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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 that 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 (Abbott, Morton, Hurley, & Conway, 2015; Schindler, Michel, & Wilson, 2015). With recent advances in early diagnosis and treatment, life expectancy has doubled in the last 20 years placing emphasis on improving quality of life. Females consistently self-report having an overall lower quality of life across international studies; however, the individual domain scores and measurement tools vary (Dill, Dawson, Sellers, Robinson, & Sawicki, 2013; Groeneveld et al., 2012; Kir et al., 2015). Few studies have been conducted to see how gender relates to health-related quality of life (HRQoL). The purpose of this study was to examine gender differences in disease-specific HRQoL in adult patients with CF and then explore gender-specific facilitators and barriers to HRQoL.

Methods: Health-related quality of life was explored using a sequential explanatory mixed methods design. The sample included 129 adults with CF recruited from outpatient clinics and inpatient units at a tertiary care center in southeast United States. Patients reported their demographics and disease-specific HRQoL using the 50-item Cystic Fibrosis Questionnaire-Revised (CFQ-R). The scores on the CFQ-R range from zero to 100, with higher scores signifying better HRQoL. Descriptive statistics and gender differences were analyzed using SPSS Statistical Software v. 23. A subsample of 15 males and 15 females subsequently took part in a 30-45 minute, semi-structured interview to build upon the survey results and describe gender-specific facilitators and barriers to HRQoL. The interviews were transcribed verbatim and analyzed using Braun and Clarke's method of thematic analysis and HyperRESEARCH software.

Results: Sixty-one males and 68 females aged 19-67 were included in the preliminary results of the quantitative data. Qualitative data analysis is ongoing. The majority of the participants were Caucasian (91.5%). Females reported a better HRQoL compared to their male counterparts in the areas of body image (62.58 vs. 62.52), weight (73.04 vs. 56.50), and digestion (71.90 vs. 71.56). In the remaining 9 areas, females reported a poorer HRQoL than males, with the most drastic differences in the areas of physical functioning (53.71 vs. 66.31), social functioning (57.11 vs. 66.80), and health perceptions (55.23 vs. 63.47).

Conclusion: The preliminary results demonstrate that females who have CF have poorer HRQoL than males in some domains, but better HRQoL in others. Further analyses will be conducted to examine how gender differences in these domains interact with other clinical variables such as BMI, lung function, and *P. aeruginosa* and *B. cepacia* status, all of which have been shown to impact both survival and HRQoL (Abbott et al., 2015; Bodnar et al., 2014; Groeneveld et al., 2015; Moco et al., 2015). Additionally, the interview data will elaborate on the 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.

Title:
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Keywords:
cystic fibrosis, health-related quality of life and mixed methods

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Abstract Summary:
Cystic fibrosis is a chronic disease that causes thickened secretions requiring daily treatments lasting 1.5 hours or more. Life expectancy has increased; therefore, improving quality of life is critical. This mixed methods study examines health-related quality of life (HRQoL) and explores its gender-specific facilitators and barriers in an adult sample.

Content Outline:
Content Outline: Gender-specific Facilitators and Barriers to Health-related Quality of Life in Adults with Cystic Fibrosis

I. Introduction

A. Cystic Fibrosis is a chronic disease with no cure.

B. Life expectancy has recently doubled placing importance on health-related quality of life.

II. Body

A. Main Point #1: Methods

1. Supporting point #1: Sequential explanatory mixed methods design

a) 129 adults recruited from a single adult cystic fibrosis center

2. Supporting point #2: Quantitative strand

a) Demographics: Gender, age, relationship status, ethnicity, religion, education

b) Cystic Fibrosis Questionnaire-Revised: disease-specific health-related quality of life instrument

3. Supporting point #3: Qualitative strand

a) 30 semi-structured interviews lasting approximately 30-45 minutes

b) Braun and Clarke's method of thematic analysis

B. Main Point #2: Results

1. Supporting point #1: 61 males and 68 females between 19 and 67 years of age

a) Females reported a poorer health-related quality of life in 9 of 12 domains.

b) Most drastic differences occurred in the domains of physical functioning, social functioning, and health perceptions

2. Supporting point #2: Qualitative analysis is ongoing

C. Main Point #3: Discussion/Conclusions

1. Supporting point #1: Further analysis is being conducted to see how gender differences in the Cystic Fibrosis Questionnaire-Revised domains interact with clinical variables.

a) Clinical variables included: BMI, lung function, and *aeruginosa* and *B. cepacia* status. All included clinical variables have been shown to impact both survival and health-related quality of life.

b) Interview data will elaborate on the quantitative findings by identifying gender-specific facilitators and barriers to health-related quality of life.

2. Supporting point #2: Conclusions

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

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Professional Experience: PhD student: 2015-Present Research Assistant: 2015-Present MSN/CNL-2014 BSN- 2012 Author on five publications I have presented at local, regional, and international conferences I completed two research training programs at The University of Alabama at Birmingham
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