

Complex Communication Needs: Nursing the Patient with Motor Neurone Disease, a Palliative Care Perspective

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- Palliative Care is a vital part of the support offered to people living with or dying from Motor Neurone Disease.
- The Palliative Care Nurse requires advanced verbal and non verbal communication skills in order to facilitate discussion about disease trajectory, symptom management and the patients' wishes for the future. This process can be more challenging when there is a need for AAC strategies or devices.
- A "Right to Speak" (Scot Gov 2012) funded improvements across Scottish Health Boards over a 3 year period.
- The Learning and Development workstream in NHS GGC's AAC Project deployed some of those resources to create targeted learning opportunities, across different locations and care groups. Resource was allocated to successful applicants to complete Masters Modules in complex communication assessment. This poster details the work carried out in relation to palliative care.

Aim:

- Case study of a hospice patient combined with a literature review to establish what communication difficulties can be experienced by nursing staff caring for a patient with MND.
- Identify ways in which nurses can improve their knowledge of AAC to better care for this patient group.
- Identify assessment tools which can assisted with achieving the most appropriate AAC.

Frustration

- Patients – Anxiety and frustration when communicating with nurses
- Nurses – Frustrated at lack of ability to communicate with patients.
- Patients disadvantaged during hospital stay if unmet complex communication need
- Care givers – Fear patients at risk due to poor communication (Finke et al, 2008)

Time

- Lack of time is frequently reported to be a barrier to successful communication between nurses and their patients with complex communication needs.
- Allocating time to explore and develop alternative strategies for communication is an important aspect of facilitating communication. (Hemsley et al 2012)

Training

- Nurses need to learn about a variety of aided and unaided AAC systems to improve the communication experience.
- In the Charter of Patient rights and responsibilities 2011 – In order to communicate and participate – patients have: the right to be informed, and involved, in decisions about health care and services -
 - "Ask any question if you do not understand something.
 - "Ask for more information if you want to know more".
 - "Be given information in a way you can understand".
 - "If you need an interpreter or a sign-language interpreter, **or other communication support**, you can ask a member of staff to arrange help for you in advance". www.gov.scot/resource/0039/00390989.pdf

Person centred health and care

- Must do with me:
- What matters to you
- Who matters to you
- What information do you need
- Nothing about me without me
- Personalised contact (www.healthcareimprovementscotland.org/our_work/person-centred_care/person-centred_programme.aspx)

Strategies for Interaction

- Determine the modes of communication used by the patient
- Pause or wait to allow time for patient to participate in the interaction
- Nurse should maintain eye contact and show an expectant facial expression
- Confirm the message communicated by the patient
- Use AAC to support understanding if necessary

Nurse involvement in AAC assessment

- All reviewed literature suggests that nurses have a vital role to play in contributing to assessment for AAC
- The holistic nature of nursing assessment has much to offer in the support of AAC assessment and the provision of patient-centred care.

Conclusions

- Patients report frustration and dissatisfaction with care when communication is impaired.
- Nurses report similar frustration along with feelings of guilt and helplessness when they are unable to meet patients needs.
- Lack of time can be a major barrier to effective communication between nurses and patients
- Nurses lack of knowledge of AAC is a barrier to effective communication.
- Holistic assessment is vital to achieving most appropriate AAC. Nurses should be involved in this multidisciplinary process.

Results/Outcomes

- Nurses should be targeted for training in AAC to help them support patients with complex communication needs, such as with MND
- This could be implemented at undergraduate level and supported as part of continuing professional development

References/any other relevant resources

Your health, your rights, The Charter of Patient Rights and Responsibilities www.gov.scot/resource/0039/00390989.pdf

Person centred health and care www.healthcareimprovementscotland.org/our_work/person-centred_care/person-centred_programme.aspx

Patient centred care - Improving Quality in the English NHS www.kingsfund.org.uk/publications/quality-improvement?gclid=CMuY-7u-7c0CFQso0wodAy0DsA

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