

# Psychoeducative and Relationship-centered Interventions for Families Living with Neuromuscular Diseases During the Affected Young Person's Transition Into Adulthood: A Meta-Synthesis

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## Background and Purpose

Neuromuscular diseases (NMD) are rare genetic conditions that present with progressive muscular weakness and limited life expectancy <sup>(1)</sup>. Living with NMD during the affected young person's transition into adulthood is associated with recurring tensions and threats to family functioning and wellbeing <sup>(2)</sup>. Families would benefit from professional support to successfully cope and develop, but little evidence exists on effective family-centered interventions.

## Research aim

The aim of this literature review was to identify psycho-educational and relationship-centered interventions to better support families living with NMD during the affected young person's transition into adulthood.

## Methods

Informed by family systems theory, a qualitative meta-synthesis was conducted <sup>(3)</sup>. Inclusion criteria for publications were peer-reviewed articles reporting original research on interventions for patients and families with NMD in nursing and related disciplines. To identify relevant literature, databases (PubMed, Cochrane Library) were searched for publications including all study designs. Data analysis followed an inductive qualitative approach <sup>(3,4)</sup>.

## Results

In total, ten publications<sup>(5-14)</sup> were included in this meta-synthesis. Six studies had a qualitative, four studies a quantitative study design. The majority of the studies were conducted in Europe (5), while two studies each were based

in Canada and Japan and one study in Australia. Based on the meta-synthesis, the following interventions were identified:

- Facilitating family communication; cultivating a shared understanding and knowledge of the disease; encouraging conversations.
- Supporting decision making and self-determination; fostering family involvement, shared decision making; open and frequent conversations on choices; support with end-of-life decisions.



(MDA, Retrieved from Facebook.com, 13.03.18)

- Offering high quality professional support: offering specialized, coordinated, interprofessional care; care following standards and protocols e.g. for transfer to adult services; good professional relationships with professionals.
- Transferring care and respite care: social support (family, friends, peers); timely, good quality respite care; external primary caregiver; support system for emergencies.

- Reinforcing shared disease-management: Reinforcement of self-management including supportive measures and effective coping strategies along the disease course; anticipation and advanced care planning.
- Informing and educating on clinical and rehabilitative procedures; stepwise information on treatment and prognosis adapted to wishes, age and psychological state.
- Offering psychological-emotional support in coping with negative emotions and difficulties (sorrow, loss, anxiety, guilt, depression, frustration); support by family, friends, peers and professional.
- Supporting cognitive appraisal, identification of positive aspects of caregiving, supporting feelings of hope and enhancing acceptance.
- Facilitating development of a sense of normalization; supporting future planning including education, work, living situation and social life; dialogue, value clarification exposure to alternative ideas and role models.
- Supporting development, facilitating individual and family development; supporting socialization and balancing proximity / detachment.

## Conclusions

It is crucial to apply a family perspective to care and consider and involve the families' larger social context, which assists the processes of normalization and socialization. Families benefit from interventions that foster self-determination, detachment and effective family communication and professionals need to support the development towards independence for each family member, while also allowing for discussions on advanced care planning and end of life.