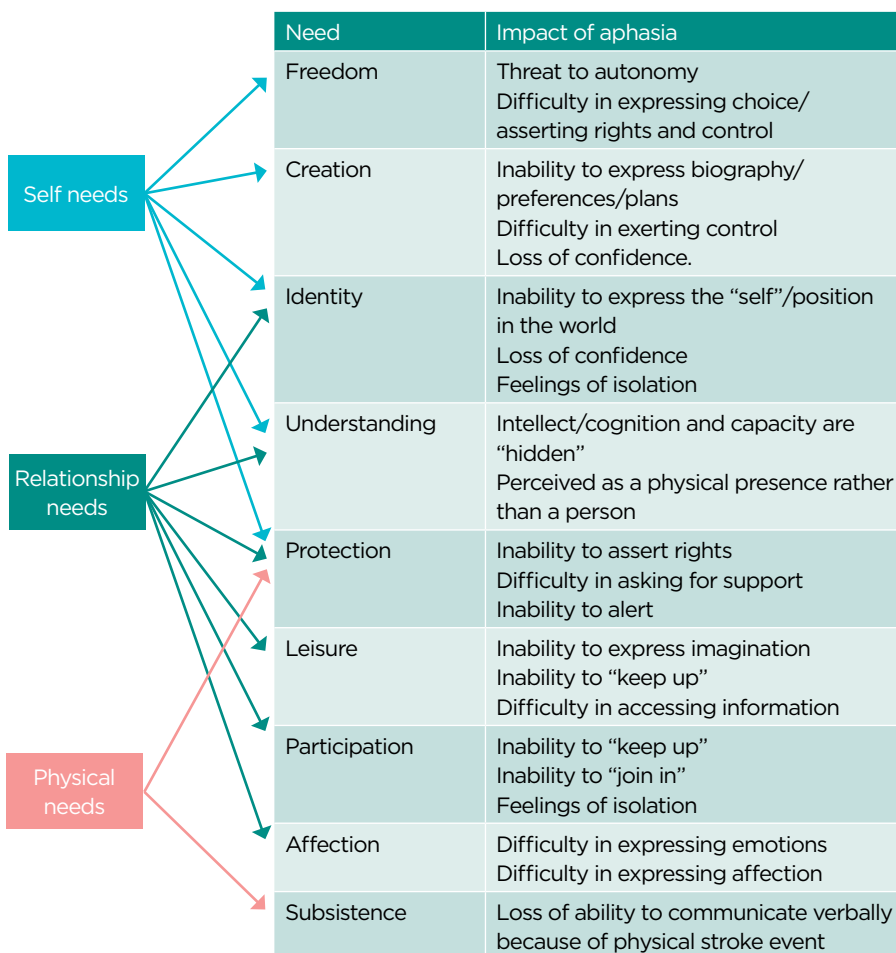
Patients' immediate concerns are more easily interpreted when relatives are on hand to translate. Knowledge of the patient's life and views equips family members to act as advocates. However, there are risks to patient autonomy if nurses heavily rely on family members. Any form of interpretation via a third person increases the chances of misinterpretation. This risk is further increased by relatives' conscious or subconscious tendency to distort patients' messages to address their own concerns.

Shadden et al (2008) report that because disability caused by stroke has a significant negative impact on all close family members, relatives' feelings of guilt, fear, stress and fatigue may filter out some of the true messages the patient is trying to express. Hedberg et al (2008) suggest that nurses require training in how best to involve relatives in decision making to ensure patients' needs are properly understood.

### Competence

Finke et al (2008) propose that time and resources should be spent on improving nurses' competence in language practice therapy, for example through training in basic speech therapy, and augmentative and alternative communication such as gesturing, picture boards and electronic communication aids. Currently, few of these are used, possibly because specialised communication techniques are considered to be time consuming and beyond the remit of nurses. However, investing in them may lead to efficiency, because effective interactions are less likely to result in misinterpretation and consequently frustration, time wasting and complaints.

FIG 1. **IMPACT OF APHASIA ON FUNDAMENTAL NEEDS**



Adapted from Max-Neef et al (1991)

Also, effective communication allows patients to express their needs and preferences and retain control over their lives.

### The quest approach

Aphasia traps people in the present because they are unable to talk about their past or express their hopes for the future. They have "lost their place" in the world.

Nystrom (2009) proposes that the best way for nurses to support patients to regain "place" is to use knowledge of their pre-stroke identities. An awareness of patients' previous competencies allows nurses to personalise communication by basing subject matters on familiar contexts. This enables patients to grasp meanings more easily and helps to provide a structure on which to base rehabilitation goals. However, this overlooks the fact that, for many patients, aphasia will remain permanent; preoccupation with the old self could therefore lead to mourning for what has been lost.

Frank (1995) suggests that a "quest"

approach is more psychologically healthy in such circumstances. Here, people are encouraged to accept their changed circumstances, and create a different future. For the nurse, this involves using the patient's history as a source of interests on which new and modified goals can be built.

### Impact of aphasia on relationships

Berkman et al (2000) propose that relationships have significant influences on physical and psychological health, providing informational, practical, decision-making and emotional support as well as opportunities for social engagement.

All these are essential to participation and belonging, and affection and pleasure. Any process or condition that impedes communication also has the potential to damage relationships and cause social isolation. To reduce aphasia's impact on relationships, nurses must create environments that help patients meet fundamental human needs associated with relationship-building and social integration.

## BOX 1. SUPPORTING SELF AND RELATIONSHIP NEEDS

### Interventions to support a sense of self

- Referring to family and friends for information and support about the patient
- Ensuring nurses are competent in language practice therapy
- Using a questing approach to help patients create a future for themselves

### Interventions to support relationships

- Using positive concept analysis and reflective practice exercises to develop compassion skills
- Adapting physical, social and attitudinal environments
- Encouraging membership of appropriate groups and communities

## Compassion skills

According to Sundin et al (2000), successful relationships and effective communication depend on compassion, and can therefore exist regardless of whether verbal interaction takes place. This suggests that where there is compassion, the isolating effects of aphasia are reduced.

However, healthcare culture is described as lacking compassion (Francis, 2013). Sundin and Jansson (2003) describe compassionate communication as “an art and creative act” so cannot be taught. Nevertheless, positive concept analysis and reflective practice exercises can develop compassion skills.

The study of patient autobiographies that describe illness experiences may support analysis of the concept of compassionate care, and provide sources of information and reflection for nurses.

Self-awareness exercises or guided imagery sessions (where people imagine themselves as having aphasia or being isolated) may improve compassion and relationship-building skills and become a basis for developing empathy skills.

## Environment

While a range of strategies can be used to adapt the physical environment, Parr et al (2003) propose that adaptations to the temporal (time) environment are key to supporting understanding. These authors state that an “etiquette of timing” governs verbal interactions. This etiquette may be broken by patients with aphasia who may struggle to keep up with the flow of conversation. As a result, their input is devalued, or they withdraw from the interaction altogether. However, if nurses are aware of this phenomenon, they are more likely to slow down the temporal environment and allow more time for interaction.

Advanced advocacy skills can modify organisational and attitudinal environments and empower patients. Pound et al (2006) suggest nurses caring for people with aphasia should undergo advocacy training because access to proficient nurse advocates is more beneficial to patients’

long-term social integration than impairment-focused therapy.

When nurses attempt to change social and attitudinal environments for patients’ benefit, they are demonstrating thoughtfulness and generosity – two essential components of kindness. Kindness has been described as an innate desire to support individuality (Johnstone, 2010). In aphasia, nurses’ kindness, expressed as a desire rather than a need to communicate, is itself a form of communication, which goes beyond spoken words.

## Nursing implications: communities

Community membership creates opportunities for socialising and provides social support. Also, Buunk et al (2002) suggest that social comparison within groups can improve participants’ motivation and self-perception, since by comparing their progress with that of others in a group, patients are able to see that they are doing well or realise that further improvements are possible. Tajfel (1982) says group membership also offers a sense of belonging and safety.

If nurses are to encourage group membership, it is important to understand that beneficial groups are defined by common illness experiences, not common medical events. Moss et al (2004) conclude that general stroke groups concentrate on motor impairment, leaving people with aphasia feeling excluded or experiencing performance anxiety. It may therefore be more appropriate to direct patients to aphasia groups than stroke groups.

## Conclusion

By reflecting upon the interrelated nature of fundamental human needs, nurses can recognise that aphasia can devastate quality of life. When the condition occurs, it is not only the physical speech mechanism that is lost. The sense of self and relationship-building skills that are essential to wellbeing are also at risk. Nurses must recognise all the consequences of aphasia on patients’ entire lives if contemporary nursing is to provide high-quality care. **NT**

● This article is a summary of Thompson J, McKeever M (2014) The impact of stroke aphasia on health and well-being, and appropriate nursing interventions: an exploration utilising the theory of human scale development. *Journal of Clinical Nursing*; 23: 3-4, 410-420.

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