

# Exploring the experience of palliative care from the perspective of the Community Learning Disability Nurse

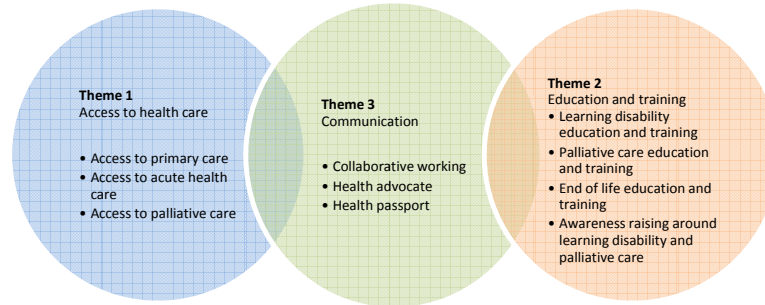
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## Introduction

The aim of this research was to explore how adults with a learning disability experience the palliative phase of an illness. A qualitative descriptive design using semi structured interviews was chosen and a non probability, purposive sample of seven Community Learning Disability Nurses (CLDNs) was recruited. Data were analysed using Burnard's 14 stages model of thematic data analysis (1991).

## Findings

The findings highlighted three main themes: (1) access to health care, (2) education and training and (3) communication. Themes and subthemes are shown in the figure below, and illustrated by some excerpts from the interviews.



The following excerpts from interviews illustrate these themes:  
Theme 1:

...letters for health screening are in inappropriate format...not understood.....

.....people with a learning disability requiring palliative care are diagnosed late... their last days ..are in acute care which is distressing for them and their families.....

Theme 2:

..I had a woman who spent three weeks in hospital..diagnosed with liver cancer ..died about one week later in acute care ...she waited too long for diagnosis and obviously things had not been picked up regarding warning indicators.....

I need to get a handle on palliative care and what services are available and how to access them ....

Theme 3:

.....exposure to people with a learning disability is now higher ( in hospital) as they will continue to access more services.....however staff come up and wheel away someone on a trolley without notification about moving them .....this can be so upsetting for clients .....

....health advocate is needed where someone outwith our service is advocating for the patient .....

## Discussion

These findings suggest that adults with a learning disability may not be receiving the most appropriate support in the palliative phase of an illness, and echo the major issues uncovered from an up to date literature review:

- People are doubly disadvantaged because the infrastructure for healthcare for this group is not robust (Read and Thompson-Hill, 2008)
- People are often diagnosed so late that palliative care is not an option (Tuffrey- Wijne,2002)
- CLDNs' understanding of palliative care, and lack of awareness of what it entails, means that they do not refer on to palliative care services
- Insular working methods mean that advice from specialists external to the speciality is not actively sought
- Lack of appropriate training and education in palliative care is a problem

## Conclusions

The research concluded that CLDNs are often unaware of what the palliative care needs of their client group are, which suggests that the extent of the unmet needs of people with a learning disability is still unknown. The CLDNs interviewed were passionate about their patient group and keen to ensure that they offer the best service and that their patients receive the care and support that they need. Although CLDNs can be viewed as a barrier to their patients accessing palliative care services because of their lack of knowledge and experience of palliative care, they may also be part of a solution. The barrier can potentially be overcome through appropriate CLDN education and training in palliative care.

## References

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- Read S and Thompson-Hill J (2008) Palliative care in relation to people with intellectual disabilities *British Journal of Nursing* 17 (8) p 506-510.
- Tuffrey-Wijne I (2002) The palliative care needs of people with intellectual disabilities; a case study *International Journal of Palliative Care* 8 (5) p222-232.

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