

Multi-Disciplinary Palliative Care for Men Living with Duchenne: A Qualitative Interview Study

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Background

- Duchenne Muscular Dystrophy (DMD) is an ultra-rare neuromuscular condition affecting 1 in 3600-6000 live male births.^[1]
- Adults receive less comprehensive and co-ordinated care compared with those in the paediatric service.^[2]
- Individuals are living longer with an exceptional illness trajectory of prolonged dwindling, frailty and high symptom burden and yet feel palliative care is not important or relevant to them.^[3,4]
- Little evidence exists looking at the role palliative care plays in this patient group and yet men with advanced disease often have insufficient care in their last years of life and the recognition of the end of life phase is difficult.^[5,6]

Aim

- To investigate QoL in adults with DMD living in the West of Scotland (WoS).

Methods

- The SEIQoL-DW tool was used to assess the five most important elements that contribute to an individual's QoL^[7] **Figure 1**, these were then used to guide qualitative interviews with 6 men in the WoS. A thematic analysis was undertaken.



Figure 1: SEIQoL-DW tool.

Introduction to SEIQoL-DW Interview

“For each of us, happiness and satisfaction in life depends on those parts or areas of life which are important to us. When these important areas are present or going well, we are generally happy but when they are absent or going badly we feel worried or unhappy. In other words, these important areas of life determine the quality of our lives... I am interested in knowing what the most important areas of your life are at the moment...” Extract from SEIQoL-DW Administration Manual.

Box 1: Introduction to SEIQoL-DW Interview.

Results

- Men living with DMD in the WoS described living good lives despite:
 - Continual deteriorating physical wellness
 - Increasing symptom burden
 - Arrested psychological development
 - Constant need to adjust
 - Unbroken uncertainty
 - High carer burden
- These men also feel “forgotten” due to perceived gaps in their multi-disciplinary care.

“I always think about what lies ahead. When you see other boys with Duchenne and you see them struggling with breathing. It scares you a bit... (I) worry about when that happens to me. When my brother died I felt like I was scared of dying as well... I know realistically what lies ahead; that can be really difficult...” Lewis.

Conclusions

- A shift in thinking is necessary to move from “death and dying” to “living well with life-limiting illness” so that the additional of such services is not seen with fear and rejection.
- Early involvement of palliative care may positively influence the course of the disease and improve QoL and survival – as it does in cancer and other conditions.^[8]
- This introduction can be done gently as part of a multi-disciplinary team, continuing in a dynamic manner as time elapses and when trigger points arise, easing symptom burden and psychological distress, and promoting advance care planning.

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