



Background

- > Role functioning is a central construct in the assessment of health-related quality of life and plays an important part in research on the impact of disease on HRQOL.
- > Due to the wide definition of roles and fluctuations in role participation across the life-span, the construct is difficult to assess.
- > A review identified over 31 measures with great variability in focus of assessment, psychometric properties, item format and popularity in the field. All existing measures are static and none takes into account the variability of social roles across the lifespan.
- > The use of qualitative approaches in the initial stages of measurement development has been increasingly recognized as a valuable strategy allowing input from future users of the tool.

Conceptual Model for Role Functioning

- > The initial conceptual model was based on the biopsychosocial model of health and disability and the International Classification of Functioning (ICF).
- > Role functioning is defined as involvement in life situations related to work for pay, household chores, social life, family life and studies (Figure 1).
- > While the bidirectional relationship between role functioning and health is recognized, the overall project goal is the development of an outcome measure focusing on the impact of health conditions on role functioning.

Focus Group Aims

- > Explore definition of role functioning and relationship to health from participants perspective.
- > Explore definitions of role domains and their relative importance.
- > Explore gender and age variations in role functioning.

Sample

- > Eight focus groups were conducted with a convenience sample of 38 English-speaking, adults.
- > Groups were stratified across 4 age groups and conducted separately by gender.
- > Mean age 41 years (range 18-79).
 - > 43% women
 - > 79% Caucasian, 13% African American
 - > 62% with chronic conditions

Method

- > Following a focus group script, participants identified relevant social roles, ranked them by importance and discussed perceptions of the impact of health on their role functioning.
- > Groups were taped, transcribed, and analyzed for thematic content.

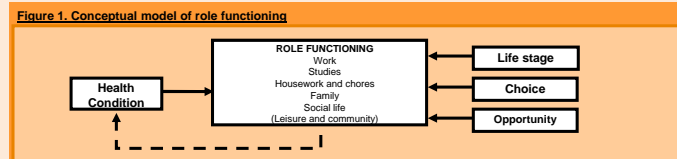
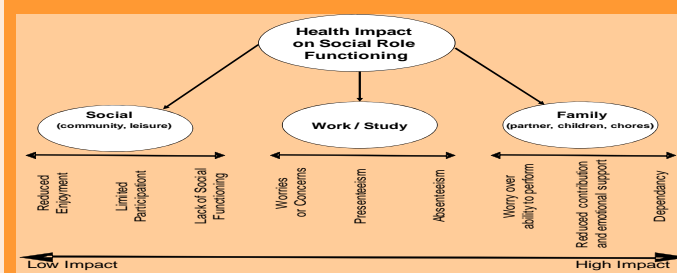


Table 1. Sample phrases of health impact on role functioning from group discussions

Role Domain	Participant quotes
Social/Leisure	"I couldn't do things I wanted to do....[like] hanging out with friends. They wanted to go out at night and I just wanted to die." "... with your friends, if everyone wants to go out and do something that you can't do then that can separate you from them and can make a wall." "And also your friends change. Like your activities change with your friends, so you loose some friends and then you move on and you find some new friends." "And she cant go to competition for cheering cause her asthma is so bad." "I was sent to go home, because I was sick and I wanted to work, but you know ..." "...if you're not doing your job at a 100% they're gonna let you know about it..."
Occupation	"I was out of work for an acute problem it effected us financially." "At work I get tired my feet hurt." "I was not able to provide for my family."
Family	"So that affects the kids, affects everybody, because everybody notices it, even it is a simple thing like a back problem." "If you can't do anything it puts the burden on the partner she has to do all of it." "Even though for a family it shouldn't be a burden it would still in the back of their heads be."

Figure 2. Working model of role functioning domains



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Role functioning definition

- > The meaning of "social role" related to social position, behavioral expectations and interpersonal interactions: "it is...where you fit in society", "knowing your spot", "how you interact with people", "the norms that society sets saying how to act".
- > Respondents provided many examples, most frequently of family roles (Table 1).
- > In addition associations were made with gender, race, various communities (e.g. friendship groups, fraternity, neighborhood, volunteer organization).

Role domains: Family Life

- > Participants of all ages and both genders identified family roles as most important.
- > Strong association with "responsibility", "support" and "social support".
- > Women expressed stronger concern of interference with the ability to take care of family members due to health problems.
- > Men were more concerned about their ability to be a "provider".
- > Older participants were most worried about losing their independence and becoming "a burden" to family members.

Role domains: Occupation

- > For people at work, occupational roles were important.
- > There was notable difference in importance by age with highest importance for younger and middle aged participants.
- > Occupational roles were primarily important as a source of financial freedom and a way to "provide for one's family".
- > Health impact was recognized primarily as absenteeism and danger of loosing income.
- > Participants were reluctant to acknowledge presenteeism.

Role domains: Social Life

- > "Friend" was the only example of a social role outside of family and work provided spontaneously.
- > We found large variability of the importance of friends and social life across age, with lowest importance for participants in middle age.
- > Social life had low importance relative to family and occupational roles.

Conclusions and future steps

- > Results suggested age and gender differences existed in the perceptions of importance of social roles, as well as concerns related to health impact across gender and age.
- > A three domain model describing the impact of health on role participation was formulated (Figure 2).
- > Findings from this qualitative study will be used to inform the development of a computerized adaptive test of health impact on role functioning with high score precision and low respondent burden.