Conceptual Mapping of Health-Related Quality of Life, Quality of Life, and Wellbeing: A Qualitative Systematic Review, and how commonly used generic measures capture these concepts.

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Abstract

Introduction: Health-related quality of life (HRQoL) is a widely used health outcome measure. However, there is considerable overlap and disagreement between HRQoL and other closely related concepts (such as Quality of Life -QoL- and Wellbeing -WB-). Bearing this in mind, we performed, through a qualitative systematic literature review, a conceptual mapping of the commonly used concepts of HRQoL, QoL and WB in order to understand its commonalities and differences. We also aimed to create a conceptual map about the coverage of both the EuroQol family of instruments as well as other commonly used generic measures of these concepts.

Methods: 1) Systematic literature review specifically targeting qualitative, quantitative, or mixed-methods studies. The focus was on studies analyzing, developing, identifying, or describing any of the three high-level concepts targeted by our study, in order to retrieve domains/dimensions, subdomains, and facets as defined by the authors. 2) Development of conceptual frameworks for HRQoL, QoL, and WB. This process involved a detailed iterative conceptual analysis and curation of domains identified in the literature. The research team deliberately grouped conceptually similar or hierarchically related domains, drawing on the evidence retrieved. 3) Mapping of final working conceptual models to common generic and EuroQol instruments was done.

Results: A total of 14,113 studies were initially identified across various databases and gray literature. 34 studies and 35 conceptual frameworks were included in the final review. From all included frameworks, 168 first-level domains, 223 second-level domains, and 38 third-level domains were retrieved. In phase 2, these domains were finally curated into 106 unique entities. HRQoL was associated with 66 unique dimensions, QoL with 49, and WB with 70. Most dimensions were mentioned by only a few frameworks, indicating low consistency in conceptual definitions. Overlap analysis showed 26 dimensions shared by all three concepts, 3 by WB and QoL, 13 by WB and HRQoL, and 11 by QoL and HRQoL. WB had 28 unique dimensions, HRQoL 16, and QoL 9. The final HRQoL model included 18 dimensions. The final QoL model included HRQoL dimensions plus 4 additional ones. The final WB model included 10 dimensions. Eight instruments were mapped to HRQoL, two to QoL, and five to WB. On average, the instruments mapped to 59.4% of HRQoL domains, 65.9% of QoL dimensions, and 34% of WB domains. The EQ-HWB instrument covered the most domains for both HRQoL (17 out of 18) and WB (5 out of 10).

Discussion: In this systematic qualitative review we show that high inconsistency and overlap among different definitions and domains of commonly used health and wellbeing concepts Health-Related Quality of Life, Quality of Life and Wellbeing. The absence of clear conceptual and operational definitions poses a major challenge in theoretically differentiating these high-level concepts, and has a significant impact in the validity of measurement tools in this large field of research. Recognizing the need for clearer conceptual definitions and proposing an initial step, this work could pave the way for new analyses and developments in the understanding and measurement of these essential concepts, as well as empirical validation exercises to test their soundness and utility.

Introduction

Health-Related Quality of Life (HRQoL), Quality of Life (QoL), and Wellbeing (WB) are commonly used terms in contemporary health and social science research (REF), strongly enriching the spectrum of outcomes used in health and social policy and research, aiming to describe or address the impact of a wide range of aspects and interventions on an individual's overall life, and not just focusing on any symptom, disease, condition, or specific dimension in particular. For example, a simple search in PubMed shows nearly 600,000 citations using these terms. A similar search in Social Science Citation Index Database, one of the most popular social science databases, brings nearly 200,000 citations.

Despite being nearly ubiquitous concepts and outcomes in health and social science, there is no agreed definition of each of these three high-level concepts of HRQoL QoL and WB, and there is considerable disagreement and conceptual overlaps that challenge their clarity and precision.[1] Promoting sound advances in outcomes research and measurement of these non-disease specific broad health measures it's clearly hindered by these conceptual conundrum.

Historically, the interchangeable use of terms like WB and QoL has led to potential misinterpretations and misapplications in health sciences.[2] Salvador-Carulla et al. have delved into these issues, proposing a conceptual framework that aids in disentangling these terms and offering clarity on their distinctions.[3] Ferrans' exploration into the definitions and conceptual models of quality of life emphasizes the intricate nuances that often go overlooked, highlighting the imperative for a more rigorous and standardized approach to their definition and measurement in health research.[4]

The ambiguity surrounding these terms is not just an academic concern; it has tangible implications in the realm of health research.[5] Inconsistent or overlapping definitions can lead to challenges in health policy design and monitoring, instrument or survey development, validation, and interpretation, potentially undermining the validity of research and policy findings.[6] For example, Smith et al. underscored the importance of distinguishing between quality of life and health status in research, shedding light on the potential pitfalls of conflating the two.[7] Such conflation may result in the misalignment of interventions with patient priorities and reduced effectiveness in improving HRQoL.

Recent scholarly endeavors have attempted to navigate this complex terrain.[8] Mukuria's scoping review, for instance, delved into health status conceptual definitions with a specific focus on the development of a new instrument, the EuroQol Health and Wellbeing instrument (EQHWB).[8] Similarly, Mulhern et al argue for a novel multi-layered 'Deep Dive' approach, aiming to inform the measurement of HRQoL in this case from its roots.[9]

These efforts and the current somewhat confusing situation around the concepts HRQoL QoL and WB highlight the pressing need for their systematic exploration, including their definitions, dimensions and their intricate interrelationships.[10] Recognizing this gap, our work embarks on an attempt to bring more clarity on these three high-level concepts.[3] This endeavor can be instrumental to both health and social sciences, from health or social policy design or monitoring to inform the development, validation, and application of generic instruments in health research.

Thus, the aim of this study was to perform a qualitative systematic literature review and to report an updated and inclusive conceptual mapping of HRQoL, QoL and WB in order to understand its commonalities and differences. Finally we also aimed to create a conceptual map about the coverage of commonly used generic instruments-measures of these concepts, and their domains/dimensions (considering the concepts of domains and dimensions as synonyms), sub-domains/dimensions, sub-themes or facets.

Methods

We followed three sequential steps: 1) systematic literature review specifically targeting qualitative or mixed-methods studies. The focus was on studies analyzing, developing, identifying, or describing any of the three high-level concepts targeted by our study, in order to retrieve domains/dimensions, subdomains, and facets as described by the authors; 2) Conceptual Analysis / Development of conceptual frameworks for HRQoL, QoL, and WB. This process involved a detailed iterative analysis and curation of domains identified in the literature. The research team grouped conceptually similar or hierarchically related domains, drawing on the evidence retrieved and arriving at a proposed conceptual framework of each high-level concept; and. 3) Common generic and EuroQol instruments were mapped onto these final working curated conceptual models.

The protocol of the systematic review was published and registered in OSF Registries.[11] We performed a systematic review of studies that use qualitative, quantitative or mixed-methods research.[12,13]

- Systematic review and concept analysis

Search strategy

We included studies with a specific focus on analyzing, developing, identifying, or describing these three high-level target concepts: HRQoL, QoL and WB. We searched for empirical and theoretical studies that report their conceptualization. If applied to a specific target population, we focused on studies targeted to the adult population -regardless of age, gender or geographic area- including all types of patients; formal and informal carers as well as the general public. Search period: from inception to Dec 2022. We selected only publications written in English, as the main studies in the academic world in all countries are typically published in English.

Eligibility criteria and study selection

Two authors independently screened titles and abstracts to exclude records that were not relevant. For all studies selected by at least one author during the initial screening, full-text articles were retrieved. Subsequently, three researchers independently assessed full texts to check if they fulfilled the inclusion criteria. Disagreements were resolved by discussion with another team member, and in case of remaining disagreement by final deliberation by all study team. We conducted no further assessment of the validity or quality of the full texts as the aim was to identify a broad range of conceptual definitions used in the literature; we felt it would be arbitrary to rate the quality of some definitions higher than others. Additionally, the range of study design and methods was expected to be too heterogeneous to have a uniform quality rating.

Conceptual analysis

We carried out a content analysis following the steps described below. Articles were included and coded in ATLAS.ti 23.[14] Coding was developed iteratively and revised continuously in discussions with all team members.

a) Descriptive Stage: In the first stage of the coding process, we engaged in a meticulous examination of the dimensions-domains, subdimensions-subdomains, and facets (or first, second, and third-level domains or dimensions) linked to the concepts of QoL, HRQoL, and WB. We did not begin with any pre-established codebook; rather, we formulated codes for each dimension as it was presented in the conceptual models or frameworks, initially using the terminology employed by the respective authors. For a visual representation of dimensions, we developed individual conceptual models for each paper, organized into first-level dimensions and, where present, second or third-level dimensions as well, respecting and depicting the hierarchical conceptual structure. The proposed conceptual structures (i.e different dimensions and their relationship) proposed by the authors were maintained in all these initial descriptive visual models.

b) Harmonization of dimensions: In the second stage of the coding process, a comprehensive synthesis of the dimensions and sub-dimensions was performed by unifying those dimensions that were synonyms or very similar considering the definitions provided by the original authors where available, or relying on the researchers' collective judgment. This was done with the purpose of clarifying an initial long list of domains and avoiding overlaps and redundancy. This work was carried out by two researchers and in case of lack of agreement, a third researcher intervened. Some dimensions were common or very similar across multiple conceptual models, while others were unique to specific ones.

c) Iterative analysis for the curation of dimensions: To comprehensively describe all dimensions outlined in the literature, regardless of whether they were categorized as first, second, or third-

level domains, a process of curation and conceptual unification was initiated. To arrive at the final dimensions for each high-level concept, a qualitative analysis was conducted. Researchers scrutinized each dimension/sub-dimension, grouping them according to categories. The construction of these categories and groupings was done by the team based on the interpretation of information described in the preceding stages and through an iterative deliberative process grounded in the evidence and work done in the initial two previously described coding stages. The grouping occurred in several stages. Initially, after reading all dimensions, the entire research team deliberated on the similarities and differences among them. Subsequently, two researchers collaborated in the first round of grouping (FJA and MB). The grouping was then reviewed by another three researchers (JC, FA and NI), who conducted a second round of grouping. The results of the second round were subsequently reviewed by the initial pair of researchers (FJA and MB), who performed a third and final round of grouping. The final listing was reviewed and agreed upon by the entire team. This rigorous and meticulous process enabled us to compile a comprehensive list of dimensions mentioned in the literature as reproducible and scientifically grounded as possible.

d) Construction of final Conceptual Models: We initiated the process of building the conceptual model of HRQoL, incorporating conceptual hierarchical structure and relations among 1st, 2nd, and 3rd level domains. Once this model was constructed, we advanced with the QoL model, acknowledging -as several studies do- that HRQoL is nested within Qol.[2] Finally, the Wellbeing conceptual model was constructed, incorporating some categories curated in the other 2 high-level conceptual frameworks.

During this last phase, we had the input of two experts to assess the high-level concepts´ conceptual face validity and other general insights: Vilma Irazola (IECS, University of Buenos Aires), with background in HRQoL and QoL work and knowledge, and Tessa Peasgood (University of Sheffield) with more background on Wellbeing.

Mapping of a set of generic instruments to our conceptual models.

Finally, in this phase, we mapped the conceptual models developed during the previous phase both with the main EuroQol family of instruments and key bolt/ons, as well as a group of key instruments that are commonly used to assess HRQOL (COOP- WONCA, SF-36, EQ-5D, SICKNESS IMPACT PROFILE, PROMIS-29, HUI, EQ-HWB, 15D), QoL (AQOL-8D, WHO-QOL), and Wellbeing (ICECAP-A, QUALITY OF WELLBEING SCALE, ICECAP-O, IWB, EQ-HWB). EuroQol bolt-ons as defined by Rencz et al were also included. Additionally, the EuroQol foundation was consulted regarding the different bolt-ons to include. A total of nine bolt-ons were considered by Rencz et al, and seven (hearing, cognition, self-confidence, sleep, social relationships, tiredness, and vision) were selected for this analysis.

Results

We sequentially describe the 4 sections of our results: 1) Qualitative systematic literature review and concept analysis; 2) HRQol, Qol and WB conceptual model construction; and 3) Mapping of a set of generic instruments to the HRQol, Qol and WB conceptual models.

Systematic review and concept analysis

Descriptive Stage

A total of 14,113 studies were identified among the different databases and gray literature. Of these, 51 were surveyed and evaluated in full text, 19 of which were eliminated for various reasons (incorrect objective (n= 11), incorrect patient population (n= 4), incorrect study design (n= 2) incorrect outcome (n= 1), other reasons (n= 1), leaving a total of 34 studies, with 35 total reported conceptual frameworks included in the final review. See PRISMA flowchart in the supplementary material 1.

Table 1 provides a brief description of the 35 frameworks surveyed, with the high-level concepts and first-level domains as established by the authors. In the supplementary material 2 we report the graphical representation of the conceptual models of each reported framework, with the concepts and domains/dimensions as defined by the authors.

Included studies were published between 1976 and 2023. Of the publications that reported where the study was conducted, the majority were Europe (9 frameworks), Asia (seven frameworks) and North America (five frameworks). In the initial analysis we found eight different "author-defined" high-level concepts evaluated among the 34 included studies (QoL, HRQoL, Capability Wellbeing, Emotional Wellbeing, Flourishing, Functional Status, Health, Health and Wellbeing, Health-Related Subjective Well-being, Psychosocial Wellbeing, Wellbeing). These were categorized -if judged adequate by the research team and based on the author's definitions- and after the team consensus, in one of the three main constructs of interest targeted by this work (HRQoL, Qol and WB). Fourteen conceptual frameworks targeted HRQoL, five described QoL, and 16 WB. Conceptual frameworks used different methodologies, and several studies used more than one methodology for their generation. The most commonly used methods included surveys (n= 12), interviews (n= 10), expert opinion (n= 7), focus group (n=6), factor analysis (n= 5) and literature review (n= 5).

Table 1. Description, high-level concepts, and main domains (level 1) of included frameworks*

Author	Year	Variable / Construct -as reported by the authors- (as	Level 1 Domains	Methods

		judged by the research team)		
Arthaud-day[15]	2005	Wellbeing (WB)	Negative affect, Cognitive evaluation, Positive affect	Survey and factor analysis
Bragin[16]	2022	Psychosocial well-being (WB)	Peace, security, justice, love/support in the family, freedom, physical health, participation in cultural/religious practices, friendship/support outside the family, self-efficacy/self-esteem, leisure activities or time to enjoy living, economic security, independent power and authority, personal capabilities/attributes, successful fulfillment of obligations	Focus groups
Breslow[17]	2016	Human Wellbeing (WB)	connections, capabilities, conditions, cross-cutting	literature review
Cella[18]	2010	Health-related quality of life (HRQoL)	Mental health, Physical health, social health, global health	Others
Colleen[19]	1993	Health and wellbeing (WB)	Social functioning, role-physical, mental health, pain, general health perceptions, role-emotional, vitality, physical functioning	Survey
Dolan[20]	2021	Wellbeing (WB)	Objective circumstances of people's lives, people's subjective selves, people's time use, people's experiential subjective wellbeing	Experts opinion
Espinosa[21]	2020	Health (HRQoL)	Family, finances, work-life, lifestyle behaviors, sense of self, physical health, resilience, spirituality and religiosity	Interviews
Espinosa[21]	2020	Wellbeing (WB)	Family, finances, work-life, lifestyle behaviors, sense of self, physical health, resilience, spirituality and religiosity	Interviews
Euroqol 1990[22]	1990	Health-related quality of life (HRQoL)	Mobility, self-care, main activity, social relationships, pain/discomfort [&]	Survey
Felce[23]	1995	Quality of life (QoL)	Material well-being, physical well-being, development and activity, social well-being, emotional wellbeing	Experts opinion
Gallagher[24]	2009	Wellbeing (WB)	Eudaimonic well-being, social well-being, hedonic well-being	Survey and factor analysis
Hunt[25]	1985	Health (QoL)	Problems with health, Areas of daily life most often affected by health	Survey
Huppert[26]	2013	Flourishing (WB)	Positive appraisal, positive characteristics, positive functioning	Literature review and experts opinion

Janabi[27]	2012	Capability wellbeing (WB)	Enjoyment, achievement, stability, attachment, autonomy	Interviews
Kaplan[28]	1976	Wellbeing (WB)	Function levels, Symptom/Problem Complexes	Experts opinion
Kim[29]	2017	Health-related quality of life (HRQoL)	Pain/discomfort, anxiety/depression, mobility, vision, self-care, usual activities, hearing, communication, cognitive function, social relationships, vitality, sleep	Survey, literature review, experts opinion
Larsen[30]	2023	Prosocial well-being (WB)	Happiness, meaning	Interviews, secondary database analysis
Manolom[31]	2015	Wellbeing (WB)	Doing, Having enough for sustaining living, Community unity, Forest and environment, Family, Thinking	Focus groups and interviews
Mao[32]	2021	Health-related quality of life (HRQoL)	Cognitive function, mind-frame, physical functioning, social wellbeing, physical senses, emotional experiences	Literature review, interviews
Marsh[33]	2019	Wellbeing (WB)	Prosocial behavior, empathy, resilience, self-acceptance, positive emotions, clear thinking, self-esteem, optimism, engagement, autonomy, vitality, positive relationships, emotional stability, meaning, competence	Survey, factor analysis
Mukuria[8]	2022	Health and wellbeing (HRQoL)	Cognition, physical sensations, copíng, autonomy and control, activity, feelings and emotions, self-identity, relationships	Literature review
Olsen[34]	2020	Health-related quality of life (HRQoL)	Mental health, social health, physical health	Others
Park[35]	2023	Emotional Wellbeing (WB)	Ability to pursue self-defined goals, insight, sense of meaning and purpose, acceptance, feeling cared for, secure, awareness, autonomy, transcendence connected to something beyond one-self, life satisfaction, overall positive state of emotions, certain types of personality, sense of agency, optimism	Literature review, experts opinion
Richardson[36]	2009	Quality of life (QoL)	Relationships, mental health, self worth, pain, senses, independent living, life satisfaction, coping	Focus group and interviews
Schalock[37]	2016	Quality of life (QoL)	Interpersonal relations, emotional wellbeing, self-determination, physical wellbeing, material well being, social inclusion, rights, personal development	Literature review, experts opinion
Suavansri[38]	2022	Wellbeing (WB)	Sense of self, experience of emotions, self-care, thoughts and feelings about the future, personal health, spirituality and religiosity, social relationships, finances	Interviews

Thumboo[39]	2018	Health-related quality of life (HRQoL)	Social health, mental health, physical health,	Interviews, focus groups
Touré[40]	2022	Health-related quality of life (HRQoL)	Citizenship and social inclusion, pain and physical discomfort, self-esteem and self-acceptance, social and interpersonal relationships, sleep and energy, body functioning, mobility and physical capacity, anxiety/depression, cognition, sense and language, wellbeing, daily activities and work, autonomy, social activities and leisure	Surveys, factor analysis, delphi method
Van Weel[41]	1995	Functional Status (HRQoL)	Feelings, social activities, daily activities, physical activities, pain, change in health, overall health	Survey
Vries[42]	2016	Health-Related Subjective WellBeing (WB)	Autonomy, positive affect/happiness, personal growth, physical independence, negative affect/feeling lost and lonely	Interviews, survey and factor analysis
WHOQOL[43]	1994	Quality of life (QoL)	Environment, Psychological domain, Spirituality/religion/personal beliefs, social relationships, physical health, level of independence	Experts opinion and focus group
Willroth[44]	2023	Psychosocial Wellbeing (WB)	Hedonic, intrapersonal aspects, interpersonal aspects, eudaimonic	Experts opinion
Wilson and Cleary[45]	1995	Health-related quality of life (HRQoL)	General health perceptions, biological and physiological factors, symptoms, overall quality of life, functioning	Experts opinion
Sintonen[46]	1995	Health-related quality of life (HRQoL)	Sleep, breathing, eating, speech, mental function, mobility, hearing, vitality, distress, usual activities, elimination, depression, vision	Questionnaires, survey
Feeny [47]	2002	Health-related quality of life (HRQoL)	Vision, hearing, speech, ambulation, emotion, cognition, pain	Surveys

HRQoL: Health-related quality of life, QoL:Quality of life, WB: Well-being.

A total of 168 top or first-level domains, 223 second-level domains (subdomains) and 38 third-level domains (facets) were retrieved from all the included frameworks. These domains were initially based on each author's definition and transcribed verbatim. The median number of top-level domains per framework was five (with a minimum of 2 to a maximum of 15). Eighteen frameworks only contemplated first-level domains, 16 included second-level domains, and only one contemplated third-level domains.

Harmonization of dimensions

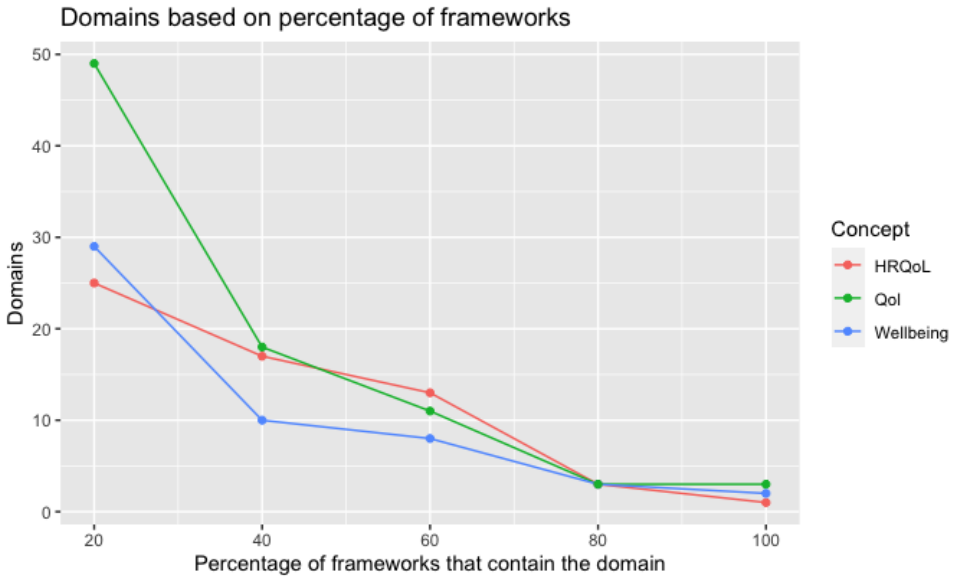
The domains-dimensions were unified into a total of 106 unique entities (without initially taking into consideration domain hierarchical level). In supplementary material 3 the unified dimensions are listed and described. Each dimension may contain one original dimension or a set of original dimensions (if these dimensions were considered synonyms or were conceptually equivalent). In most cases, final dimensions contained only one (n= 45) or two (n= 21) dimensions reported by the original authors. The median number of original dimensions contained per final dimension was 2. The final dimensions that included the most original dimensions were Feelings and emotions (n=35); Social and interpersonal relationships (22) and Usual activities (20).

Findings from Iterative Analysis for Dimension Curation

If we consider all reported non-duplicated and curated dimensions, HRQoL had a total of 66 associated unique dimensions, QoL had 49, and wellbeing had 70. Many of these domains were considered by only one or a few reported conceptual frameworks, so, the number of dimensions could change significantly if we took into consideration the proportion of frameworks where dimensions were shared. Figure 1 shows how the number of dimensions of HRQol, QoL and WB decrease based on the percentage of frameworks that incorporate each of them within each high-level concept. As can be seen in the graph, for the three concepts, most dimensions were mentioned in a low proportion of frameworks. Very few domains showed high consistency (being included in almost all frameworks that assess the same concept) in each case. This indicates a low consistency/robustness in the domains that comprise each concept. Supplementary material 4 shows all initial dimensions included in each concept based on different stringency criteria (i.e the number of times each domain is repeated in different frameworks of the same concept).

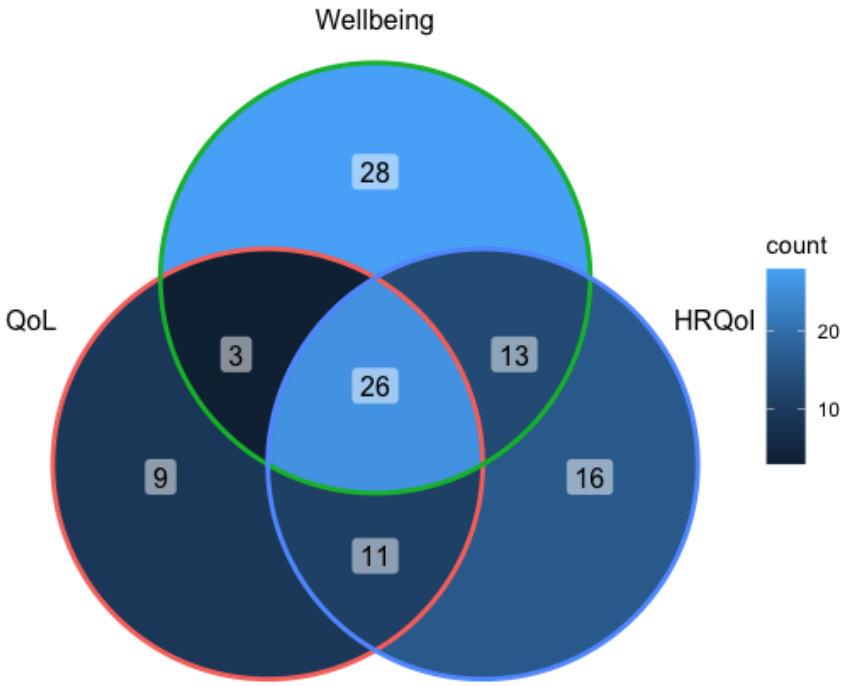
Analyzing the degree of overlap and singularity among the concepts, it can be observed that out of the 106 total curated domains, 26 were shared by the three concepts; 3 by WB and QoL; 13 by WB and HRQoL; 11 by QoL and HRQoL. Regarding unique dimensions included in a single high-level concept, WB had 28, HRQoL 16 and QoL 9 (Figure 2).

Figure 1 Distribution of Domain quantity by concept based on frequency of repetition in different frameworks by concept.



Qol = 5 frameworks, WB = 16 frameworks, HRQoL = 14 frameworks. The percentage of frameworks that contemplate each domain is established for each concept. At 50%, at least 3 frameworks for Qol, 8 frameworks for WB and 7 frameworks for HRQoL.

Figure 2. Graphic description of domain coverage and overlap among HRQoL, QoL and WB.



Construction of final Conceptual Models

In order to generate conceptual models as robust as possible based on the data obtained, dimensions that were covered by at least 1/3 of the frameworks for each concept were evaluated and considered as potential candidates for the final conceptual model. Based on this, graphic representations were made, showing the dimensions and their connections and with the concept of interest, for each high-level concepts. Figures 3, 4, and 5 show graphs of the three concepts. These graphs provide a significant amount of information besides the most frequent domains in each high-level concept: 1) The **size** of each domain node: each node size is proportional to the frequency of inclusion of each domain in each initial framework; 2) **Directionality**: each arrow has a direction that reflects the hierarchical relation among domains/concept established by any of initial high-level frameworks; and 3) Arrow **thickness**: it reflects the frequency of the depicted relationship among two domains/concept in the initial surveyed frameworks.

Figure 3: HRQoL possible candidate domains, based on the frequency of the domains in the original frameworks (at least present in one-third). Frequency, relationships, and directionality (see explanation in text).

Figure 4: Qol possible candidate domains, based on the frequency of the domains in the original frameworks (at least present in one-third). Frequency, relationships, and directionality (see explanation in text).

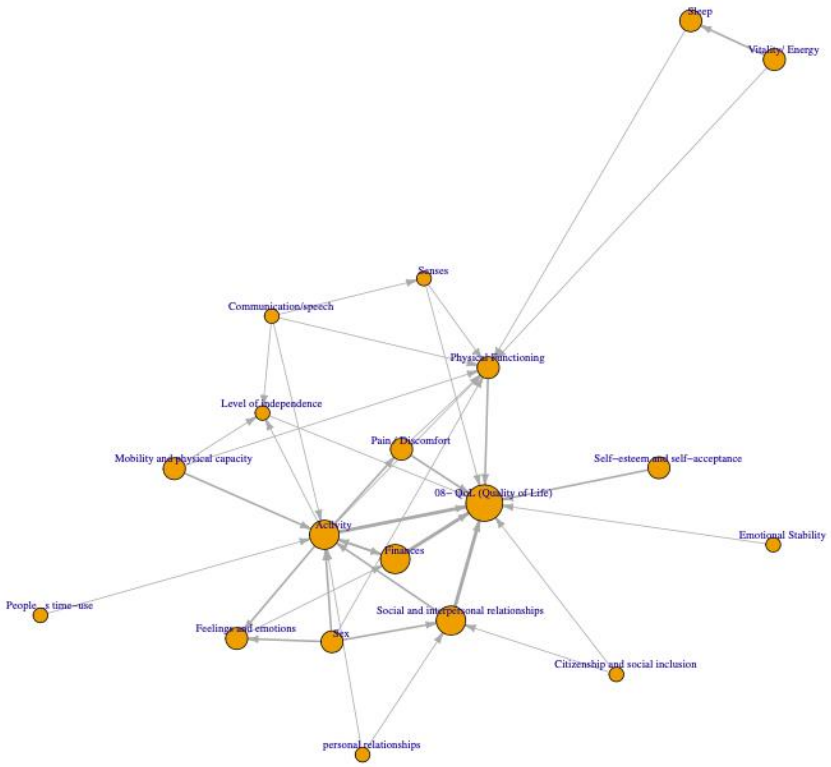
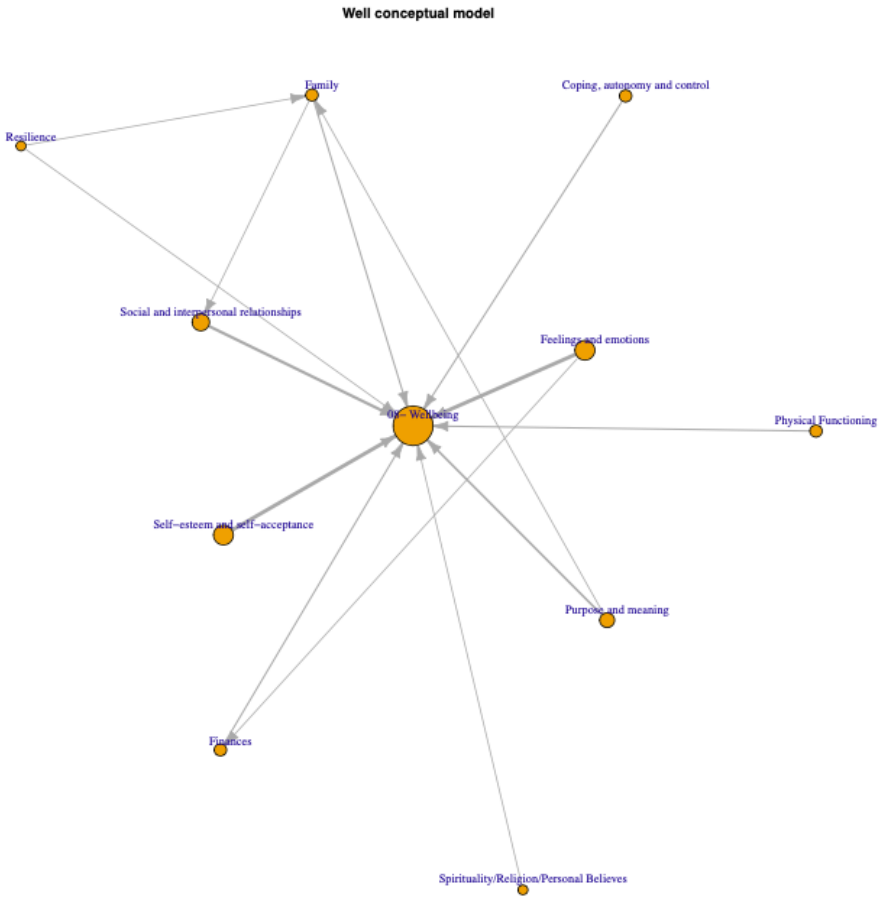


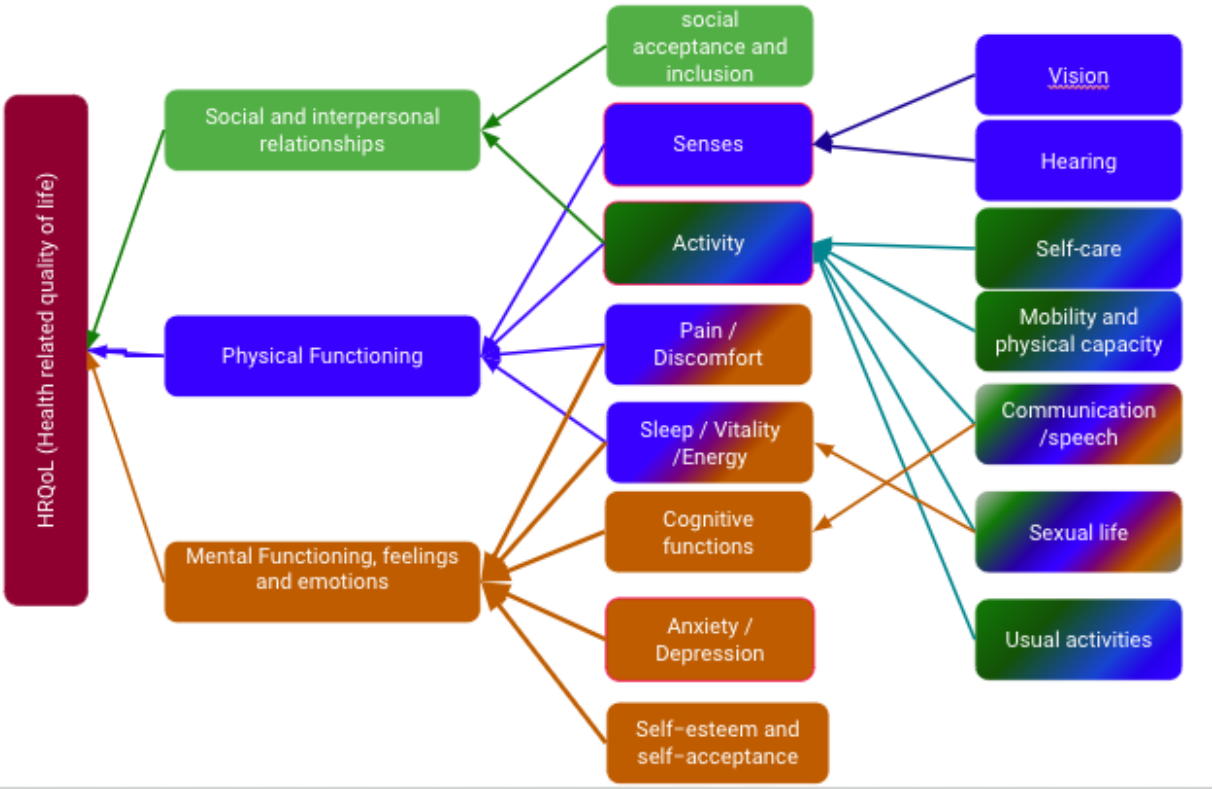
Figure 5: WB possible candidate domains, based on the frequency of the domains in the original frameworks (at least present in one-third). Frequency, relationships and directionality (see explanation in text).



Through a deliberative process, and to maintain coherence between and within concepts (for example, contemplating HRQoL as -by definition- nested within QoL). Each concept was simplified based on the domains and connections previously observed. Figures 3, 4, and 5 show the final conceptual models. For better schematization, a sequence of colours was used based on the connections between the domains. As can be seen in the graphs, the second level domains share the colours of the first-level domains they are part of. In turn, the third-level domains have the colour combination of the second-level domains to which they are connected. The final HRQoL conceptual model includes a total of 18 domains, grouped in three levels of hierarchy (1st level domains, 2nd level domains or subdomains, 3d level domains or facets). The final Qol conceptual model includes HRQoL, and in turn, it includes 4 additional first-level domains. In the case of WB, the final conceptual model included 10 domains, of which only one was a second-level domain, “Family”, which was connected to “Purpose and meaning” and to “Social and interpersonal relationships”. As can be shown in the Figures, WB had fewer higher-order domains. This does not necessarily mean that within Feeling and Emotions there are fewer true domains in WB, but what we show is what we found in the literature: this was the high-level concept with the more inconsistent domain inclusion, so fewer domains were finally

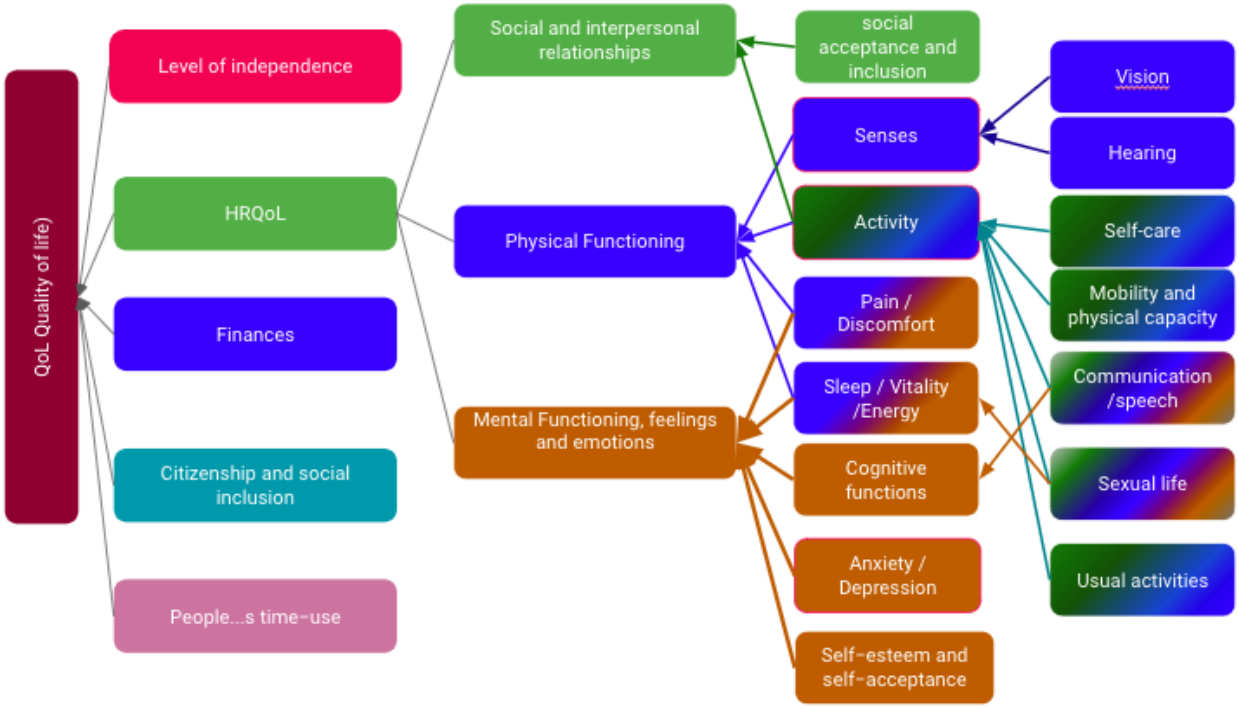
incorporated using our initial validity check that considered for final frameworks domains that were included in one third or more of the initial frameworks.

Figure 3. HRQoL conceptual model



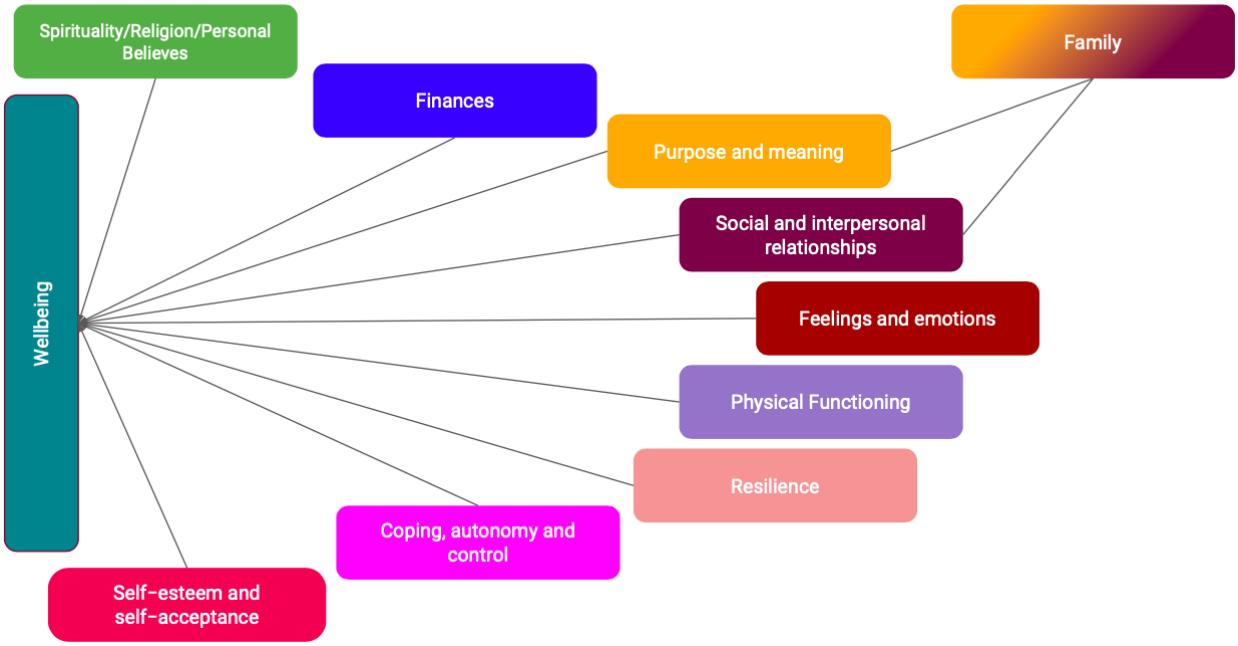
Each first-level domain has a colour (green, blue, and brown), second level domains share the colour(s) of the top-level domains they are part of, as do third-level domains with second-level domains.

Figure 4. QoL conceptual model



The same HRQoL colourimetry was maintained, while independent colours were added for the new QoL first level domains. Although "Finance" and "Physical functioning" share the same colour, they are not connected.

Figure 5. Well-being conceptual model



In the case of Wellbeing, there is only one second-level domain, "Family", which shares the colours of the two domains to which it belongs.

Mapping of a set of generic instruments to our conceptual models.

Eight instruments were mapped for HRQoL (COOP-WONCA, SF-36 , EQ-5D + 47 20 48 BOLT-ONS, SICKNESS IMPACT PROFILE, PROMIS-29, HUI-3 , 15D and EQ- HWB [table 2]), two instruments to QoL (AQOL-8D, WHO-QOL [table 3]) and five instruments to Wellbeing (ICECAP-A, QUALITY OF WELL BEING SCALE, ICECAP-O, IWB, EQ- HWB [table 4]). Of the conceptual frameworks developed, the tools mapped on average 59.4% of the domains for HRQoL (minimum and maximum of 33.3% and 94.4%; respectively), 65.9% for Qol (59.1 and 72.7), and for 34% Wellbeing (minimum and maximum of $30 and 50%; respectively).

Of the eight instruments mapped to HRQoL, the EQ-HWB was the one that was shown to include fully or partially more domains concerning the domains of the conceptual model of HRQoL (17 out of 18). The EQ-HWB was also the instrument with the most domains of the conceptual framework of wellbeing partially or fully covered (5 out of 10).

Table 2. HRQoL conceptual model mapping to commonly used instruments

	COOP-WONCA	SF-36	EQ-5D	BOLT-ONS	EQ-5D + BOLT-ONS	SICKNESS IMPACT PROFILE	PROMIS-29	HUI	EQ-HWB	15D
Activity	✓	O	✓		✓	✓	✓		✓	✓
Usual activities	✓	O	✓		✓	✓	✓		✓	✓
Anxiety / Depression		✓	✓		✓		✓		✓	✓
Physical Functioning	O	✓	O		O	✓	✓	✓	✓	✓
Cognitive function				✓	✓	O		✓	✓	✓
Communication/speech						✓		✓	✓	✓
Mental functioning, feelings and emotions	✓	✓	O		O	✓	✓	✓	✓	✓
Hearing				✓	✓			✓	✓	✓
Mobility and physical capacity	O	✓	✓		✓	✓	✓	✓	✓	✓
Pain / Discomfort	✓	✓	✓		✓		✓	✓	✓	✓
Social and interpersonal relationships	O	O		✓	✓	✓	✓		✓	
Self-esteem and self-acceptance				O	O				✓	

Self-care		✓	✓		✓	✓		✓	✓	
Vision				✓	✓			✓	✓	✓
Social acceptance						O	✓		✓	
Sleep/Vitality/ Energy		✓		✓	✓	✓	✓		✓	✓
Sex										✓
Senses								✓	✓	✓

We used a ballot box with a bold check (✓) for those dimensions that were explicitly mentioned in the instrument, whereas an O was used when the dimensions were conceptually or semantically mentioned. When those two premises were not fulfilled, an empty space was left in the cell.

Table 3. QoL conceptual model mapping to commonly used instruments

	AQOL-8D	WHO-QOL
Activity	✓	✓
Usual activities	✓	✓
Anxiety / Depression	✓	
Physical Functioning	O	✓
Cognitive function	✓	✓
Communication/speech	✓	✓
Mental functioning, feelings and emotions	✓	✓
Hearing	✓	
Mobility and physical capacity	✓	✓
Pain / Discomfort	✓	✓
Social and interpersonal relationships	✓	✓
Self-esteem and self-acceptance	O	✓
Self-care	✓	
Vision	✓	
Social acceptance	O	✓
Sleep/Vitality/ Energy	✓	✓
Sex	✓	✓

Senses	✓	✓
Level of independence	✓	✓
Finances		✓
Citizenship and social inclusion	O	
People's time-use		

We used a ballot box with a bold check (✓) for those dimensions that were explicitly mentioned in the instrument, whereas a O was used when the dimensions were conceptually or semantically mentioned. When those two premises were not fulfilled, an empty space was left in the cell.

Table 4. Wellbeing conceptual model mapping

	ICECAP-A	QUALITY OF WELLBEING SCALE	ICECAP -O	IWB	EQ-HWB
Coping, autonomy and control	✓	✓	✓		✓
Social and interpersonal relationships	O		O		✓
Finances					
Feelings and emotions	✓	O	✓	✓	✓
Family					
Purpose and meaning				✓	
Spirituality/Religion/Personal Believes				✓	
Self-esteem and self-acceptance					✓
Physical Functioning		✓			✓
Resilience					

We used a ballot box with a bold check (✓) for those dimensions that were explicitly mentioned in the instrument, whereas a O was used when the dimensions were conceptually or semantically mentioned. When those two premises were not fulfilled, an empty space was left in the cell

Discussion

In this qualitative systematic review, we performed an exhaustive survey of current conceptual frameworks of Health-Related Quality of Life, Quality of Life, and Well-Being; and after an in-

depth inter-conceptual, conceptual, and subconceptual analysis and curation, we propose a single conceptual framework of each of these commonly used high-level concept in health and social science. Additionally, we map commonly used generic measurement instruments to these three concepts, showing they almost universally have partial coverage.

This is to our knowledge the first systematic and comprehensive endeavor that aims to perform this task. We found no other studies that describe, or contrast these high-level concepts and propose a unified definition. However, several authors have already pointed out the problem of their current conceptual "noise" regarding their definitions, and the possibility of clearly differentiating them. Moore et al. highlighted the conceptual difficulties in defining QoL and posited that HRQoL is an artificial measure, as patients must distinguish between the part of their life influenced by health and other areas not appreciably influenced by health.[48] Other studies support this view, noting that the concepts of HRQoL and many definitions of QoL are not clearly differentiated from the concepts of health.[2]

Similarly, the concepts of QoL and WB are oftentimes umbrella terms that encompass many interpretations and methods of assessment, according to Gasper.[49] Although well-being tends to focus more on satisfaction and affective states, while QoL encompasses a broader, multifaceted assessment of the living conditions and resources available to an individual or group, these concepts are interrelated and often overlap. This confusion is understandable, as the concepts themselves are not well defined. A review of the term "well-being" highlighted the lack of a consistent definition.[50] In addition, these concepts may have different interpretations in different regions or cultures,[51] which makes it even more difficult to have unified concepts.

Strengths

Our review shows that, in addition to the lack of clear conceptual definitions both within and between concepts, the different domains assigned to each concept are also not sufficiently consistent and oftentimes overlap. As health research continues to evolve, establishing clear, coherent, and consistent conceptual frameworks is of utmost importance. This effort represents a significant advance, bringing unprecedented clarity and depth to the understanding and application of these three high-level health-related concepts. By moving in this direction, we aim not only to improve our understanding of HRQoL, QoL, and WB but also to contribute to the quality and impact of health research and practice that incorporates these concepts.

This research highlights the need to continually reflect on the definitions, domains, methods, and applications of these concepts to ensure that health policies and programs meaningfully address the areas of life that are important to people, thereby improving their quality of life and well-being in a comprehensive manner.

Limitations

It is crucial to recognize some limitations of this study. Firstly and fundamentally -similarly to all non-objectively verified constructs or high-level concepts-, and though there are thousands of studies reporting and “measuring” HRQoL, QoL and WB, this does not provide definitive proof that these concepts exist or are truths in nature. An inherent assumption of our study is that these concepts exist and are distinct entities, and we simply try to depict and clarify their boundaries. Secondly, we were “quality or methodologically agnostic” and we included all conceptual frameworks found in the literature, not distinguishing or weighting more heavily those that were derived in one manner or another (i.e expert derived conceptual frameworks were similarly treated to those derived by qualitative or quantitative research methods). Thirdly, the conceptualization of these high-level concepts may vary across countries and cultures. Nevertheless, our goal was to develop a broad description of "mainstream conceptual models" that could be refined in future studies to examine aspects such as cultural, geographic, or other differences. Fourthly, we had a commonly found weakness in systematic reviews: we included studies published in English. Though we included several articles from non-English speaking countries, and this could introduce a selection bias, we do not consider it a significant shortcoming. Fifthly, most of the conceptual frameworks lacked clear definitions both of the high-level concept and of the included domains. Thus, concept and domain harmonization was performed based on the best authors' judgment. However, transparency was maintained by having the complete list of domains and a clear description of the process that arrived at the final proposed conceptual frameworks. Finally, in our work, we did not include another high-level concept commonly found in the literature: health status. Although it was our initial idea, both the extremely high numbers of the published articles and the authors' team's decision that it was a broader less directly related concept made us exclude this concept from the present study, and is something that could be done by future studies.

Further steps

Future research can improve and strengthen our work in several ways a) Empirical and methodologically sound studies can explore and test -both with qualitative and quantitative psychometric research- the validity of these proposed high-level conceptual frameworks, b) Further research can explore the geographic and cultural diversity of these high-level concept frameworks, and also include non-English conceptual frameworks not included in our study, c) Other studies can incorporate other related high-level concepts such as health status in order to broaden the scope of our study.

Conclusions

The absence of clear conceptual definitions poses a major challenge in theoretically differentiating health-related quality of life, quality of life and wellbeing, which has a significant impact in the validity of measurement tools in this field of research. This paper serves as an initial step, shedding some light -or darkness- on overlooked domains in these three common high-level

concepts, as well as assessing the comprehensiveness of the instruments to assess them. Recognizing the need for clearer conceptual definitions and aligned frameworks, is an important step towards new analyses and developments in the understanding and measurement of these essential concepts, as well as empirical validation exercises to test their soundness and utility.

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