Determinants of Health in Children with Chronic Illness

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Abstract

Quality of life (QOL) may be defined as one's perception of his or her position in life in relation to personal expectations and desires. This definition takes into account the subjective and multifactorial nature of QOL. Recent studies have indicated that current QOL measurement tools do not adequately address the child's subjective perception. Based on this, we used the GapS questionnaire to identify disease-specific aspects of QOL and ascertain self-reported determinants of health (DOH's) in pediatric patients with chronic illnesses. We conducted 46 semi-structured interviews using the parent-child dyad approach in the rheumatology, orthopedics, gastroenterology (GI) and cystic fibrosis (CF) clinics at The Hospital for Sick Children (SickKids). Children were asked to determine items that were important to their health, and rank them on a visual analog scale (VAS). English speaking children between the ages of 5 and 18 years old were included in the study. There were significant differences in "items related to physical activity" between patients in CF and Rheumatology, indicating that there are differences in health related quality of life (HRQOL) determinants between different pediatric chronic diseases. There were also significant differences in the self-reported DOH's for "items related to physical activity" and "items related to friends/family support" between males and females. Socioeconomic status (SES) did not appear to play a role in the selection of self-reported DOH's but further studies must be done to address this possibility. Intriguingly, when comparing pediatric patients from the CF clinic with those in rheumatology, there were various self-reported DOH's that differed between the two groups, indicating that disease specific measures may play an important role in assessing QOL in pediatric patients. In conclusion, our findings suggest that measurement of HRQOL is subjective and individualistic in nature, and that disease-specific determinants do exist.

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Introduction

With medical advances, children with conditions that used to be fatal are now living longer with persistent manifestations of disease. Although the exact statistics are unknown, it is estimated that by the year 2015, 1.2 billion children between the ages of 5 to 14 years old will have a form of chronic disease.[2] Further, in 2005 the World Health Organization (WHO) predicted the burden of disease as measured by the disability adjusted life year (DALY), for those between the ages of 0 to 29 to be 112 million for males and 108 million for females for a total of 220 million.[3] In 2004, the National Health Interview Survey in the US identified that 7% of US children have a health condition of greater than three months duration that limits their activity compared to 1.8% in 1960.[4,5] Another study showed that 31% of US children were affected by chronic conditions with 5% of these children having severe conditions requiring frequent physician contact.[6] In Canada, 5% of children ages 12 to 19 reported having one chronic health condition and 1% reported having two or more.[7] These studies indicate that pediatric chronic diseases are prevalent and are on the rise.

Chronic diseases are influenced by multiple factors both genetic and environmental. Of the factors that influence health, also known as determinants of health (DOH), socioeconomic status is a fundamental determinant that has been correlated with poorer health outcomes. Patients with diabetes mellitus from the lowest income quintile are 44% more likely to require hospitalization compared to the highest income quintile.[8] In adults, a lower socioeconomic status is associated with a higher likelihood of developing inflammatory polyarthritis[9] as well as having a poorer outcome and quality of life.[10] Moreover, lower socioeconomic status is associated with poorer disease outcome determinants in children with CF[11] and poorer glucose control in those with diabetes.[12] In contrast, a higher socioeconomic status has been shown to be an independent risk factor for childhood irritable bowel syndrome.[13] Taken together, these findings indicate that socioeconomic status is an important determinant of health, and lower SES is often associated with poorer health outcomes and quality of life.

A fundamental concept to understanding factors impacting ones health is health related quality of life (HRQOL). HRQOL is defined by the WHO as the " physical, psychological and social domains of health, as perceived by the patient, which are influenced by a patient's experiences, beliefs and expectations of their disease and treatment".[14] Measuring HRQOL by placing a value on health states is important in assessing patient outcomes and influencing policy.[15] This definition of HRQOL also highlights its subjective and multifactorial nature.

Recently, our research group began piloting a tool known as the GapS questionnaire to try and capture the individualistic and multifactorial nature of HRQOL.[16] The GapS quality of life tool is based on Michalos' multiple discrepancies theory. Michalos' theory proposes that overall life satisfaction can be measured by the difference or 'gap' between one's current life circumstance and the difference between: 1) what one has and what one wants, 2) what one has and what is considered to be the ideal; 3) what was has in comparison to what a reference group has; 4) one's present circumstances and what one expects or expected them to be; 5) one's present HRQOL and the best HRQOL experienced in the past; 6) one's personal attributes and the attributes of one's environment.[17] These were then modified based on feedback received from participants and their families. Preliminary GapS questionnaire findings for children with chronic illnesses showed that "having good friendships", "being happy" and 'getting along with your parents" were ranked as the most important for overall HRQOL.[18] These findings highlighted that psychosocial rather than physical or medical factors appeared to be the most important for the HRQOL of children with chronic illnesses.

This study sought to build on the findings of the pilot GapS questionnaire to determine if SES played a role in the self-reported determinants of health. To accomplish this, portions of the GapS questionnaire were used in a number of ambulatory clinics for children with chronic disease.

Methods

Population/Sampling

Participants between the ages of 5 to 18 years old that were diagnosed with a chronic illness (defined as a disease lasting three months or more) were recruited from The Hospital for Sick Children (SickKids) chronic disease clinics. This age group was selected arbitrarily due to the complexity of the task. This was a qualitative study which enrolled 46 families: 18 from Cystic Fibrosis (CF), 14 from Rheumatology, five from Gastroenterology (GI), five from Orthopedics, three from neurology and one from endocrinology. Participants were recruited through a convenience sampling method while attending routine appointments in clinic. Ethics approval for the project was obtained through the Research and Ethics Board at SickKids. Signed informed consent was obtained from both the parent and child (verbal assent was attained whenever appropriate). Patients and families who were not proficient in English and those patients who were coming to the clinic for a first consultation were excluded from the study. Demographic information including the child's age and grade level at school, parents' education, living arrangements and the first three digits of the postal code were obtained.

Interviews

Interviews were conducted in a semi-structured format by a trained interviewer and included the child and the parent/family member accompanying the child to the appointment. A semi-structured interview format was chosen in order to gain the unique perspective of each of the families and to understand the reasoning for why specific HRQOL determinants were chosen. Open-ended questions were used as much as possible to prevent bias.

A parent-child dyad approach was also used during the interview process for a number of reasons. First, it enabled us to get accurate information from the children with the help of their parents, while minimizing the unreliability of having a parent proxy. Second, it allowed us to get the parents' opinion on whether or not the self-reported determinant of health the child chose was accurate to the best of their knowledge. This approach has been utilized previously as a useful alternative to parent-proxies.[19]

Measurement of Self-Reported Determinants of Health

For the first step, participants used portions of the GapS questionnaire to aid them in choosing their determinants of

Use this list to help you come up with the TOP 3 to 10 things that influence your life

Social
- Number of friends you have
- Being able to make new friends
- Getting along with other kids our age
- ✓ Having good friendships
- Time spent with our friends
- Getting told that you have done a good job at something
- Feeling pressured by other people

Family
- Getting along with your family
- ✓ Time spent with your family
- Your behaviour at home

Living Situation
- Having pets
- Moving homes a lot
- Your life at home
- Where you live

Financial and Material
- How much money your family has
- The stuff (toys) your have
- How much food you have to eat

Physical Health
- ✓ Being physically able to do everything you enjoy doing (e.g. kicking a ball, running, watching TV, playing video games)
- ✓ Being able to take care of yourself (e.g. getting dressed, going to the bathroom, and taking a bath without help)
- Being in pain/not being in pain
- Having energy
- Feeling unwell because of your illness
- ✓ Living with your illness
- Having to get treatment or take medicine
- Having to go to the doctor or hospital
- Sleeping well at night
- Enjoying your food

Cognitive Abilities
- Being able to learn new things
- Being able to remember things (e.g. taking your medicine, stuff you learn at school, chores you have to do)
- Getting good marks at school
- Self Reflection
- Your height and/or weight
- Being happy most days
- Being sad most days
- Worrying about yourself
- Worrying about other people you know
- The place religion has in your life
- How you feel about yourself (e.g. how you like your personality, the way you look, how smart you are)
- How you feel about being a boy or a girl
- Being able to cope/or not being able to cope with your problems
- Caring about the environment and what is happening in the world around you
- Achieving your goals
- Caring about your future

Activities
- Being able to join in hobbies and after-school activities (e.g. dance, sports, art, music, clubs and groups)
- Reading, watching TV or movies, or playing video games
- Going to shows, restaurants, sports events, or shopping
- Going away for vacation or camp
- ✓ Having independence (e.g. being allowed to do the things you like doing, being able to make your own decisions)

School
- Being happy at school
- Missing school
- Getting along with your teachers
- Your behaviour at school
- Being able to do the things you need to do at school

Sexuality
- Whether or not you have a boyfriend or a girlfriend
- Being happy with your boyfriend or girlfriend
- Being sexually active

Work
- Missing work
- Being happy at work
- Being able to do the things you need at work

Is there anything else that is REALLY INFLUENTIAL to your Quality of Life that you can't find on this list?

✓ Driving _____

_____

_____

_____

Figure 1. Teaser List used from the GapS questionnaire

HRQOL. Participants were given access to a "teaser list" (Figure 1) to help them articulate their thoughts. They were given the choice to use the list, and were also able to add items not included on the list. Participants were to pick ten items they considered were important determinants of their health. The number ten was chosen arbitrarily by the developers of the GapS.[20]

For the second step, each of the items chosen was then ranked from the "least important" to the "most important" on a visual analog scale (VAS). Each of the scales were provided on a single page to enable the children to compare the items to one another.

Finally, feedback about the choices was sought in the qualitative debrief. The participants were asked to provide a rationale for each of the items chosen, as well as to explain why an item was ranked high or low.

Analysis

Self-Reported Determinants of Health

For the analysis, each of the self-reported determinants of health items was assigned a weight, which was used as a predictor of relative importance of each item. Each self-reported determinant of health on the child's list was given a weight by measuring the location of the management on the VAS from the *least important* (0) to the *most important* (14). The items were grouped into a total of nine categories based on similarity. These categories were: 1) items related to food 2) items related to physical activity 3) items related to medication/treatment 4) items related to friends/family support 5) items related to sleep 6) having energy 7) being in pain/not being in pain 8) living with my illness 9) being able to take care of myself. Items that were outliers (e.g. only reported by one child) and did not fit into one of the above categories were excluded from the analysis. If items from a single category were chosen multiple times by the same participant, the weights were added together and the total weight was used.

Socioeconomic Status (SES)

SES was assessed using the forward sortation area (FSA) boundary file from the 2006 Canadian census, which matches the first three digits of the postal code with the average household income. The protocol used for accessing and utilizing FSA analysis was followed.[21] Secondly, the median income of all of the families combined was determined. For the purpose of this paper, any income that was less than the median was considered "low" and anything greater was considered " high".

Statistical Analysis

Statistical analysis was performed on each of the grouped categories using the Mann-Whitney-Wilcoxon (MWW) test. The median, min, max and interquartile range (IQR) was calculated for each of the categories using MS Excel (Excel 2011 version 14.1.0). The MWW test was utilized for the statistical analysis using an online calculator (available: http://elegans.som.vcu.edu/~leon/stats/utest.html). The categories of health determinants were compared to one another based on gender, socioeconomic status and clinic type.

Results

A total of 46 participants with chronic illnesses between the ages of 5 to 18 years old were recruited at The Hospital for Sick Children. Due to the convenience sampling method, there was a large representation from CF and rheumatology, as well as a greater number of females than males. The study enrolled 46 families: 18 from CF, 14 from Rheumatology, five from GI, five from orthopedics, three from neurology, 1 from endocrinology. There were 27 females and 19 males recruited. The median age of the participants enrolled was 12 years old. The median household income was $75,174.

Of the participants in the study, 70% of the patient families had at least one parent with university/college education, and 20% had at least one parent with a secondary school diploma (Figure 2). 27 of the participants (59%) came from two-parent households, compared to 13 (28%) of the participants who came from one-parent households (Figure 2). Three families declined to participate in the study due to time constraints. 15 of the children had an Individual Education Plan (IEP) for a variety of reasons (e.g. needing extra time, being gifted). These children were included in the analysis because it was believed that the IEP did not affect their ability to express the factors that were important to their health.

In order to compare the different self-reported DOH's picked by the participants; their responses were grouped into nine broad categories (see methods). The majority of the items chosen by the participants fell into one of these nine categories. Items that did not fit into the categories were not included in the analysis. The median, maximum and minimum weights as well as the IQR were calculated for each category to be used for the statistical analysis (Table 1).

Table 1. Median, Min, Max and Interquartile Range (IQR) for the categories of determinants of health chosen by the participants. Each determinants of health was assigned a weight using a visual analogue scale from least important (0) to most important (14) and grouped into the nine categories above

Determinant of Health	Median	Min	Max	Interquartile Range
Items related to food	14	7.1	52.4	16.075
Items related to physical activity	13.2	3	38	3.4
Having energy	13.2	8.4	14	2.275
Items related to feeling unwell/pain	13.1	5.5	21.3	1.9
Items related to medication/treatment	14	3.3	40.2	15.8
Living with my illness	14	3.5	14	1.6
Items related to sleep	12.8	6.6	14	3.05
Items related to friends/ family support	13.25	7	28	5.775
Items related to self-sufficiency	13	9.2	28	2.475
Hobbies	10.5	0.3	12.6	4.85

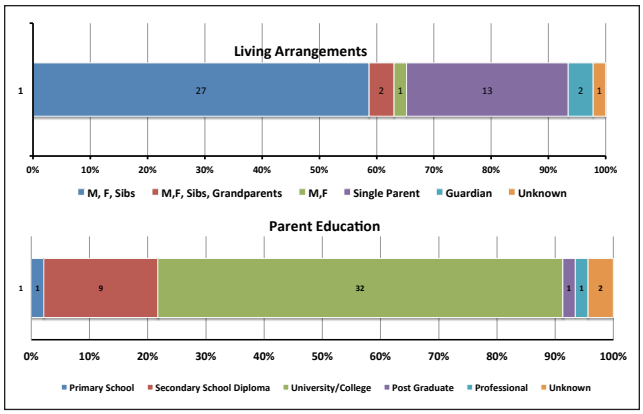

Figure 2. 100% cluster bar graphs showing the distribution of A. living arrangements and B. Parent education in the population studied. Numbers inside the bars represent the absolute number of families with that criteria. (M= male, F= female, Sibs= siblings)

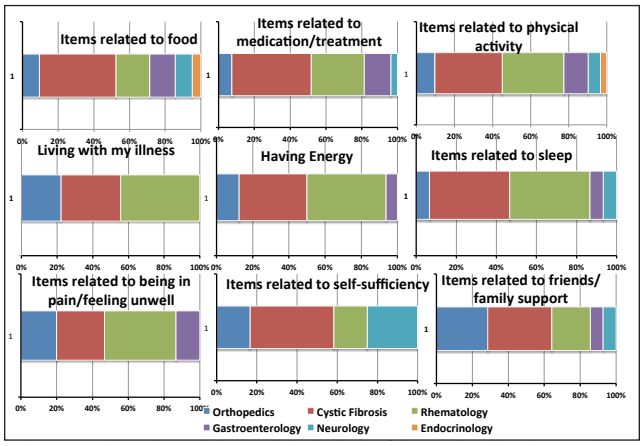

Figure 3. 100% cluster bar graphs showing relative distribution of the items chosen by patients in each clinic. Legend at the bottom indicates the clinic.

Table 2. Results of the Mann-Whitney test comparing the item weights for males vs. females in each of the categories shown. Items related to friends/family support and items related to physical activity were significantly different between the two groups (P<0.05)

Category	Median (Male, Female)	P value
Items related to food	13.5, 20.4	0.277
Having energy	12.45, 13.45	0.495
Living with my illness	14.0, 14.0	0.796
Items related to sleep	11.0, 13.1	0.351
Items related to friends/family support	**18.9, 12.5**	**0.016**
Items related to physical activity	**14.0, 11.0**	**0.014**
Items related to self-sufficiency	14.0, 12.0	0.116

Interestingly, it was noted that there were differences between the clinics in the category selection as outlined by the 100% cluster bar graphs (Figure 3). "Items related to food" and "items related to physical activity" were almost equally chosen by subjects in each of the clinics. In contrast, for categories such as " having energy", " being in pain/feeling unwell" and "living with my illness", approximately 40% of the children that chose these category were in rheumatology and the other 25 to 35% were in CF. Similarly, for "items related to sleep", 40% of the children that chose this category were in rheumatology and the other 40% in CF.

Items related to self-sufficiency appeared to be the most important to children with CF (42%), followed by neurology (25%). "Items related to medication/treatment" appeared to be the most important for children with CF (45% of the items selected), followed by rheumatology (30%) and gastroenterology (15%) (Figure 3). There were significant differences between males and females with respect to " items related to family/friend support", and "items related to physical activity"(Table 2). In contrast, when comparing high vs. low -income families to determine if socioeconomic status played a role in self-reported DOH's, it was found that there were no significant differences (Table 3). Finally, since CF and rheumatology had the greatest number of participants, we decided to compare these two clinics in order to test the hypothesis that children with different chronic diseases may use different determinants of health to assess their HRQOL. There were significant differences with respect to "items related to physical activity" between the two categories (Table 4).

Table 3. Results of the Mann-Whitney test comparing item weights of low vs. high income for each of the categories shown. There were no significant differences between the low and high income for the items chosen

Category	Median I (low, high)	P value
Items related to food	13.8, 14.0	0.619
Having energy	13.1, 13.6	0.341
Items related to medication/treatment	12.9, 19.7	0.077
Living with my illness	12.4, 14.0	0.248
Items related to sleep	13.3, 12.5	0.603
Items related to friends/family support	13.6, 11.7	0.428
Items related to physical activity	13.3, 13.3	0.418
Items related to being in pain/unwell	13.1, 14.0	0.409

Table 4. Results of the Mann-Whitney test comparing item weights for CF vs. Rheumatology for each of the categories shown. Items related to physical activity were significantly different between the two groups (P< 0.05)

Category	Median CF, (Rheumatology)	P value
Items related to food	14.0, 30.2	0.217
Having energy	13.4, 13.3	0.943
Items related to medication/treatment	27.0, 12.9	0.069
Living with my illness	14.0, 13.2	0.289
Items related to sleep	10.9, 13.7	0.150
Items related to friends/family support	13.6, 10.1	0.180
Items related to physical activity	**14.0, 8.8**	**0.002**
Items related to being in pain/unwell	14.0, 12.5	0.136
Items related to self-sufficiency	13.1, 13.0	0.881

Discussion

Completing this study enabled us to uncover a few important findings. First, in our statistical analysis, there were no significant differences in the determinants chosen to determine HRQOL between high and low-income families. This indicates that the role that socioeconomic status plays in self-reported HRQOL determinants (if any) may be more complicated than comparing high vs. low-income populations across these nine categories. Numerous studies have shown that a low SES is associated with a lower HRQOL, for example in patients with CF[11], cerebral palsy[22] asthma,[23] and sickle cell disease.[24] In contrast, findings from the GapS study found that none of the children chose economic status determinants, such as " how much money your family has" or " how much stuff you have", as being factors important to their quality of life.[18] This finding suggests that family income may not be an important consideration for the pediatric participants when choosing factors that influence their health. A small sample size likely contributed to our findings in this population; small numbers only allowed us to divide our subjects into "high" vs "low" income families. Future studies will continue looking at the relationship between SES and self-reported DOH.

This study found that there were significant differences in self-reported DOH's between males and females with respect to "items related to physical activity" and "items related to friends/family support". Other studies have been unable to find significant differences in HRQOL between males and females with juvenile idiopathic arthritis.[25] Interestingly, one study showed female patients with CF reported a significantly lower HRQOL compared to males. Specifically, females reported significantly lower scores in the HRQOL domains related to family activity, family cohesion, self-esteem and physical functioning.[26] Intriguingly, our findings indicate that females scored "items related to friends/family support" as well as "items related to physical activity" as less important to their overall HRQOL when compared to males. Taken together these findings indicate that there are significant differences in self-reported DOH's between males and females, and provides some indication that the relative importance of a specific DOH may influence how one perceives it impacts their HRQOL.

In this study, we also discovered that self-reported DOH's may be significantly different for patients with various chronic illnesses. We chose to compare participants in the cystic fibrosis clinic with those in rheumatology because we had the greatest number of responses from these two clinics. Further, the sample size for the remainder of the clinics was too small to allow meaningful comparison. There was a significant difference in "items related to physical activity" between participants in CF compared to rheumatology. To the best of our knowledge, there are no other studies comparing HRQOL determinants between different pediatric chronic diseases. It has been shown that physical activity has a profound impact on overall survival,[27] as well as improving QOL[28] in the CF population. In contrast, the role of exercise in improving HRQOL in pediatric arthritis is controversial. Some studies have shown that in patients with juvenile idiopathic arthritis (JIA), inactivity was associated with increased disability and a poorer overall quality of life,[29] whereas others have shown that exercise has no impact on HRQOL.[30] Interestingly, a qualitative study noted that children with arthritis often needed to overcome their negative perceptions of exercise in order to successfully participate in physical activity.[31] Taken together with the finding that patients in rheumatology ranked "items related to physical activity" as being significantly less important than those in CF, these findings indicate that although beneficial, the child's challenges with exercise may impact their view on its importance to HRQOL. These findings highlight some of the important implications for how we define, monitor and evaluate HRQOL in pediatric chronic illnesses. Second, they suggest that incorporating exercise programs into the management of CF may improve patients' overall HRQOL.

Our findings also suggest that disease specific determinants likely exist that can be utilized to better understand and measure HRQOL in children with various chronic illnesses. For example, patients with rheumatic disorders most frequently selected "items related to sleep" and "items related to being in pain/unwell" as important determinants of their HRQOL. This is in keeping with similar findings from Butbul et al., which showed that sleep disturbances strongly correlated with increased pain and a decreased HRQOL in this patient population.[32] This finding suggests that these factors may be important in defining and measuring rheumatology specific-QOL determinants. Similarly, for patients with CF, "items related to food", "items related to self-sufficiency" and "items related to medication/treatment" appeared to be the most important for this patient population. This suggests that these determinants may be utilized to determine disease-specific determinants for this patient population. For children in GI, "items related to food", "items related to medication/treatment" and "items related to being in pain/feeling unwell" seemed to be the most commonly picked items. These findings correlate with other domains on the Pediatric Quality of Life Inventory (PedsQL),[33] which showed through a qualitative interview that items related to "food and drink limits", "medicines", and "physical symptoms such as stomach pain", were important HRQOL measurements in this population.[34] Taken together, our findings suggest that there may be important disease specific HRQOL determinants that can be used to improve measurement tools in pediatric populations.

From this study, one can also conclude that self-reported DOHs are subjective and individualistic in nature. There was variability in the self-reported determinants of health chosen both within an individual clinic, as well as when compared between clinics. Further, we showed that there was significant variability in self-reported determinants of health between males and females. Finally, we showed that there was some indication that disease specific determinants exist since some DOH's were chosen more frequently by patients in some clinics than in others. These findings provide evidence that self-reported DOH's are unique and subjective. It is suggested that in the development of HRQOL measurement tools, the subjective nature of HRQOL should be considered.

These results must be considered in the light of several possible limitations. These include a small sample size, variability in sampling between males vs. females and between clinics, as well as a high median family income. Due to the sampling method, a small number of patients were recruited from orthopedics, gastroenterology, neurology and endocrinology. This likely explains why we did not uncover disease specific items for these

patient populations. Future studies will address these gaps in our study. Convenience sampling generated a larger proportion of females interviewed than males. However, we were still able to elicit significant differences between the genders in self-reported DOHs. A larger sample size, and a larger proportion of males in the sample may yield further significant differences between the two genders. We did not find significant differences between high vs. low-income groups. A small sample size did not allow us to separate families into income quintiles for a more accurate measurement and a greater sensitivity to uncover potential differences that exist between various income brackets. Finally, the median family income for our patient population was $75,174. According to statistics Canada, the median household income for all census families in Canada in 2010 was $69,8603.[5] The higher median income in the families we interviewed compared to the median across Canada may also influence our findings regarding socioeconomic status and HRQOL. Future studies should include a larger array of income brackets for analysis. Although our sample size was limited, our data indicates that there are significant differences between males and females and between various clinics to support the conclusion that self-reported DOH and disease-specific determinants have important implications for measuring HRQOL in the pediatric chronic disease population.

In conclusion, we found that certain HRQOL determinants were significantly different between males and females as well as between different chronic diseases, specifically CF and rheumatology. We did not find any significant differences in the HRQOL determinants based on socioeconomic status. These findings suggest that measurement of HRQOL is subjective and individualistic in nature, and that disease-specific determinants do exist. Understanding and incorporating some of these concepts into HRQOL measurement tools will be fundamental for an accurate, and individualistic understanding of HRQOL.

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