Original Article

Development and Testing of an Instrument on Health Related Quality of Life among Patients with Chronic Obstructive Pulmonary Disease

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Abstract

Health-related quality of life is increasingly seen as an important outcome in clinical medicine but there is a lack of context suitable reliable and valid instruments to assess health related quality of life of patients suffering from chronic respiratory illness. The objective of this study was to develop and test an instrument to measure the health related quality of life of patients suffering from chronic obstructive pulmonary disease. An instrument containing key components of quality of life was synthesized through a comprehensive review of pertinent literatures and unstructured interviews with four patients suffering from chronic obstructive pulmonary disease. Initially 60 items instrument was developed and the instrument was tested for content and construct validity with health professionals that included two nursing experts, a chest physician, a psychologist, and a psychiatrist. Based on their feedback, 56-items instrument was finalized for further testing. The prepared instrument was tested among 40 patients who were clinically diagnosed to have chronic obstructive pulmonary disease. To ensure the reliability of the instrument, Cronbach's alpha test was performed, considering alpha value of ≥0.8 as a reliable instrument. The result of this study showed that the overall standardized Cronbach's alpha measures of internal consistency were 0.903, 0.936, 0.853 and 0.917 for the total health related quality of life and it's physical, social and psychological domains respectively. Similarly, the inter-item correlation among domains of health related quality of life had ranged from 0.714 to 0.823 which were highly significant at 99% confidence level. Based on the findings, it is concluded that this health related quality of life instrument demonstrated a significant level of reliability and validity and it also indicated to serve as a useful tool to assess health related quality of life of patients suffering from chronic obstructive pulmonary disease.

Keywords: Health related quality of life, Instrument development, Patients, Chronic obstructive pulmonary disea*se*

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a major cause of morbidity and mortality worldwide. It represents a substantial economic and social burden throughout the world (GOLD, 2013). COPD patients commonly experience dyspnea, fatigue, weight loss, anorexia, anxiety and depression (GOLD, 2013; Seamark, Blake, Seamark, & Halpin, 2004) as well as intolerable dyspnea, lower levels of self-efficacy, and greater disability in advanced stage of COPD (Yohannes, 2007). The burden of COPD to patients is high and many studies demonstrated that COPD patients have impaired quality of life compared to healthy person in all physical, social and psychological dimensions (Hu & Meek, 2005; Janssen, Franssen, Wouters, Schols, & Spruit, 2011; McSweeny, Grant, Heaton, Adams, & Timms, 1982; Salik, Ozalevli, & Cimrin, 2007).

Health related quality of life (HRQoL) is a broad multidimensional concept that typically encompasses self-reported measures of functional ability, psychological state, social function, and individual perception of his/her health (Beck & Shah, 2012). To understand the effects of a health condition on well-being and functioning in chronic illness patients, it is important to capture the view of the patients.

HRQoL is the main concern for health care professionals and is used in health care settings to measure the effects of chronic illness, offering a better understanding of how illness interferes with a person's day to day life (Eriksson & Lindstrom, 2007). Both generic and disease specific quality of life measurement instruments such as 36-Item Short Form Health Survey (SF-36), World Health Organization Quality of Life Questionnaire-BRIEF (WHOQOL-Brief), St. Georges Respiratory Questionnaire (SGRQ), Chronic Respiratory Questionnaire (CRQ) and so on have been developed in Western and European countries and they were validated and used in many countries (Jones & Forde, 2009; Molen, 1999; Ware, Snow, Kosinski, & Gandek, 1993; WHO, 2004). However, available HRQoL tools include very little information about psychological and social health and they were not directly applicable in our context. Hence, there is a lack of context suitable validated instruments to assess HRQoL of patients suffering from chronic respiratory illness in developing countries like Nepal. Therefore, this study was conducted with the aim of developing and testing of an instrument to assess the health related quality of life of patients suffering from chronic obstructive pulmonary disease.

Methodology

The development of HRQoL instrument was carried out in four stages: (i) Identification of relevant HRQoL concepts, and its dimensions, (ii) Testing of construct validity, (iii) Pilot testing of the preliminary questionnaire, and (iv) Analysis of inter item relationship and internal consistency of the instrument.

HRQoL concepts, items, and domains were initially identified by reviewing related literatures on chronic obstructive pulmonary disease and previously published QOL instruments such as SGRQ, SF-36, CRQ and WHOQOL-BRIEF (Jones & Forde, 2009; Molen, 1999; Ware, et al., 1993; WHO, 2004) as well as hospital anxiety and depression scale (Zigmond & Snaith, 1983). Furthermore, additional information was collected through unstructured interviews among four COPD patients attending at Chitwan Medical College in Chitwan, Nepal and initially identified domains and items were revised accordingly.

A 60 items of HRQoL were identified: first two items were global indicator of quality of life and health and remaining items were grouped into 3 domains: physical domain (22 items), psychological domain (18 items) and social domain (18 items). A 5 point rating scale was developed where each item score was ranged from 1-5: not at all (1), a little (2), moderately (3), very much (4) and extremely (5). Responses were elicited with reference to the previous 3 months. At the end, all negative mode questions scores were converted into positive mode and the scores were summed, where a higher score indicates higher quality of life.

After development, the instrument was reviewed by three PhD scholars (Nursing Campus Maharajgunj) for face validation and then it was given to two nursing experts specialized in medical surgical nursing (working in Nursing Campus Maharajgunj), a chest physician (working in Chitwan Medical College), a psychologist (working in Institute of Medicine) and a psychiatrist (working in Chitwan Medical College) for the assessment of construct validity.

On the basis of feedback from experts, irrelevant items related to sexual life, and severity of illness were deleted accordingly. The final revised instrument, containing 56 HRQoL measuring items was developed first in English language and then translated to Nepali language. Both versions of instruments were edited by language experts. The instrument in Nepali language was again translated back to English language by language expert through the third person translation process for the consistency in meaning of both versions of the instruments. On the basis of feedback, necessary modification was done in the instrument. However, Nepali language instrument was used for data collection purpose.

The final version of the instrument was pilot tested among 40 patients who were clinically diagnosed to have COPD and attending at outpatient department of Narayani Samudayak Hospital in Chitwan from 8th June 2014 to 8th July 2014. Before data collection, ethical approval was obtained from the institutional review board of Institute of Medicine, Tribhuvan University and administrative approval for data collection was obtained from Narayani Samudayak Hospital.

For the analysis, scores of all negative mode questions were converted into positive mode, and a high score denoted better health or fewer problems. The reliability of the instruments was established by calculating Cronbach's alpha ('α') value, considering the alpha value of ≥0.8 as a highly reliable instrument (Polit, Beck, & Hungler, 2001). The alpha value for quality of life instrument was computed by using IBMSPSS version 20 for window.

Results

The mean age of the patients and standard devation was 71.0 ± 7.59 years (range 56.0- 83.0 years), half of the patients were female, and 70% of patients were illiterate. The median years since diagnosis of COPD and interquartile range was 6.0 (3.0 to 12.0) years and most of the patients (88.0%) were on regular medicine for COPD treatment More than half of the patients were suffering from at least one co-morbid condition. However, only 22.5% of patients had history of hospital admission in the last 3 months (not shown in table).

TABLE 1

Health Related Quality of Life on Different Domains

n=40

Items in Domains of HRQoL	Item Statistics		Item Total Statistics		
	Item Mean	SD	Mean Scale Mean if Item Deleted	Corrected Item-Total Correlation	α value if item deleted
Items in physical domain	2.80	0.70	6.64	0.76	0.89
Items in social domain	3.34	0.56	6.10	0.83	0.84
Items in psychological domain	3.30	0.73	6.14	0.83	0.82

Average item mean =3.15 (min 2.80 to max 3.34) Average scale mean: 9.44 (1.82)

Higher mean scores indicate higher quality of life or fewer problems

Inter item correlation mean: 0.75(min 0.714 to max 0.823)

Cronbach's alpha (α) value of items in total HRQoL=0.895

Standardized Cronbach's 'α' value=0.903

Table 1 shows that the patients had lower mean score of HRQoL on physical domain compared to social and psychological domains. The standardized Cronbach's alpha value for total HRQoL was 0.903 and the inter items correlation mean was 0.75 (min 0.714 to max 0.823).

TABLE 2

Items of Quality of Life in Physical Domain

n=40

Items in Physical Domain	Item Statistics		Item Total Statistics		
	Item Mean	SD	Scale Mean if Item Deleted	Corrected Item-Total Correlation	α value if item deleted
Experienced problem of coughing	2.35	1.33	50.82	0.65	0.92
Experienced problem of sputum	2.40	1.35	50.77	0.55	0.93
Experienced wheezing	2.93	1.59	50.25	0.57	0.93
Experienced shortness of breath	1.85	1.00	51.32	0.72	0.92
Experienced tiredness	3.82	1.20	50.65	0.51	0.93
Experienced Physical pain	3.33	1.25	49.85	0.54	0.93
Experienced shortness of breath while getting out of bed	3.55	1.06	49.62	0.62	0.93
Experienced shortness of breath while sitting or lying still	3.83	0.98	49.35	0.70	0.92
Experienced shortness of breath during bath or shower	3.40	1.13	49.77	0.67	0.92
Experienced shortness of breath while dressing yourself	3.75	0.95	49.42	0.74	0.92
Experienced shortness of breath while walking	2.30	0.72	50.87	0.55	0.93
Experienced shortness of breath while climbing up stairs	2.15	0.70	51.02	0.65	0.93
Experienced shortness of breath while kneeling or stooping	3.65	1.03	49.52	0.79	0.92
Experienced shortness of breath while lifting or carrying groceries	2.50	0.99	50.67	0.47	0.93
Experienced shortness of breath while going out for shopping	2.75	0.95	50.42	0.61	0.93
Experienced problem in light activities performance	3.33	0.92	49.85	0.73	0.92
Experienced problem in moderate physical activities performance	2.48	1.01	50.70	0.59	0.93
Experienced problem in strenuous activities performance	2.00	0.68	51.17	0.60	0.93
Experienced number of attacks free days per week	2.13	1.20	51.05	0.74	0.92

Average Items mean: 2.80 (min 1.85 to max 3.82) *Average scale mean =53.17 (13.33)*

Higher mean scores indicate higher QOL or fewer problems

Inter item correlation mean: 0.433 (min 0.103 to max 0.873)

Cronbach's 'α' value of items in physical domain: 0.929

Standardized Cronbach's 'α' value=0.936

Table 2 shows that the mean score was lower on shortness of breath, restriction on strenuous activities, experience of attack free days, shortness of breath while climbing up stairs, and shortness of breath while walking. The standardized Cronbach's alpha value of 19 items HRQoL on physical domain was 0.936 and inter item correlation mean was 0.433 (min 0.103 to max 0.873).

TABLE 3

Items of Health related Quality of Life in Social Domain

n=40

Items in Social Domain	**Item Statistics**		**Item Total Statistics**		
	Item Mean	**SD**	**Scale Mean if Item Deleted**	**Corrected Item-Total Correlation**	**α value if Item Deleted**
Satisfied with family relationship 2.98	0.77	43.80	0.48	0.84	
Received caring support from family member during illness	2.98	0.77	43.80	0.40	0.84
Received economic support from family member during illness2.93	0.86	43.85	0.44	0.84	
Received support from friends and neighbor	2.93	0.76	43.85	0.40	0.84
Satisfied with neighbor/friend	3.00	0.75	43.77	0.40	0.84
Experienced interference in usual social activities	2.95	0.93	43.82	0.53	0.83
Felt dependent on other	4.25	1.01	42.52	0.52	0.84
Felt burden on others	4.37	1.01	42.40	0.49	0.84
Experienced unable to go to religious places or place of entertainment 2.80	0.99	43.97	0.44	0.84	
Experienced any difficulty in interacting with people	4.05	1.08	42.72	0.60	0.83
Experienced financial difficulties in treatment	3.27	0.91	43.50	0.65	0.83
Experienced feeling of being excluded by other	4.15	1.08	42.62	0.62	0.83
Experienced difficulty in visiting to friend or relatives	2.60	1.08	44.17	0.62	0.83
Experienced difficulty to plan social activities in advanced	3.52	1.40	43.25	0.40	0.85

Average item mean = 3.34 (min 2.60 to max 4.37) *Average scale mean: 46.77(7.88)*

Higher mean scores indicate higher HRQoL or fewer problems

Inter item correlation mean: 0.293 (min -0.106 to max 0.804)

Cronbach's 'α' value of items in social domain: 0.848

Standardized Cronbach's 'α' value=0.853

Table 3 displays that the mean score was lower on visiting to religious places or places of entertainment. The standardized Cronbach's alpha value of 14 items HRQoL on social domain was 0.853 and inter items correlation mean was 0.293 (min -0.106 to max 0.804).

TABLE 4

Items of Health related Quality of Life in Psychological Domain

n=40

Items in Social Domain	**Item Statistics**		**Item Total Statistics**		
	Item Mean	**SD**	**Scale Mean if Item Deleted**	**Corrected Item-Total Correlation**	**α value if Item Deleted**
Felt restless or tense	3.63	1.17	42.57	0.65	0.91
Experienced sudden feeling of panic or afraid during breathing difficulty	3.68	1.12	42.52	0.66	0.91
Avoided certain things, places or activities due to fear of catching illness	3.68	1.25	42.52	0.65	0.91
Experienced frightening feeling about something unpleasant to happen	3.33	1.12	42.87	0.69	0.90
Experienced worrying thoughts in mind	3.53	1.11	42.67	0.79	0.90
Concerned about future consequences of breathing problem	3.58	1.22	42.62	0.72	0.90
Felt tearful or crying even at small issue	3.78	1.25	42.42	0.73	0.90
Felt happy with personal life	2.88	0.61	43.32	0.41	0.91
Enjoyed the things as in the past	2.08	0.89	44.12	0.56	0.91
Experienced feeling of having meaningful life	2.80	0.56	43.40	0.70	0.91
Lacked self-confidence	3.35	1.12	42.85	0.49	0.91
Experienced low in energy or worn out	2.35	0.53	43.85	0.51	0.91
Felt helpless in dealing with problem	3.88	1.20	42.32	0.57	0.91
Felt hopeless in the situation	3.70	1.24	42.50	0.75	0.90

Average item mean=3.30(min 2.07 to max 3.87)   Average scale mean: 46.20 (10.18)
Higher mean scores indicate higher HRQoL or fewer problems
Inter items correlation mean: 0.41(min 0.059 to max 0.853)
Cronbach's 'α' value of items in psychological domain=0.914
Standardized Cronbach's 'α' value=0.917

Table 4 displays that the items like enjoying the things as in the past, and feeling low in energy or worn out had lower mean score of quality of life on psychological domain. The standardized Cronbach's alpha value of 14 items of HRQoL on psychological domain was 0.917. The inter items correlation mean was 0.41 (min 0.059 to max 0.853).

Discussion

This study was conducted to ascertain the validity and reliability of the instrument developed to assess the quality of life of patients suffering from chronic obstructive pulmonary disease. The initial testing of instrument indicated that patients had significantly impaired physical health in compared to social and psychological health. Similar findings were also revealed in other studies (Desikan, Mason, Rupp, & Skehan, 2002; Garrido et al., 2006; Obaseki, Erhabor, Awopeju, Obaseki, & Adewole, 2013; Stahl et al., 2005).

The testing of this instrument found that the internal consistency (Cronbach's alpha) for the quality of life exceeded 0.80 for all three domains and for total quality of life score (0.936, 0.853, 0.917 and 0.903 for physical, social, psychological and total respectively). These values indicated that the instrument is highly reliable, as the score of more than 0.80 is highly reliable (Polit, et al., 2001). The inter-item correlation among domains of health related quality of life had ranged from 0.714 to 0.823 which are all highly significant at 99% confidence level. Evidence of the reliability and validity of the instrument in this sample is appropriate for the evaluative feedback to health professionals, health systems, and policy makers. Hence, this tool can be used to assess the quality of life of patients suffering from chronic obstructive pulmonary disease.

Conclusion

Health related quality of life instrument generated highly satisfactory result in terms of validity and reliability. However, further testing among larger number of patients suffering from COPD and more evidence of construct validity is necessary. Further research need to include testing of this instrument on hospital admitted COPD patients and to triangulate with other methods of measurement for corroborated and disparity results.

Acknowledgement

Authors would like to express special thanks to Prof. Dr. Sarala Shrestha (Nursing expert), Dr. Dipesh Maskey (Chest physician) and Asso. Prof. Takma K.C (Nursing expert), Dr. Mita Rana (Psychologist) and Dr. Shailendra Adhikari (Psychiatrist) for their constructive feedbacks and suggestions during tool development process. We would also express our deep appreciation to Mr. Govinda Dhungana (statistician) and Mr. Bibhav Adhikari (Statistician) for their statistical guidance. In addition, we wish to express our gratitude to all the patients suffering from COPD who generously participated and willingly shared their experiences in the interviews.

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