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A qualitative study on people with Duchenne muscular dystrophy and caregivers' experiences during the transition process from pediatric to adult healthcare

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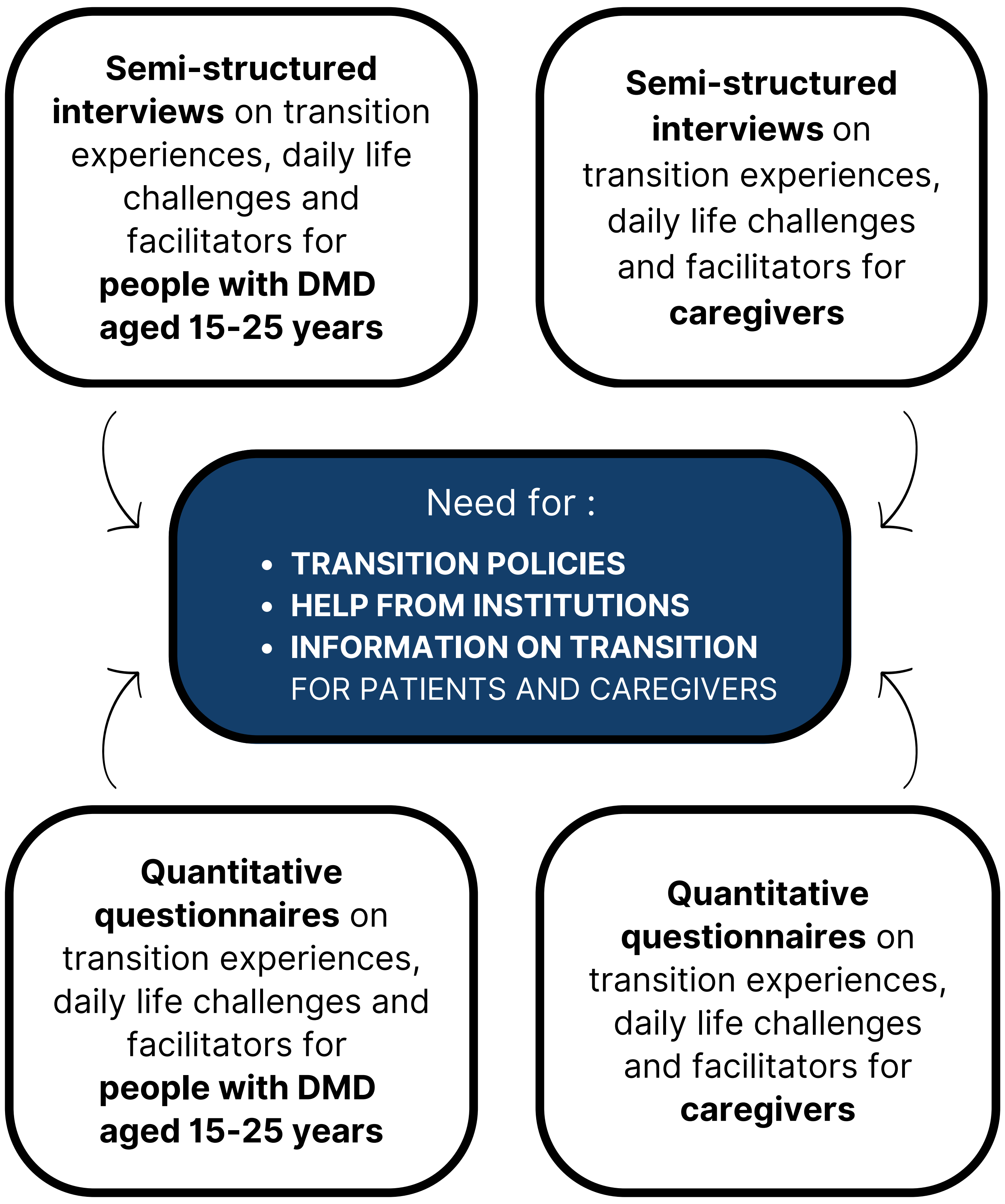
Transition from pediatric to adult-centered healthcare involves both medical and psychological needs of adolescents and young adults. This process can be especially complex in rare neurological diseases, including neuromuscular disorders. **Duchenne Muscular Dystrophy (DMD)** is a rare X-linked disorder characterized by progressive muscle degeneration, causing the loss of independent ambulation and severe multisystem complications. Over the past few years, the survival perspectives for people with DMD have improved, leading to the **need for a transition process** from pediatric to adult healthcare.



Semi-structured interviews on transition experiences, daily life challenges and facilitators for **people with DMD aged 15-25 years**

Semi-structured interviews on transition experiences, daily life challenges and facilitators for **caregivers**

Need for :

- **TRANSITION POLICIES**
- **HELP FROM INSTITUTIONS**
- **INFORMATION ON TRANSITION** FOR PATIENTS AND CAREGIVERS

Quantitative questionnaires on transition experiences, daily life challenges and facilitators for **people with DMD aged 15-25 years**

Quantitative questionnaires on transition experiences, daily life challenges and facilitators for **caregivers**

Aim

Explore the **experiences of adolescents and young adults** with DMD and **their families** in three countries (Italy, German, Canada), identifying the challenges and supportive factors of their transition process. How to improve health care, including rehabilitation systems, for individuals with DMD and other rare diseases?

Conclusions

Without structured guidelines, young people and their families feel left alone during this process.
The experiences of people with DMD and families across various countries will inform recommendations to **improve the knowledge and development of transition programs** from pediatric to adult care systems.

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"GrowDMD: Growing into Adulthood with DMD - Comparing Patient Experiences and Systems to Optimize Care"

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