Gender-Specific Facilitators and Barriers to Health-Related Quality of Life in Adults With Cystic Fibrosis

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Purpose

Cystic fibrosis (CF) is a chronic, genetically transmitted disease.

CF causes thickened secretions that impede mucus clearance in the gastrointestinal, respiratory, and reproductive tracts, thereby requiring daily treatments that last 1.5 hours or more.

With recent advances in early diagnosis and treatment, life expectancy has doubled in the last 20 years placing emphasis on improving quality of life.

Women consistently self-report having an overall lower quality of life across international studies.

The purpose of this study was to examine gender differences in disease-specific health-related quality of life (HRQoL) in adults with CF and then explore genderspecific facilitators and barriers to HRQoL.

Methods

Sequential Quantitative -> QUALITATIVE mixed methods design

123 adults with CF

Reported disease-specific HRQoL using 50-item Cystic Fibrosis Questionnaire-Revised (CFQ-R)

Scores on CFQ-R range from 0 to 100, with higher scores signifying better HRQoL

Descriptive statistics and gender differences analyzed using SPSS Statistical Software v. 23

Subsample of 15 men and 15 women took part in a 30-45 minute, semi-structured interview

Interviews transcribed verbatim and analyzed using Braun and Clarke's method of thematic analysis and Nvivo 11 Pro software

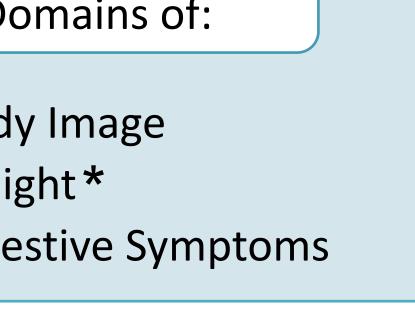


Poorer HRQoL in the Domains of:

- Body Image
- Weight*
- Digestive Symptoms

Poorer HRQoL in the Domains of:

- Physical Functioning *
- Role Functioning
- Vitality
- Emotional Functioning *
- Social Functioning *
- Eating Difficulties
- Treatment Burden
- Health Perception
- Respiratory Functioning



• <u>Men:</u>

Physical

- strength Available
- resources Male roles

Mean age:

31 Years

Insurance

Women: Labeling

Results



Open about

time

- Incorporated others into treatment
- Women:

Social

- "Those who need to
- know" Feeling

different

Men and Women: Positive

- perspective Spirituality or
- religion Support
- Uncertainty
- Women: Negative impact of social
- media Anxiety related to taking meds in public/large crowds

Weight • <u>Men:</u>

- Muscle mass
- Women:
- Happy being thin
- Went against care providers'

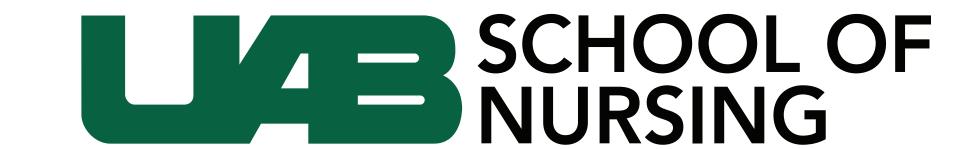
advice

Conclusions

Results demonstrate that women with CF have poorer HRQoL than men in some domains, but better HRQoL in others.

Interview data elaborated on quantitative findings by identifying gender-specific facilitators and barriers to HRQoL using the participants' rich narratives and thick descriptions of their lived experience.

Study findings will offer insight into priority areas for delivery of comprehensive, individualized care that will improve the quality of life for people with CF.



Knowledge that will change your world



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^{* =} Statistical significance at $p \le 0.05$