

Measuring the Quality of Life of Individuals With Severe Disabilities and Complex Medical Needs

Jennifer Boyle, BA, NJ LEND Family Discipline Fellow
Amy Kratchman, BA, NJ LEND Family Discipline Coordinator

Background

Measuring Quality of Life (QOL) requires a multifaceted approach. For individuals with severe disabilities and complex medical needs, measuring QOL is especially challenging. As a result, comparatively little QOL research has focused on this group.

I investigated QOL among individuals with severe disabilities and complex medical needs, with the goal of identifying the factors associated with a high Quality of Life.

Methods

- Identified a validated QOL survey called the San Martin scale and obtained permission to use it.
- Included two subgroups:
 - **Surveyed** the families of those requiring assistance to answer questions. Utilized the San Martin scale and other questions (10 individuals)
 - **Interviewed** those able to answer questions about themselves related to their QOL (11 individuals)

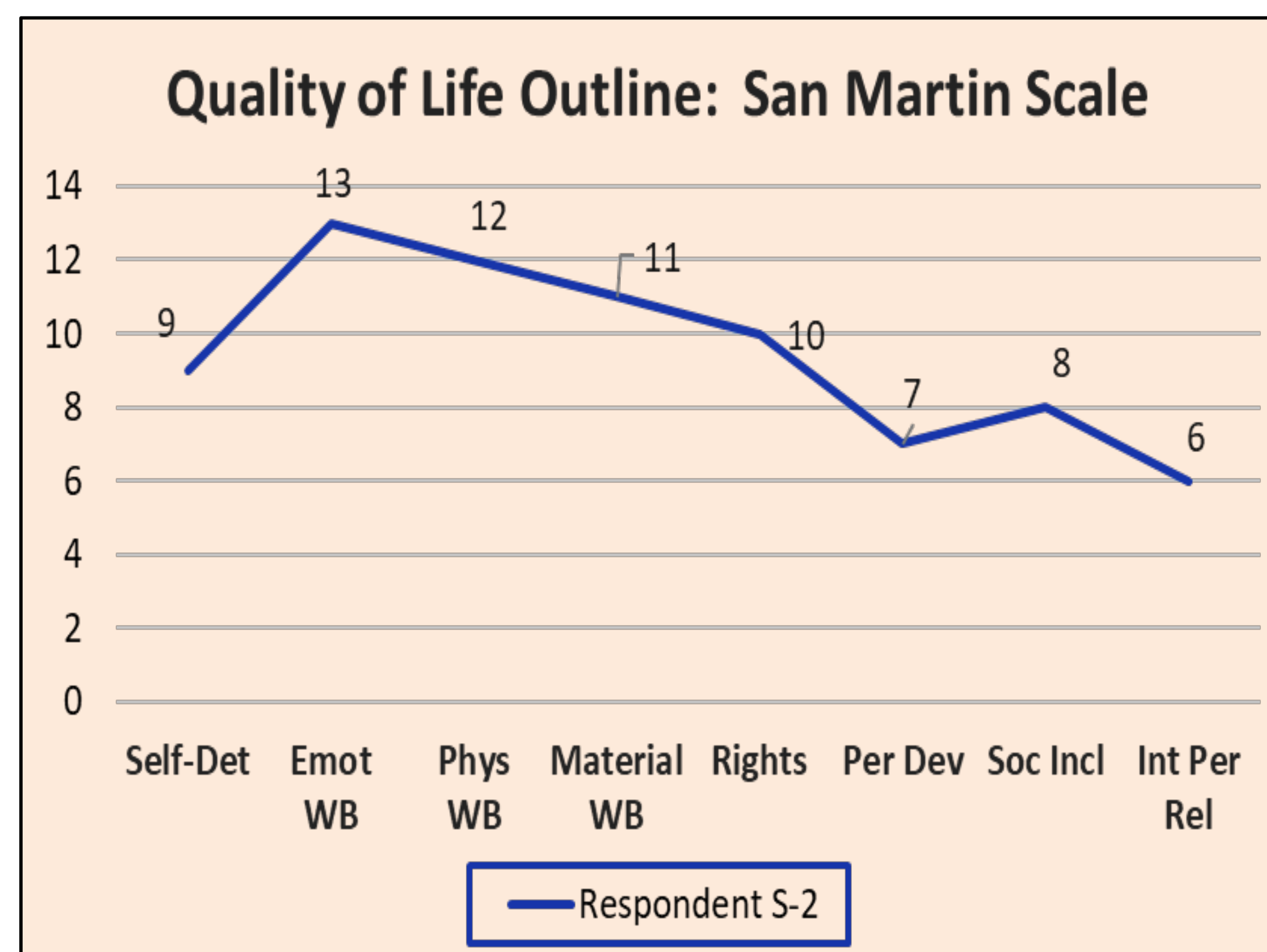
Results

- In the **San Martin surveyed group**, QOL values ranged from the 1st to the 93rd percentile
- Individuals with the highest QOL scores:
 - Scored highest in the Physical Well-Being and Interpersonal Relationship domains
 - Have a wide variety of social experiences via their family connections
 - Live at home, often with extended family nearby. Most have siblings in the home
 - Have nursing support at home
- Individuals with the lowest QOL scores:
 - Scored lowest in the Interpersonal Relationship domain
 - Are more isolated from family and the community. (e.g., one lives in a group home with no outside activities; one is medically fragile and homebound)
 - Have little variety of life experiences
- In the **interviewed group**, participants reported QOL values of 5 – 10 (10 = totally satisfied). 45% reporting a 9 or 10. Factors strongly associated with high QOL:
 - Contributing to the well-being of others, especially advocating for others with disabilities (64%)
 - A meaningful spiritual life (64%)
 - A close, teamwork-based relationship with a parent; usually a mother (55%)
 - Self-expression, often through writing (36%)

Eight factors influencing Quality Of Life



Sample QOL Scoring from San Martin Scale



Respondent S-2 Overall QOL Index = 97 (41st percentile)