What Dimensions are Missing in EQ-5D-5L? Identifying Supplementary Dimensions for Use in Chronic Disease Patients Through Various Stakeholders Engagements

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BACKGROUND

There has been a paradigm shift from the World Health Organization's (WHO) definition of health as "a state of complete physical, mental and social wellbeing" to "positive health"- a more inclusive and fitting term for people suffering from chronic diseases as it implies that they have the capacity to adapt to their new health states[1-3]. The EQ-5D albeit a popular patient-reported outcome measure (PROM) used in health technology assessment has been criticized for inadequate content validity due to its limited five (four physical & one mental) dimensions when applied in chronic disease states. Supplementary dimensions ("bolt-ons") have been developed in recent years to improve its content validity[4].

AIM

We examined the concept "health" among chronic disease patients, healthy individuals, and clinicians to identify supplementary dimensions. These can be used as bolt-ons for improving EQ-5D-5L's content validity in clinical settings. .

METHOD

Participants were purposively sampled based on age, disease co morbidity (patients) and working experience (clinicians). We employed one-on-one semi-structured interviewing using verbal probing techniques to elicit participants' lived experience of "health" and "illness" by asking them what health and being unhealthy meant to them. They were then requested to self-complete the EQ-5D-5L questionnaire. After completing the questionnaire, they were invited to mention if there were important aspects of health or illness that were not already covered by EQ-5D-5L.We applied thematic analysis on the recorded transcript to identify the health concepts (dimensions). We identified the top four dimensions and presented them together with the five dimensions of EQ-5D to the participants for ranking in the order of one to five (one indicating the highest importance and relevance to their health). Participants were instructed to assign the same number ranking to two or more items if they felt that the items are of equal importance including all nine items.

RESULTS

We presented the sociodemographic and health characteristics of the 23 participants in chart 1, ranking results of the health dimensions in table 1 and health dimensions elicited from the thematic analysis in table 2. In addition to EQ-5D dimensions. the top four dimensions elicited were: "sleep". "cognition, "energy" and "relationships" proposed by 19, 17, 18, and 12 participants, respectively.

Chart 1: Participants types & their profiles (N=23)

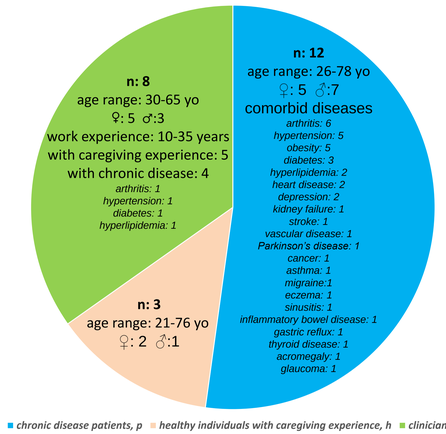

Table 1: *Ranking results on dimensions among participants.

	MO	SC	UA	PD	AD	S	C	E	R
Rank 1									
p(n=12)	100	100	100	100	100	91.7	91.7	100	66.7
h(n=3)	100	100	100	100	66.7	66.7	100	66.7	0
c(n=8)	100	100	100	100	100	100	100	100	75.0
Rank 2									
p(n=12)	0	0	0	0	0	8.3	8.3	0	16.7
h(n=3)	0	0	0	0	0	0	0	33.3	66.7
c(n=8)	0	0	0	0	0	0	0	0	25.0
Rank 3									
p(n=12)	0	0	0	0	0	0	0	0	16.7
h(n=3)	0	0	0	0	33.3	33.3		0	0
c(n=8)	0	0	0	0	0	0	0	0	0
Rank 4									
p(n=12)	0	0	0	0	0	0	0	0	0
h(n=3)	0	0	0	0	0	0	0	0	33.3
c(n=8)	0	0	0	0	0	0	0	0	0
Rank 5									
p(n=12)	0	0	0	0	0	0	0	0	0
h(n=3)	0	0	0	0	0	0	0	0	0
c(n=8)	0	0	0	0	0	0	0	0	0

AD, anxiety/depression item; **C,** cognition bolt-on item; **c,** clinician participant; **E,** energy bolt-on item; **h,** participant without chronic ailment; **SC,** self-care item; **MO,** mobility item; **n,** number of participants; **p,** patient participant; **PD,** pain/discomfort item; **R,** relationship bolt-on item; **S,** sleep bolt-on item; **UA,** usual activities item. *Participants could assign ≥ one item the same rank. Data are presented in proportions (%) within each of the three participant subgroups. For example, 100% under rank 1 for "MO" among patients (p) participants (total 12 patients) indicate all 12 patients assigned rank 1 to "mobility" item. The percentages under rank 1 to 5 should add up to 100% for each item among each participant subgroup

Other the other sporadically highlighted dimensions fell outside WHO physical, mental and social health constructs and constituted "determinants of health" or "quality of life" concept, they were opined by the participants who proposed them to be integral to "health"

Table 2: Identified health concepts / dimensions

Themes	Examples of quotes
absent of ailment	"Not being burdened by any chronic health whether physical or mental/psychological health conditions" PF19 (clinician)
independence in mobility, self-care, and activities	"Being independent, able to walk without difficulty and able to take care of own needs and do life daily routine and basic activities" PF6 (patient)
absent physical discomfort	"…to be free of aches and pain" PF3 (patient)
positive psychological state & mood	"To be in a positive state of mind, not feeling down, overly stressed, or easily overwhelmed and anxious with things" PF2 (patient)
good sleep	"Sleep is such a vitally important aspect of health. Someone with poor health generally do not sleep well." PF15 (patient)
high energy level	"a person in good health has high energy level", "feeling tired…no energy when one is unhealthy" PF8 (patient) "Anyone with depression, sleep problems or guess any kind of physical sickness will feel tired…it can be either physical, mental or both" PF22 (clinician)
intact cognition	"Although am still able to be walk and take care of myself after the stroke, I find my memory is poorer… take longer to process info. This mental aspect certainly worsens my overall health" PF5 (patient)
close relationships & active community participations	"Social interactions, connectedness and forming close relationships are important…in our society, we still highly value family and community contributions and it affect how we view our life and health holistically" PF7 (healthy)
self-worth & control	"You can see someone in good health will carry herself with great confidence. She will have strong self-esteem and in control of her life and situations." PF5 (healthy)
personal autonomy & dignity	"Health should also encompass the freedom to choose how I want to be treated, to have a say in my disease management as this body belongs to me. Even if this body is breaking down and it is time to go, part of it is still healthy if it is treated with respect."PF6 (patient)
adaptive coping	"I view health as being still able to adapt and cope with all kinds of curveballs that life throws me and overcome them- whether they challenge or hurt me physically or mentally." PF3 (patient)
sense of satisfaction/contentment	"Being healthy also means having inner peace, have peace with oneself and being able to accept life as it comes, let go of things one cannot change and move on. Being in harmony with universe and surrounding environment somewhat yin-yang balance." PF13 (patient)
spirituality/sense of purpose	Health is being bestowed by God; our body is just a vessel to carry out God's work…it is willed by God" PF1 (patient) "A healthy person generally has a vision of life - a mission and leading a purposeful meaningful useful life" PF9 (healthy)
conducive environment, social & financial security	"I think health is wider than what the individual feel or can or cannot do. We should consider things like having nutritious food available, basic clean water, good weather not too hot or cold, absent of natural disaster, good economy having enough money and stable geopolitical situation. One cannot be healthy without all of these in place." PF2 (patient)

CONCLUSIONS

- ***Viewed through the lens of various stakeholders using health as a concept, we identified additional dimensions to be relevant, and we can consider adding these dimensions to EQ-5D to improve its content validity in chronic disease patients in the clinical setting.***
- ***EQ-5D dimensions are ranked higher than other dimensions.***

References

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