

BACKGROUND

Motor Neurone Disease (MND) is a life-limiting progressive neurological disease affecting approximately two people per hundred thousand (Irish Motor Neurone Disease Association (IMNDA), 2014). A palliative care approach to MND has been advocated for many years with MND identified as one of the non-malignant diseases for which access to specialist palliative care is provided and encouraged. In Ireland, as in most countries, individuals with malignant disease remain the most frequent beneficiaries of palliative care services. While palliative services are accessible to a small number of non-malignant diseases, the hope for the future is easy access for all those with life-limiting illness (Irish Hospice Foundation, 2008).

AIMS AND OBJECTIVES

This study aimed to explore and gain understanding of the experiences of nurses caring for individuals with Motor Neurone Disease.

The objectives of the study were:

- To explore nurses' experiences of caring for individuals with MND in the specialist palliative care inpatient setting
- To identify challenges when caring for individuals with MND

METHODS

A phenomenological approach was adopted in accordance with the work of van Manen. Research approval was received from relevant institutions. Participants were selected through purposive sampling (Fig. 1).

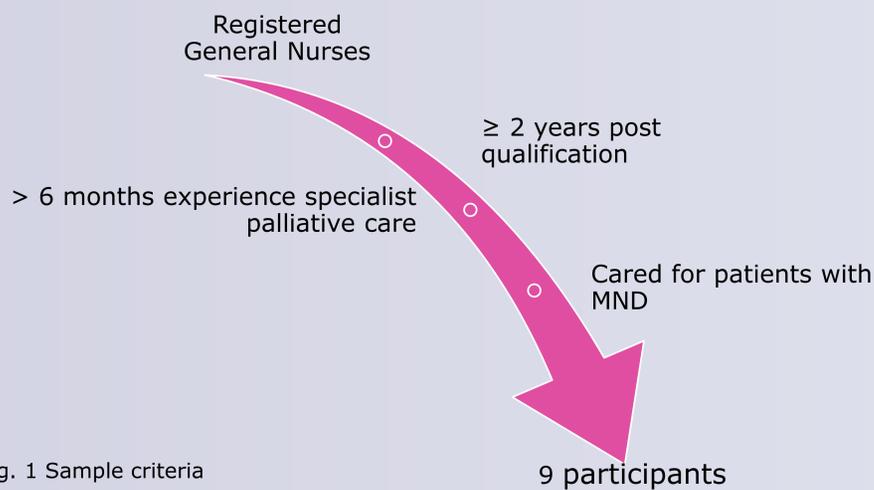


Fig. 1 Sample criteria

A semi-structured, one-off, one-to-one interview was carried out with each participant. Participants were asked to describe their experiences of caring for patients with MND in the specialist palliative care inpatient unit.

Thematic analysis was carried out in accordance with van Manen's approach resulting in emerging themes.

FINDINGS

What Palliative Care can offer MND

- Attitudes and Acceptance
- Admissions
- Symptoms
- Benefits
- Multidisciplinary input
- Place of care

Participants acknowledged the benefits of palliative care input including in relation to control of symptoms and invaluable input from members of the multidisciplinary team. They outlined reasons for admission to the unit. Varying attitudes and acceptance of palliative input were recognised.

Caring for the individual with MND

- Communication
- Trust
- Sense of Humour
- Distress

Communication issues were identified as significant challenges caring for those with MND. Many distresses were acknowledged. The importance of building trust was highlighted. Use of humour was thought to positively influence the patients' experiences although this depended on the individual nurse and patient.

FINDINGS

Nursing the individual with MND

- Experience
- Rewards
- Feelings and Emotions
- Time and Staffing

Participants discussed the wide range of emotions they experience caring for those with MND. Previous experience with MND was considered beneficial. Some described rewarding aspects of caring for these patients. All participants acknowledged extra time required caring for those with MND with lack of time and staffing level issues negatively impacting on care.

Aspects of care

- Control
- Planning
- Other patients

Many participants alluded to the need for these patients to regain some sense of control over their care and the challenges this can present. The majority of participants reported many differences between caring for those with MND compared to those with other malignant and non-malignant conditions and as a result extra planning may be required. The impact on the care of other patients when caring for those with MND was highlighted.

Moving forward

- Ethical considerations
- Best place

Future care for those with MND was discussed in relation to ethical issues such as hydration and nutrition and artificial ventilation. Participants questioned the place for patients with MND in the inpatient unit moving forward, querying if this was the most suitable environment for these individuals.

CONCLUSION

This study provided useful insight into the experiences of nurses caring for patients with MND in the specialist palliative care inpatient unit.

There is a need to continue to advocate for support and education for HCPs caring for individuals with MND. The potential benefits of future research involving other HCPs within specialist palliative care is highlighted. Research investigating the best place of care for those with MND moving forward is also encouraged.

REFERENCES

- Irish Hospice Foundation (2008) *Palliative care for all: Integrating palliative care into disease management frameworks*, Dublin: HSE and IHF.
Irish Motor Neurone Disease Association (2014) *Your personal guide to Motor Neurone Disease*. Dublin: IMNDA.