RESEARCH | Article in Press

Assessment of the content validity of the EQ-HWB in caregivers of children and adolescents with autism spectrum disorder

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Received: 12 May 2026 / Accepted: 21 October 2026
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Abstract

Objective This study aimed to evaluate the content validity of the EuroQol Health and Wellbeing (EQ-HWB, v1.2 'experimental modified', 2024) in caregivers of children and adolescents with autism spectrum disorder (ASD), specifically examining its comprehensiveness, relevance and comprehensibility, with the aim of providing population-specific evidence to inform the application and interpretation of the EQ-HWB among Chinese caregivers of children and adolescents with ASD and to contribute to its broader international evaluation.

Methods In 2025, semi-structured, in-depth web-based interviews were conducted to evaluate the content validity of the EQ-HWB with 31 caregivers of children and adolescents with ASD. Participants were recruited from two patient advocacy associations in China. Data were analysed using framework analysis following the COSMIN guidelines, with particular attention to the aspects of relevance, comprehensibility, and comprehensiveness.

Results Caregivers had a mean age of 40.3 years, while children with ASD had a mean age of 10.3 years (range, 8–17 years). Overall, relevance, comprehensibility, and comprehensiveness were generally rated positively. The most relevant items were "anxiety", "frustration", "sadness/depression", "loneliness", and "sleeping difficulties," broadly reflecting caregivers' health and wellbeing under sustained caregiving demands. However, as a generic measure, the EQ-HWB showed several limitations in this caregiver sample. Sensory and physical functioning items had limited relevance: "getting around inside or outside," for example, was often seen as more applicable to older adults or people with physical disabilities. Some examples within the "day-to-day activities" item showed weak contextual fit, with "work" less relevant for full-time homemakers and "shopping" complicated by the shift to online purchasing (both raised by 12/31, 38.7%). Comprehensiveness was also questioned: 13 participants (41.9%) noted the absence of content on economic or financial strain, and 14 (45.2%) felt the instrument inadequately captured caregiving-specific social experiences, particularly reduced social participation. Conceptual overlap between the "control" and "coping" items was raised by 17 participants (54.8%). Response options were considered appropriate, and 29 participants correctly understood the "last 7 days" timeframe, with 15 participants (48.4%) preferring a longer recall period of 14–30 days.

Conclusion The EQ-HWB showed acceptable content validity among Chinese caregivers of children and adolescents with autism, although limitations remained regarding certain physical-functioning items, the contextual fit of examples, and the coverage of caregiving-specific burden.

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https://doi.org/10.1186/s12955-026-02661-2

Published online: 26 October 2026

Keywords Qualitative study · EQ-HWB · Content validity · Caregiver · Autism spectrum disorder · Chinese

Introduction

The EQ Health and Wellbeing (EQ-HWB) is a generic instrument designed to assess interventions across health, social care, community, and caregiver populations. Developed with a strong focus on carer-related quality of life, it captures broader wellbeing impacts on caregivers, including social and emotional spillover effects arising from another person's health condition. The EQ-HWB is available in both long and short forms and covers a wide range of domains relevant to health, social care, and caregiving [1].

Although quantitative evidence supporting the psychometric properties of different EQ-HWB versions in caregivers is increasing [2–7], qualitative evidence remains limited. Existing qualitative studies, including cognitive interviews and think-aloud exercises, generally support the content validity and acceptability of the EQ-HWB across diverse populations. For example, in an Italian study, informal carers reported generally good comprehension and strong relevance of both the EQ-HWB and its short version (EQ-HWB-9) for capturing broader health and wellbeing impacts [8]. Caregiver-focused research in Australia, particularly among parents of children with chronic health conditions, found that psychosocial items were highly relevant and closely aligned with caregiving burdens, and the instrument was viewed as comprehensive and well received overall [9]. Positively framed items were often appreciated for providing emotional balance, although some sensory domains (e.g., "seeing", "hearing") were occasionally considered less relevant or somewhat confusing in terms of wording [9].

Introducing any new measure into a specific population requires rigorous evaluation of its psychometric properties, with content validity regarded as a foundational and most critical step according to COSMIN guidelines [10]. Content validity evaluates the extent to which the instrument comprehensively and relevantly captures the construct of interest, encompassing aspects such as item relevance to the target population, comprehensibility, and overall appropriateness [10–12]. The EQ-HWB and EQ-HWB-9 experimental and experimental modified versions were previously validated quantitatively in China across various populations, including older adults, patients with anxiety and/or depression, caregivers of children with COVID-19 infection and the general population [13–18]. However, these quantitative studies mainly rely on scale scores, correlations, and factor structures, offering limited insight into item interpretation, cultural appropriateness of wording and examples, caregiving relevance, and potentially missing dimensions [8–10]. Therefore, evidence regarding the content validity of the EQ-HWB among Chinese caregivers remains limited [19], creating a significant gap for finalising the EQ-HWB and supporting its application.

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterised by difficulties in social communication, restricted and repetitive behaviours, and frequent co-occurring conditions such as intellectual disability and mental health issues [20]. In China, prevalence is estimated at approximately 0.7%–1.0%, affecting millions of individuals with a strong male predominance [21]. Caring for children and adolescents with ASD imposes intense, lifelong demands on caregivers—including constant supervision, behavioural management, and substantial financial burdens—that commonly result in high stress, exhaustion, social isolation, and marked impairment in physical, emotional, and social wellbeing [22–25]. Qualitative studies in China have further identified how these impacts manifest in the local context, including psychological distress, financial burden, difficulties in family and social relationships, stigma, and limited access to services [26–29]. However, these studies have generally focused on only some of these aspects. Taken together, their findings indicate that caregiving impacts extend across multiple domains and highlight the need for a comprehensive instrument capable of capturing their broad effects when assessing caregivers' health and wellbeing.

Although evidence supporting the content validity of the EQ-HWB is growing, no study has yet evaluated it specifically in caregivers of children and adolescents with ASD. Given that caregivers are an intended target

population of the EQ-HWB, this evidence gap warrants population- and context-specific investigation. The EQ-HWB long form warrants evaluation in this population because it covers a broader range of domains relevant to caregiving experiences, such as self-identity, autonomy, and relationships, that closely match the complex realities of ASD caregiving. The present exploratory qualitative study therefore aimed to assess the content validity of the EQ-HWB long form in this group, focusing on comprehensiveness, relevance, comprehensibility, and appropriateness. As an internationally applicable generic instrument, any revision of the EQ-HWB should be informed by cumulative qualitative and quantitative evidence across countries, cultures, populations, and caregiving contexts, rather than by any single study. Accordingly, this study was intended to provide complementary evidence from Chinese caregivers of children and adolescents with ASD, rather than to directly revise or redevelop the instrument.

Methods

Study design

A qualitative study was conducted between August and December 2025, using semi-structured, in-depth interviews to assess the content validity of the EQ-HWB (v1.2, 'experimental modified', 2024) among caregivers of children and adolescents with ASD. Interviews were conducted online via Tencent Meeting software, audio-recorded with participants' consent, and all data were anonymised and securely stored in accordance with institutional data protection policies. A multidisciplinary expert group comprising a qualitative researcher, two EuroQol experts, an ASD specialist, and two representatives from patient associations contributed to the development of the interview guide and interpretation of the findings. Qualitative and EuroQol perspectives informed the methodological design, supporting standardised data collection and analysis. The interview guide included concept elicitation, think-aloud procedures, and cognitive probes, while the analytical framework combined predefined codes based on EuroQol guidance and COSMIN concepts with inductively identified concepts. ASD and patient association perspectives helped ensure that the study reflected caregivers' lived experiences and informed the assessment of the EQ-HWB's content validity. The study protocol and informed consent form were approved by the Institutional Review Board of The Hong Kong Polytechnic University (reference no. HSEARS20230911002), and written informed consent was obtained from all participants.

Participants

Participants were recruited through two ASD patient support organisations in China: *the Hangzhou Xingjuexing ASD Patient Association* (a registered organisation serving approximately 700 ASD families) and *the Guangzhou Rong'ai Home Special Children Service Centre* (a community-based organisation that provides support services, family programmes and advocacy for children with ASD and their caregivers). Inclusion criteria were as follows: (1) being a parent of a child aged 8–17 years with a clinical diagnosis of ASD; (2) having served as the primary caregiver for more than 5 years; (3) having no self-indicated cognitive impairments; (4) having no diagnosis of ASD; and (5) being able to provide informed consent. Although all members of the patient associations were either individuals with ASD or their family members, participants were required to present the research team with documentation confirming that their child had received an ASD diagnosis from a clinical psychiatrist to verify eligibility. Recruitment aimed for approximately 30% of participants to be fathers and at least 10% to be caregivers of girls, with quota sampling used to ensure balance in the children's ages (50% aged 8–12 years and 50% aged 13–17 years).

Recruitment

Recruitment was conducted in collaboration with patient associations. First, the research team discussed and confirmed the details of the recruitment plan with the president and chief manager of the patient association. Then, the chief manager informed all members of the patient association about the project through their internal social network. Members who were interested informed the manager of their willingness to participate via the internal social network. Third, the manager verified the eligibility of interested respondents, collected their information, and sent it to the research team for double-checking. Once confirmed, all eligible respondents were invited to join a study-specific group on WeChat, the most widely used multi-purpose social media app in China. The project information and consent form were shared with them by the research team through the online survey group. Finally, respondents who agreed to participate and provided informed consent were contacted by the research team to schedule an interview. The date and time for the interview were determined in coordination with the respondents.

Instrument

We used the 2024 'experimental modified' (v1.2) Simplified Chinese, self-complete version of the EQ-HWB long form, obtained from the EuroQol Research Foundation through a collaborator agreement. The EQ-HWB v1.2 consists of 25 items assessing a broad range of health and wellbeing experiences. Participants rate each item on a 5-level scale (difficulty, frequency or severity), reflecting on the past 7 days [30]. The Simplified Chinese version was developed and linguistically validated under the supervision of the EuroQol Research Foundation's Version Management Committee, including translation, back-translation, cognitive debriefing interviews and review procedures.

Interview procedures

Interviews were conducted by a single interviewer (YSX), who has a background in psychology and extensive qualitative research experience. Before data collection began, the interviewer received standardised training in the study protocol, think-aloud method, and cognitive interviewing techniques. Three pilot interviews were then conducted to assess participants' understanding of the interview questions, estimate interview duration, and evaluate the feasibility of the interview procedures and interviewing techniques. As participants understood the requirements well and remained focused, the introductory explanation was shortened to reduce repetition and participant burden, and the scheduled mandatory break was changed to an optional break to maintain interview continuity. No substantive changes were made to the interview guide or its core content. The pilot interviews were prospectively designated as such and were not included in the final analysis. Data saturation was achieved across the 31 formal interviews, and the pilot interviews yielded no unique content; their exclusion was therefore unlikely to materially affect the findings.

The interviews consisted of four sequential phases designed to assess the content validity of the EQ-HWB in line with COSMIN guidelines [10] and were conducted under a structured protocol that included clear protections for study participants and measures to ensure standardised, neutral, and participant-centred administration (Table A2). In phase I, participants completed a brief background questionnaire to collect demographic and contextual information. In phase II, concept elicitation was conducted using open-ended questions (e.g., "How has your child's ASD or its management affected your quality of life and wellbeing?") to explore the impact on caregivers' health and wellbeing, without reference to predefined domains. In phase III, participants completed the EQ-HWB using a concurrent think-aloud protocol. Before the formal task, the interviewer introduced and demonstrated the think-aloud procedure, emphasising that there were no right or wrong answers and that participants should verbalise their thoughts naturally. After one practice item, participants read each item and its response options aloud, selected a response, and explained their reasoning. To standardise the procedure and protect participants' rights

and wellbeing, a structured implementation and contingency protocol was developed, covering interviewer training, task familiarisation, autonomy and privacy safeguards, and the management of sensitive content. Participants could pause, skip any item, or terminate the interview at any time. Participants' questions were recorded and discussed during the subsequent cognitive interview to avoid disrupting or influencing the think-aloud process. In phase IV, targeted cognitive interview probes systematically evaluated the relevance and comprehensibility o*f* the item and response options, the comprehensiveness of coverage (including potential overlap or redundancy between items), and the suitability of the response options and the recall period. The interview guide is included in the Appendix (Table A1).

Data analysis

Independent coding and consensus discussions were used to support coding consistency and the reliability of the findings. All interviews were transcribed verbatim by a trained researcher (YSX), and a second researcher (RX) checked each transcript against the corresponding audio recording to ensure accuracy. The transcripts were imported into NVivo and analysed using a framework analysis approach [9]. Two researchers (YSX and RX) independently coded all transcripts, then discussed and resolved coding discrepancies by consensus. Analysis was guided by the coding suggestions developed by EuroQol for the EQ-HWB validation project and by COSMIN concepts of relevance (extent to which items captured caregivers' experiences), comprehensiveness (coverage of key domains), and comprehensibility (clarity of item wording and examples), while allowing additional concepts to be identified inductively. Representative quotations were used to illustrate the coding categories and substantiate the interpretations. Coding categories were not mutually exclusive; therefore, a participant's response could be assigned to multiple codes, and frequency counts did not necessarily sum to the total number of participants. Concept elicitation identified caregivers' spontaneously reported health and wellbeing experiences and whether these were captured by the EQ-HWB. Think-aloud explored participants' immediate interpretation, response choices and rationale, and spontaneously reported difficulties. Cognitive debriefing was the primary component for assessing item relevance and comprehensibility, overall content comprehensiveness, and the appropriateness of response options and the recall period. Additionally, for the assessment of comprehensiveness, concepts identified during concept elicitation were mapped to the EQ-HWB. Important concepts not adequately represented were coded as potentially missing content and considered alongside cognitive interview feedback in the overall assessment of comprehensiveness. Codes were applied to relevant text segments, and the framework was iteratively refined by adding new codes for emerging concepts. Data collection ceased when saturation was achieved, defined as the absence of new concepts, findings, or terms in both concept elicitation and cognitive debriefing across two consecutive interviews.

Quotations are labelled with anonymised participant IDs (e.g., F01_B08), where "M" indicates a mother caregiver and "F" a father caregiver; the two digits following the letter represent the participant number; "B" or "G" denotes the child's gender (boy or girl); and the final two digits indicate the child's age in years.

Results

Participant characteristics

Interviews lasted 80–105 min, excluding break time. Data saturation was achieved after 28 interviews, with an additional three interviews conducted to confirm saturation, for a total of 31 interviews. Caregivers had a mean age of 40.3 years, were predominantly mothers (64.5%), and 96.8% had attained tertiary or higher education. Most children with ASD (71.0%) were aged 8–12 years. Caregivers perceived their child's ASD severity as mild in 22.6% of cases, moderate in 38.7%, and severe in 38.7%. Detailed participant characteristics are presented in Table 1.

Table 1 Characteristics of caregiver interview participants ($N=31$)

Characteristics	*N* (%) / Mean (SD)
Caregiver	
Age (years)	40.3(4.9)
Role	
Father	11 (35.5)
Mother	20 (64.5)
Educational level	
Secondary or below	1 (3.2)
Tertiary or above	30 (96.8)
Number of children	
= 1	20 (64.5)
> 1	11 (35.5)
Years caring for a child with ASD	
5–10	23 (74.2)
> 10	8 (25.8)
Diagnosed chronic disease	
Yes	4 (12.9)
No	27 (87.1)
Diagnosed mental health problem	
Yes	7 (22.6)
No	24 (77.4)
Self-reported financial status	
Below local average	16 (51.6)
Equal to local average	11 (35.5)
Above local average	4 (12.9)
Child	
Age group (years)	
8–12	22 (71.0)
13–17	9 (29.0)
Sex	
Male	25 (80.6)
Female	6 (19.4)
Caregiver-perceived ASD severity level	
Mild	7 (22.6)
Moderate	12 (38.7)
Severe	12 (38.7)
Comorbidities	
ADHD	13 (41.9)
Epilepsy	5 (16.2)
None	13 (41.9)

Note: N, total sample size; n, number of participants; SD, standard deviation; ASD, autism spectrum disorder; ADHD, attention-deficit/hyperactivity disorder

Concept elicitation

During concept elicitation, caregivers reported concepts corresponding to most EQ-HWB items. The most frequently mentioned concept was "sleep" (16/31, 51.6%), followed by "day-to-day activities", "anxiety", and "frustration" (each 15/31, 48.4%), as well as "enjoyable activities" (13/31, 41.9%) and "exhaustion" (12/31, 38.7%). By contrast, "seeing" and "hearing" were not spontaneously raised. Beyond EQ-HWB content, caregivers also identified additional important dimensions, most notably financial situation (12/31, 38.7%) and caregiving-related worries (10/31, 32.3%), followed by appetite, social participation, marital relationship, self-image and weight management, sense of happiness, and social discrimination and stigma (Appendix, Table A3).

Relevance and comprehensibility

Table A5 (Appendix) shows the relevance and comprehensibility of the EQ-HWB items. Figures 1 and 2 provide a visual summary of participants' ratings for comprehensibility and relevance, respectively. Most items were considered relevant to caregivers' health and wellbeing and easy for most participants to understand, particularly emotion-related and psychosocial items (e.g., "anxiety", "frustration", "sadness/depression", "loneliness", "feeling unsupported", "sleep", and "exhaustion"—mentioned by all). In contrast, mobility-related, sensory, and certain self-care items showed relatively lower relevance.

The concept of "doing day-to-day activities" was understood by all participants. However, concerns were raised about the examples: "work" was viewed as less applicable by full-time caregivers and "shopping" as less representative of contemporary daily life (due to online services), collectively noted by 12 participants (38.7%). Although most still regarded "working" as an important aspect of daily functioning that should be retained, eight participants (25.8%) suggested adding examples more closely related to caregivers' situations (such as caring for children or buying groceries). Most participants considered "doing enjoyable activities" relevant to maintaining wellbeing, particularly under caregiving pressures (29/31, 93.5%), and the item was correctly understood by all participants as referring to activities that bring pleasure or relaxation, although two participants (2/31, 6.5%) suggested adding examples that better reflected their leisure activities.

"Getting around inside or outside" was considered relevant to their HWB by 20 caregivers (64.5%), whereas 11 (35.5%) found it less relevant because they viewed it as more applicable to people with physical disabilities. Several comprehension issues emerged: three participants (9.7%) felt the wording was unnatural; two (6.5%) interpreted it differently (as either walking ability or restrictions on going out due to caregiving responsibilities); and six (19.4%) commented that the examples focused too heavily on physical disability aids (e.g., "walking sticks", "wheelchairs") without adequately reflecting limitations experienced by the general population or caregivers.

The "self-care" item was rated as relevant to caregivers' self-care by 22 participants (71.0%) and as comprehensible by 24 (77.4%). Ten participants (32.3%) highlighted its multidimensional nature, distinguishing basic physical self-care (e.g., washing, using the toilet, getting dressed, eating) from "caring for your appearance" as a higher-level psychological aspect. For "seeing", only 17 (54.8%) found the item relevant to their own circumstances, with 10 (32.3%) considering it irrelevant and four (12.9%) misinterpreting it as referring to somatic symptoms of depression/anxiety or to disability. Even fewer participants considered "hearing" relevant to caregivers' circumstances (11/31, 35.5%), with 17 (54.8%) viewing it as irrelevant and three questioning its connection to caregiving.

"Physical pain" was generally relevant to caregivers' physical health, with a small number of participants finding the item inapplicable or unclear and suggesting that examples, such as joint pain and headache, be included to aid understanding. "Physical discomfort" showed similar patterns, while a few viewed the examples (feeling sick, breathless, itching) as insufficiently representative or reported difficulty judging severity.

Emotion-related items performed strongly. "Anxiety", "frustration", and "sadness/depression" were viewed as highly relevant to caregivers' emotional distress under sustained caregiving demands and easy to understand by all participants. "Feeling hopeless" was relevant to caregivers' outlook on the future by 28 caregivers (28/31, 90.3%); three (9.7%) participants found it inapplicable because they never think about the future or see "no point" in doing so, and some noted the item was abstract without a clear reference point for "hope". "Feeling negative about yourself" was relevant to caregivers' self-perceptions (26/31, 83.9%), although a small number reported comprehension difficulties (e.g., vague wording or misinterpretation as feelings toward others) and suggested examples for clarity. "Feeling unsafe" was considered relevant to caregivers' sense of safety by 20 caregivers (20/31, 64.5%). While comprehension was generally good (22/31, 71.0%), nine participants (29.0%) reported difficulties, including unclear wording (1/31, 3.2%), narrow interpretations as self-harm or suicide risk (2/31, 6.5%), a perceived mismatch between the stem and physical-safety examples (4/31, 12.9%), or examples that did not meaningfully aid understanding (2/31, 6.5%).

https://doi.org/10.1186/s12955-026-02661-2

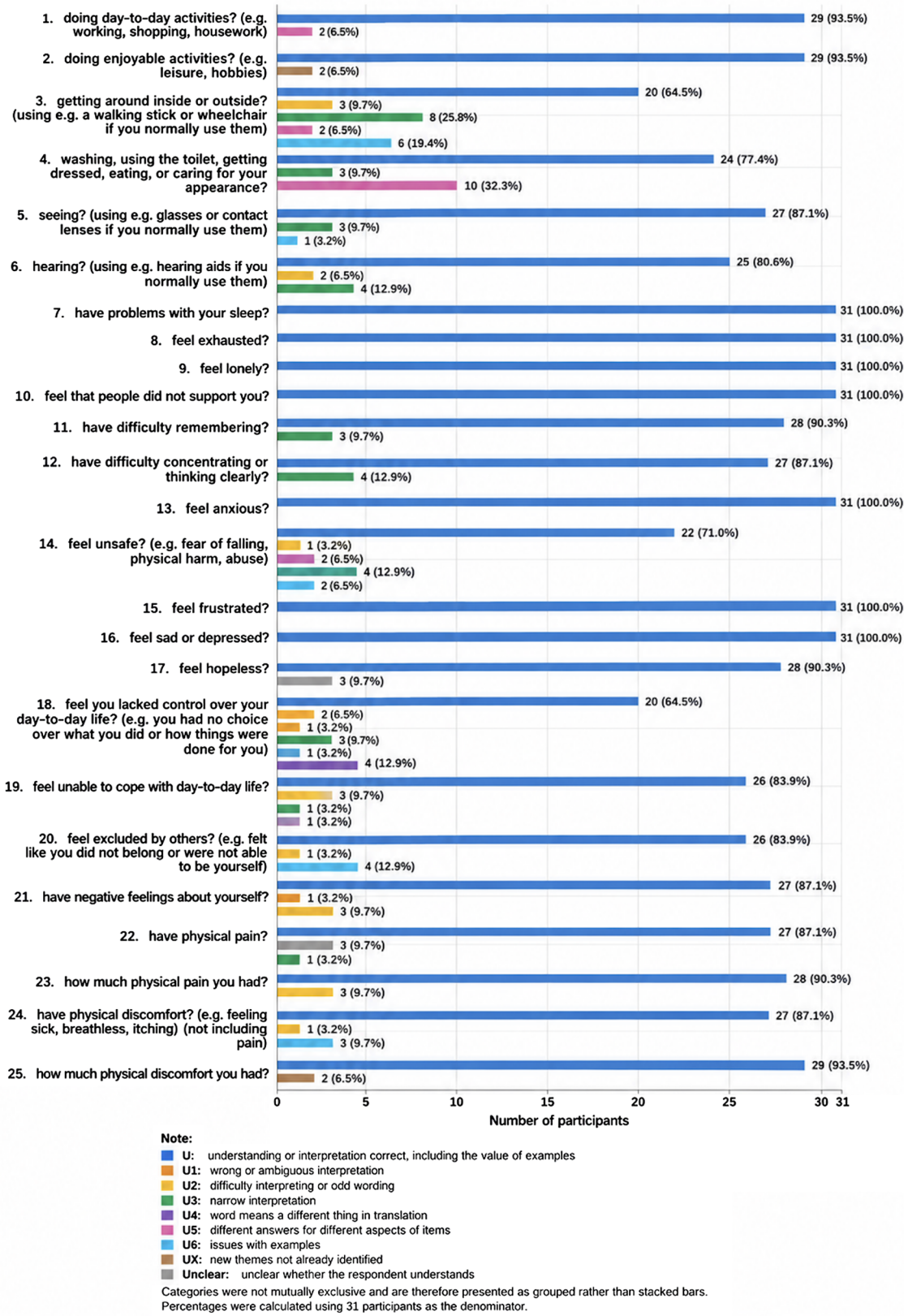


Fig. 1 Comprehensibility of the EQ-HWB ($n=31$)

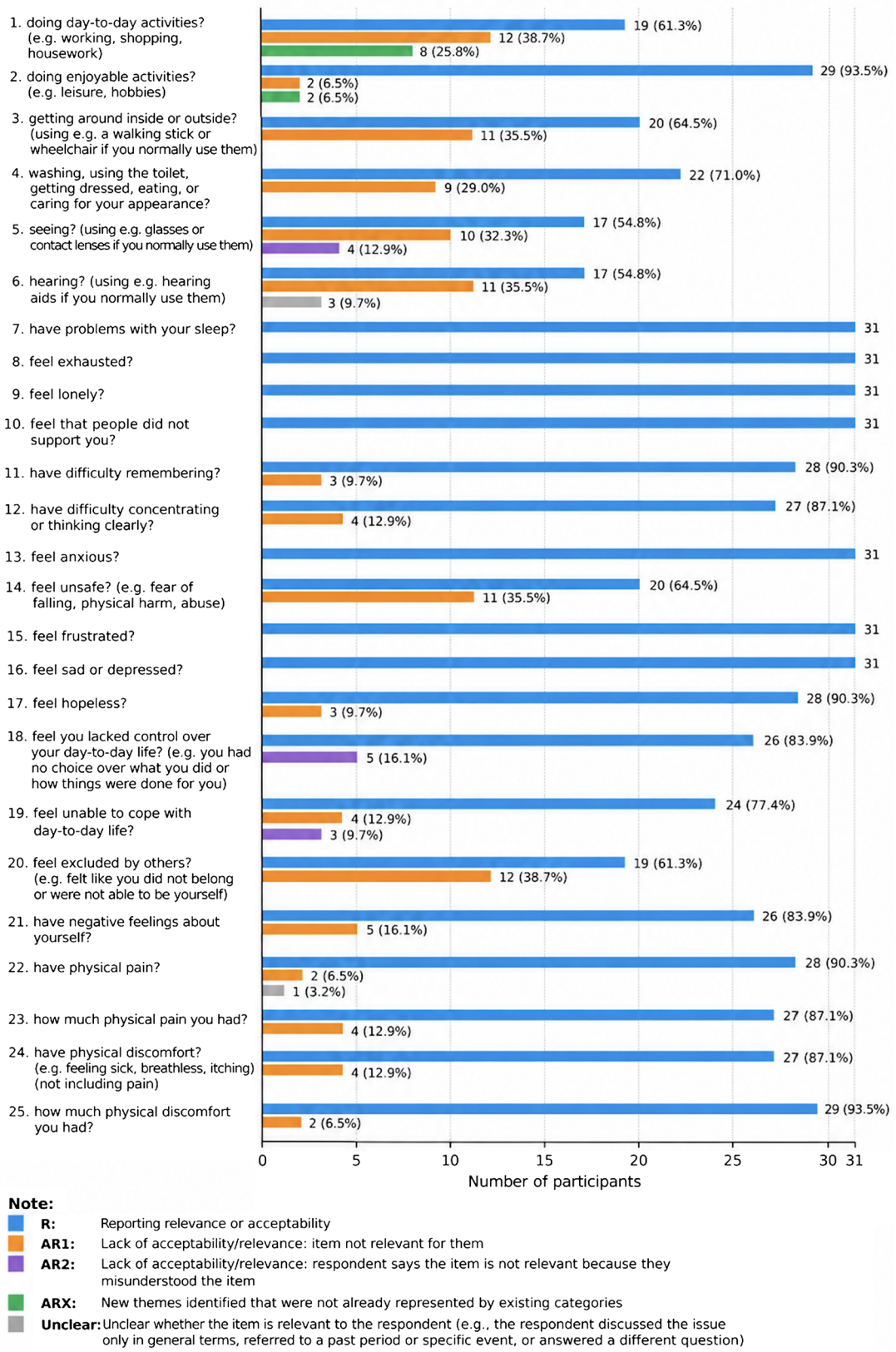


Fig. 2 Relevance of the EQ-HWB ($n=31$)

"Difficulty remembering" and "difficulty concentrating or thinking clearly" both showed relevance to cognitive functioning (28, 90.3% and 27, 87.1%, respectively) and good comprehensibility (28, 90.3% and 27, 87.1%, respectively). However, 10 participants (32.3%) recommended splitting the latter item into two separate items. "Loneliness" and "feeling unsupported" by others were rated as relevant to social and emotional experiences. and comprehensible by most participants. In contrast, "feeling excluded by others" was rated as relevant to experiences of social exclusion by only 19 (61.3%), primarily because caregiving limited work, outings, and social participation, thereby reducing daily social contact and experiences of exclusion; 12 (38.7%) considered it inapplicable. Comprehension was generally good, although some participants described the wording as abstract or the examples as insufficiently clear regarding context (family, work, or social groups).

Items on "feel you lacked control over your day-to-day life" and "feel unable to cope with day-to-day life" were considered relevant to perceived control and coping in daily life (26/31, 83.9% and 24/31, 77.4%, respectively) with occasional interpretation challenges (e.g., such experiences apply only to severe illness, or ambiguity in the wording and examples).

Comprehensiveness

Participants' views on the EQ-HWB were nearly evenly split. Sixteen considered the instrument broadly comprehensive, reporting that it adequately captured the key aspects of their health and wellbeing, while the remaining 15 identified important gaps, particularly those closely tied to caregiving experiences (Appendix, Table A6).

The most frequently reported missing content centred on three domains. First, 14 participants (45.2%) felt the instrument did not sufficiently capture caregiving-specific psychological burdens, including coping stress, prolonged vigilance, emotional exhaustion, and difficulties regulating their own emotions when the care recipient exhibited behavioural or emotional problems. Second, 13 participants (41.9%) highlighted the absence of economic or financial strain, which they viewed as a major influence on overall wellbeing; one participant noted, "*The financial pressure on the family is very high… income decreases while expenses increase.*" Third, 12 participants (38.7%) reported that social relationships and support, including family dynamics, social networks, and experiences of stigma, were insufficiently reflected. Fewer participants mentioned other gaps, such as the effects of stress on appetite or eating (4/31, 12.9%) or the absence of items assessing positive emotions, hope, or meaning in life (4/31, 12.9%).

Participants compared items with overlapping concepts and were asked to indicate which one they would remove from the EQ-HWB, if any. The strongest perceived redundancy, reported by 17 participants (54.8%), was between Item 18 (feel you lacked control over your day-to-day life) and Item 19 (feel unable to cope with day-to-day life). Of these participants, 11 (11/17, 64.7%) favoured retaining "coping" because it more directly reflected health status, while 6 (35.3%) preferred "control". Moderate overlap was identified among the social items ("loneliness", "unsupported" and "excluded by others") by 8 participants (25.8%) and among the emotional distress items ("frustration", "sadness/depression", "hopeless", "negative feelings about yourself") by 7 participants (22.6%).

Appropriateness

Most participants considered the EQ-HWB response options clear and easy to understand (Appendix, Table A7). Both the severity scale and the frequency scale were regarded as understandable by most participants (28/31, 90.3%, each). Participants could distinguish between response levels based on their personal experiences, with some interpreting frequency options in approximate proportions (e.g., "none of the time" as 0%, "sometimes" as roughly one-third of the time, and "often" as around half the time). Only a small number (2/31, 6.5%) suggested that some response categories may be redundant, such as the overlap between "severe" and "very severe".

Regarding response-format preferences, participants expressed mixed views. For the "physical pain" item, participants showed mixed preferences. Twelve participants (38.7%) preferred a severity-based scale, arguing

that symptom intensity better reflects overall health status regardless of how often the symptom occurs. Nine participants (29.0%) favoured a frequency-based scale because it is easier to quantify objectively. The remaining 10 (32.3%) viewed both approaches as broadly similar. A comparable pattern emerged for the "physical discomfort" item, where 14 (45.2%) preferred severity, nine (29.0%) preferred frequency, and eight (25.8%) expressed no strong preference.

Regarding the recall period, most participants correctly understood the "past 7 days" time frame (29/31, 93.5%) and appropriately limited their responses to experiences within the previous week (Appendix, Table A8). Only two participants (6.5%) referred to longer-term events. Opinions on the suitability of the 7-day recall period were divided nearly equally: 16 participants (51.6%) considered it appropriate because it matches weekly life cycles and routines, while 15 (48.4%) felt that it was too short to capture chronic or periodic physical and mental health issues and suggested extending it to 14 days or one month instead.

Additionally, several emotional items were perceived as conceptually overlapping, e.g., "frustrated", "sad or depressed", "hopeless", and "negative feelings about yourself". Items "feel you lacked control over your day-to-day life" and "feel unable to cope with day-to-day life" were also viewed as conceptually similar. For the item "excluded by others", the example "not able to be yourself" was considered unclear in relation to exclusion or isolation; 4/31 participants (12.9%) recommended using examples that more directly convey rejection, neglect, or a lack of belonging. (Appendix, Table A9)

Discussion

This study provides qualitative evidence on the experimental modified EQ-HWB among Chinese caregivers of children with ASD. Overall, the instrument demonstrated acceptable content validity in this population. Most items were highly relevant to caregivers' lived experiences of health and wellbeing and were readily understood, while the measure was perceived as broadly comprehensive. Nevertheless, some refinements, particularly to examples, item wording, and item placement, may further enhance relevance, reduce cognitive burden, and improve applicability for caregiver populations.

Relevance was highest for psychosocial and caregiving-related items. All participants endorsed the relevance of "sleep", "exhaustion", "loneliness", "lack of support", "anxiety", "frustration", "sadness/depression". Caregivers linked these domains to the emotional labour of managing their child's behavioural challenges, interrupted sleep, financial strain, and uncertainty about their child's future, which is consistent with the intense, daily demands of ASD caregiving. Cognitive items ("memory", "concentrating/thinking clearly") and physical symptoms ("pain", "discomfort") were also widely endorsed as reflecting the cumulative toll of long-term care. In contrast, sensory ("seeing", "hearing") and the "mobility" and "self-care" items showed somewhat limited relevance, with many viewing them as more pertinent to older adults or people with physical disabilities. "Feeling unsafe" and "feeling excluded" were similarly less salient for most, though a minority highlighted context-specific safety concerns (e.g., public stigma or behavioural crises). These patterns mirror findings from Australian caregiver research, where physical and sensory items were likewise seen as peripheral for parents of children with chronic conditions [9]. Placing such low-relevance items early in the questionnaire was noted by several participants as potentially discouraging completion.

Comprehensibility was generally high, with most participants demonstrating correct interpretation of most items. However, three recurring challenges emerged. First, narrow interpretations occurred when items were framed around severe disability (e.g., "mobility", "self-care", "seeing" and "hearing"), leading some caregivers to dismiss them as irrelevant to their own relatively intact physical health. In contrast, the "self-care" item was well understood in a Hong Kong face-validity study [19]. This difference may reflect variations in sample composition: the Hong Kong study involved general adults, whereas the present study focused on primary caregivers, who may be more likely to interpret the item in relation to illness or physical impairment. Second, abstract wording or mismatched examples created confusion. The "unsafe" item produced a clear multidimensional conflict

between its psychological stem and physical-safety examples (e.g., fear of falling, physical harm, and abuse), consistent with a Hong Kong EQ-HWB face-validity study in which participants were uncertain whether the item referred to emotional or physical safety [19]. Similarly, both the "mobility" item referencing aids and the "control" item with parenthetical phrasing "how things were done for you" were considered disconnected from everyday caregiving realities. Third, some items were perceived as multidimensional: "self-care" covering both basic (washing, using the toilet, getting dressed, eating) versus higher-level self-care (caring for one's appearance); "concentrating or thinking clearly" was suggested to be split by 10 participants into distinct attentional versus logical processes; and emotional items ("frustration", "sadness/depression", "hopelessness", "negative self-feelings") were seen as lying on a continuum of intensity. These issues echo earlier research that indicates the value of clearer, caregiver-relevant examples (e.g., replacing "shopping" with "buying groceries" or adding "taking care of the child" to the "day-to-day activities" item) [9], and the potential limitations of composite items covering multiple domains [31–33].

Although more than half of the participants positively evaluated the comprehensiveness of the EQ-HWB, the remaining caregivers identified several important gaps, most frequently caregiving-specific psychological burden, financial pressure, and broader social support and stigma issues. While the EQ-HWB items address general feelings of loneliness, lack of support, and social exclusion, many participants viewed these as overly generic and insufficiently sensitive to the distinctive forms of ASD-related stigma they encounter. The items might be seen as inadequate to capture societal misconceptions, public judgement, blame directed at parenting practices, and the pervasive misunderstanding of ASD, which are factors that may result in profound social withdrawal, strained family and community relationships, and a chronic sense of being "othered" [34]. Additionally, generic wording underestimated the depth of isolation caused by the visible and unpredictable nature of ASD behaviours [35]. Moreover, participants also noted conceptual proximity among several items, specifically, "lack of control" versus "unable to cope", "loneliness" versus "lack of support" versus "exclusion", and overlapping negative emotions. Although this overlap reflects the interrelated nature of these constructs, clearer differentiation through refined wording or examples could be introduced.

Limitations

Several limitations should be addressed. First, the sample did not fully represent caregivers across all child age groups. Caregivers of children younger than 8 years were not included because of the predefined age eligibility criterion, while caregivers of children aged over 13 years were under-represented. This may limit the applicability of the findings across younger childhood and later adolescence, as caregiving roles, stressors, and support needs may differ from those of caregivers of younger children and adolescents. Second, participants were generally well educated and were recruited from two large urban areas in eastern and southern China with relatively abundant rehabilitation resources. This recruitment strategy may have introduced selection bias, potentially overrepresenting caregivers with better access to services, higher health literacy, and more resources. The findings from this study may not reflect the experiences of more disadvantaged or underserved caregiving populations, particularly those living in central and western China or rural areas. Third, ASD severity information was based on caregivers' subjective perceptions rather than clinician-assigned severity, as relevant clinical data were either unavailable or not standardised (e.g., DSM-5 support levels). These ratings should therefore not be interpreted as clinical assessments. As this qualitative study focused primarily on content validity rather than statistical subgroup comparisons, the small and uneven subgroup sizes, together with the absence of standardised clinical severity data, precluded further exploration of whether caregivers' views on the relevance and comprehensiveness of EQ-HWB items differed by child age, sex, perceived ASD severity, or support needs. Fourth, although participants reported no difficulties reading the questionnaire, some accessed the interviews via mobile phones. Prolonged small-screen use may have reduced their concentration and increased fatigue, potentially limiting the depth of some responses. Finally, the online format restricted observation of non-verbal cues, which may have constrained

probing of sensitive issues or clarification of ambiguities. Future research should include more diverse caregiver samples, use standardised clinical classifications, and explore more effective interview formats to further assess the transferability of the findings and the content validity of the EQ-HWB.

Conclusions

The EQ-HWB performs well as a generic health and wellbeing measure for Chinese ASD caregivers. Evidence-based refinements to examples, wording consistency, item order, and the recall period may further strengthen its content validity and acceptability without altering the core conceptual framework. Such adjustments could improve applicability across caregiver populations and support the finalisation of the instrument.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1186/s12955-026-02661-2.

Acknowledgements We gratefully acknowledge the contributions of all participants recruited from the Hangzhou Xingjuexing (星觉醒) ASD Patient Association and the Guangzhou Rong'ai (融爱) Home Special Children Service Centre.

Author contributions YSX: Data Curation, Formal Analysis, Investigation, Methodology, Project Administration, Software, Writing – Original Draft, and Writing – Review & Editing.TP: Conceptualization, Validation, Writing – Review & Editing.FR: Conceptualization, Validation, Writing – Review & Editing.RHX: Conceptualization, Data Curation, Formal Analysis, Funding Acquisition, Methodology, Resources, Supervision, Writing – Original Draft, and Writing – Review & Editing.

Funding This study was funded by the EuroQol Research Foundation (1804-RA). The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review or approval of the manuscript; and decision to submit the manuscript for publication.

Data availability The datasets generated and/or analysed during the current study are not publicly available due to concerns regarding participant privacy and confidentiality, but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate The study protocol was approved by the Human Research Ethics Committee of the Hong Kong Polytechnic University (reference no. HSEARS20230911002). The study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Informed consent was obtained from all participants.

Consent for publication Not applicable.

Competing interests T.P., F.R., and R.H.X. are members of the EuroQol Group. F.R. is employed by the EuroQol Research Foundation. F.R. serves as co-editor-in-chief at Health and Quality of Life Outcomes and had no involvement in the editorial or peer review process for this manuscript. The other authors have no conflicts of interest. The views expressed are those of the authors and do not necessarily reflect the views of the EuroQol Research Foundation.

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References

1. Brazier J, Peasgood T, Mukuria C. The EQ-HWB: overview of the development of a measure of health and wellbeing and key results. Value Health. 2022;25. https://doi.org/10.1016/j.jval.2022.01.009.
2. Bailey C, Peasgood T, Michalowsky B. The psychometric performance of the eq health and wellbeing in caregivers of persons living with dementia. Value Health. 2025;28. https://doi.org/10.1016/j.jval.2025.04.2168.
3. Bailey C, Dalziel K, Constable L. Validity and reliability of the EQ-HWB in parents of children with health conditions. Value Health. 2025;28. https://doi.org/10.1016/j.jval.2025.05.013.
4. Bailey C, Dalziel K, Constable L. The performance of the EQ-HWB-S as a measure of quality-of-life of caregivers in families that have experienced adverse events. Eur J Health Econ. 2024. https://doi.org/10.1007/s10198-024-01688-w.
5. Bailey C, Dalziel K, Jones R. The Validity of the EuroQol Health and Wellbeing Short Version (EQ-HWB-S) Instrument in Parents of Children With and Without Health Conditions. PharmacoEconomics. 2024. https://doi.org/10.1007/s40273-024-01351-5.
6. Kuharic M, Mulhern B, Sharp LK. Comparison of the EQ-HWB and EQ-HWB-S with other preference-based measures among united states informal caregivers. Value Health. 2024;27. https://doi.org/10.1016/j.jval.2024.03.003.
7. Zhang G, Yang Z, Luo N. Comparing the Measurement Properties of the Preliminary Version of the EuroQol Health and Well-Being and EQ-5D-5L in Patients, Healthy General Public, and Caregivers. Value Health Reg Issues. 2025;47:101081. https://doi.org/10.1016/j.vhri.2025.101081.
8. Masutti S, Falivena C, Purba FD. Content validity of the EQ-HWB and EQ-HWB-S in a sample of Italian patients, informal caregivers and members of the general public. J Patient-Reported Outcomes. 2024;8. https://doi.org/10.1186/s41687-024-00706-y.
9. Bailey C, Peasgood T. (2025). Content Validity of the EQ-HWB in caregivers of children with health conditions: C. Bailey, T. Peasgood. Patient-Patient-Centered Outcomes Res, 1–11.
10. Prinsen CAC, Mokkink LB, Bouter LM. COSMIN guideline for systematic reviews of patient-reported outcome measures. Qual Life Res. 2018;27:1147–57. https://doi.org/10.1007/s11136-018-1798-3.
11. Uttley L, Carlton J, Woods HB. A review of quality of life themes in Duchenne muscular dystrophy for patients and carers. Health Qual Life Outcomes. 2018;16:237. https://doi.org/10.1186/s12955-018-1062-0.
12. Prinsen CAC, Vohra S, Rose MR. How to select outcome measurement instruments for outcomes included in a 'Core Outcome Set' - a practical guideline. Trials. 2016;17:449. https://doi.org/10.1186/s13063-016-1555-2.
13. Xu RH, Rencz F. Psychometric Properties of the Modified EQ Health and Wellbeing and its Shorter Version in a General Chinese Population: A Comparative Analysis With EQ-5D-5L, SF-6Dv2, ICEpop CAPability measure for Adults, Short Version of Warwick-Edinburgh Mental Wellbeing Scale, and World Health Organization Well-Being Index 5-Item. Value Health. 2025;28(8):1241–52. https://doi.org/10.1016/j.jval.2025.04.2151.
14. Liao M, Rencz F, Yang Z, Xiang J, Luo N. Validity and responsiveness of the EQ-5D-5L, EQ-HWB and EQ-HWB-9 to measure health and wellbeing impact of heatwaves among older adults. Health Qual Life Outcomes. 2026. https://doi.org/10.1186/s12955-026-02521-z.
15. Xu RH, Yang C, Rencz F. Exploring Recall Periods for EQ-5D-5L and EQ-HWB-9: A Hong Kong Population Study. Value Health. 2026. https://doi.org/10.1016/j.jval.2026.01.001.
16. Zhou W, Ding B, Busschbach J, Herdman M, Yang Z, Lu Y. EQ-5D-5L or EQ-HWB-S: Which is the Better Instrument for Capturing Spillover Effects in Parental Carers of Children with COVID-19? PharmacoEconomics. 2025;43(5):555–67. https://doi.org/10.1007/s40273-025-01473-4.
17. Xu RH, Yang C, Xu Y, Marten O, Rencz F. Psychometric Properties of the Experimental and Modified EQ-HWB and EQ-HWB-9 in Patients with Anxiety and/or Depression in China. Value Health. 2026. https://doi.org/10.1016/j.jval.2026.06.004.
18. Xu RH, Yang C, Rencz F. A Quantitative Exploration of the Performance of a Potential Health and Well-Being Visual Analog Scale (EQ-HWB VAS) for the EQ-HWB-9. Value Health. 2026;29(8):1471–80. https://doi.org/10.1016/j.jval.2026.02.013.
19. Wong EL-Y, Cheung AW-L, Wong AY-K, Yang Z. Face validity of the EQ health and wellbeing instrument (EQ-HWB) in Hong Kong. J Patient-Reported Outcomes. 2026;10(1):108. https://doi.org/10.1186/s41687-026-01075-4.
20. Lord C, Elsabbagh M, Baird G. Autism spectrum disorder. Lancet. 2018;392:508–20. https://doi.org/10.1016/S0140-6736(18)31129-2.
21. Jiang X, Chen X, Su J, Liu N. Prevalence of autism spectrum disorder in mainland china over the past 6 years: a systematic review and meta-analysis. BMC Psychiatry. 2024;24(1):404. https://doi.org/10.1186/s12888-024-05729-9.
22. Liu Y, Fisher KR. Struggle for recognition, rights, and redistribution: Understanding the identity of parents of children with autism spectrum disorder in China. Front Psychol. 2022;13:981986. https://doi.org/10.3389/fpsyg.2022.981986.
23. Hayes SA, Watson SL. The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children With and Without Autism Spectrum Disorder. J Autism Dev Disord. 2013;43(3):629–42. https://doi.org/10.1007/s10803-012-1604-y.

24. Onyishi CN, Sefotho MM, Victor-Aibodion V. Psychological distress among parents of children with autism spectrum disorders: A randomized control trial of cognitive behavioural therapy. Res Autism Spectr Disorders. 2023;100:102070. https://doi.org/10.1016/j.rasd.2022.102070.
25. Su X, Cai RY, Uljarević M. Predictors of Mental Health in Chinese Parents of Children with Autism Spectrum Disorder (ASD). J Autism Dev Disord. 2018;48(4):1159–68. https://doi.org/10.1007/s10803-017-3364-1.
26. Feng Y, Ng TYC, Lu D, Chan LML, Li J, Chau PH, Kwok JYY. Raising Autistic Children in Mainland China: A Qualitative Study of Parental Experiences and Challenges. J Autism Dev Disord. 2025. https://doi.org/10.1007/s10803-025-06877-x.
27. Wang X, Zhai F, Wang Y. Interplay between tradition and modernity: stress and coping experiences among parents of children with Autism in Beijing, China. Behav Sci (Basel). 2023;13(10). https://doi.org/10.3390/bs13100814.
28. Ng CSM, Ng SSL. A qualitative study on the experience of stigma for Chinese parents of children with autism spectrum disorder. Sci Rep. 2022;12(1):19550. https://doi.org/10.1038/s41598-022-23978-0.
29. Fan X, Ko KS. (2025). Chinese caregivers' experiences parenting children with autism spectrum disorder: a descriptive qualitative study [Original Research]. Volume 16–2025. https://doi.org/10.3389/fpsyt.2025.1514948.
30. Peasgood T, Mukuria C, Brazier J. Developing a new generic health and wellbeing measure: psychometric survey results for the EQ-HWB. Value Health. 2022;25. https://doi.org/10.1016/j.jval.2021.11.1361.
31. Rencz F, Janssen MF. Analyzing the Pain/Discomfort and Anxiety/Depression Composite Domains and the Meaning of Discomfort in the EQ-5D: A Mixed-Methods Study. Value Health. 2022;25(12):2003–16. https://doi.org/10.1016/j.jval.2022.06.012.
32. Pham M, Craig BM, Rencz F. The psychometric performance of the EQ-5D-5L composite and component items in the U.S. General population and by age group. Qual Life Res. 2025;34(12):3649–61. https://doi.org/10.1007/s11136-025-04053-3.
33. Engel L, Whitehurst DGT, Haagsma J, Janssen MF, Mulhern B. What is measured by the composite, single-item pain/discomfort dimension of the EQ-5D-5L? An exploratory analysis. Qual Life Res. 2023;32(4):1175–86. https://doi.org/10.1007/s11136-022-03312-x.
34. Papadopoulos C, Lodder A, Constantinou G. Systematic Review of the Relationship Between Autism Stigma and Informal Caregiver Mental Health. J Autism Dev Disord. 2019;49:1665–85. https://doi.org/10.1007/s10803-018-3835-z.
35. Prommersberger M, Witzmann M, Schuwerk T. Needs, Challenges, Burdens and Interventions for Informal Caregivers of Adults with Autism Spectrum Disorders (ASD): A Scoping Review. Rev J Autism Dev Disorders. 2026. https://doi.org/10.1007/s40489-026-00552-2.

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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