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ORIGINAL ARTICLE

Assessing caregiving experience in COPD: content validity of the Zarit Burden Interview in Canadian and Portuguese caregivers

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ABSTRACT

Purpose: Informal caregivers play an important role in chronic disease management but their experience is often neglected. The objective of this study was to explore the content validity of the Zarit Burden Interview (ZBI) in caregivers of individuals with COPD in Canada and Portugal.

Materials and methods: Cognitive debriefing interviews were conducted with informal caregivers of individuals with moderate to very severe COPD. Participants completed the ZBI and verbalised their thinking process to assess the adequacy of the questionnaire's content and instructions. Content validity was assessed using deductive content analysis of interviews and descriptive statistics of questionnaire responses.

Results: Nine caregivers from Canada (age = 67 ± 8 years) and 13 from Portugal (age = 69 ± 7 years) participated. For Canadian caregivers, 3/22 items were not understood, and 8/22 items were not relevant to at least 1/3 of them. For Portuguese caregivers, 1/22 items were not understood, and 20/22 items were not relevant to at least 1/3 of them. The distribution of response choices was approximately symmetrical for 17/22 items in the Canadian sample. The response option "no/never" was selected by at least 75% of Portuguese participants for 18/22 items.

Conclusions: The instrument was well understood by caregivers of people with COPD, but its relevance is uncertain.

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Caregivers; COPD; cognitive debriefing interviews; caregiver burden

➤ IMPLICATIONS FOR REHABILITATION

- Informal caregivers provide essential care for people living with disability and chronic disease, but their experience is often neglected.
- The Zarit Burden Interview assesses caregiver burden but has not been validated in caregivers of people with chronic obstructive pulmonary disease.
- In its current form, the Zarit Burden Interview does not adequately represent the experience of COPD caregivers.
- We recommend selecting tools that assess caregiver burden that have been validated in the caregiver population of interest.

Introduction

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality [1]. The disease trajectory is characterized by a gradual decline in health status, increasing symptoms (e.g., breathlessness, fatigue), and fluctuations between stable and unstable disease states (i.e., acute exacerbations) [2]. As the disease progresses and the experience of symptoms (e.g., breathlessness, fatigue) increase, individuals with COPD become restricted in their daily activities and require support to coordinate care tasks, manage symptoms, mobility, and personal care [3,4]. The primary source of this support is from people who have an important personal relationship with the care-receiver, including relatives, partners, friends, or neighbors, who are referred to as family, significant others, or informal caregivers [5,6]. We will refer to them as informal caregivers.

Several literature reviews indicate that caring for individuals with COPD is a challenging experience [7–10] with significant, positive and negative, impacts on informal caregivers' lives. One narrative review of caregiver burden in COPD reported that all 18 studies described negative impacts of caregiving, but only 4 described positive aspects of caregiving [7], although the exact prevalence of positive and negative experiences of caregivers of individuals with COPD is unknown. In caregivers of individuals with COPD, greater caregiver burden has been found to be associated with increased caregiving hours per week, diminished mental and emotional health of caregivers', poor quality of the caregiver-patient relationship, and decreased physical health of

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the individual with COPD [7,9–12]. The burden experienced by caregivers may also increase if the amount of care they provided increases with the progression of COPD. This is in line with the wear-and-tear hypothesis, which considers that the accumulation of care demands impairs caregivers' well-being, leading to negative impacts of caregiving over time [13]. Nevertheless, positive impacts of caregiving have also been identified that are related to personal growth and satisfaction in being able to do something useful for the person receiving care [7].

The amount of informal caregiving and the degree of caregiver burden have also been found to differ across ethnic groups and cultures. Compared to white caregivers, ethnic minority caregivers tend to provide more hours of care [14], experience worse physical and mental health [15], and less frequently access professional support services [15]. Research has also shown that perceptions of caregiving vary across cultures, with individualistic countries having a more negative perception of caregiving than collectivist countries [16]. Individualistic cultures value independence and self-determination, whereas collectivist cultures value loyalty to members of their group. Thus, caregiving may imply a reliance on others, which contradicts with the values of an individualistic culture [16]. Cultural perceptions of caregiving are considered critical, as they impact caregiving decisions and experience of caregiver burden [16,17]. There is a dearth of research exploring cultural differences of COPD caregivers and experience of caregiver burden. Our study begins to address this gap by examining caregiver burden in an individualistic country (i.e., Canada) and a collectivist country (i.e., Portugal).

Formal and routine assessment of the impact of caregiving in COPD is not typically conducted in clinical practice, although such evaluation could identify individuals most in need of support and allow the initiation of services to improve caregivers' experience. While some instruments have been used to assess the caregiving experience in COPD in research studies [18–20], a better understanding of their suitability to the COPD population in a clinical setting is necessary for specific inferences to be made from the instrument scores to assist research and clinical practice [21].

The Zarit Burden Interview (ZBI), originally developed to assess the experience of informal caregivers for those with Alzheimer's disease [20] is a self-report questionnaire which assesses the impact of caregiving on health and psychological well-being, finances, social life and in the relationship between the caregiver and the care-receiver [22]. The ZBI has been administered to caregivers of patients with stroke, Parkinson's disease or chronic kidney failure [23–25] and COPD [26–32]. There are several versions of the ZBI including the original version comprising 22 items, and several shorter versions which include between four and twelve items [33–35]. Although the ZBI is user-friendly, and it has been validated in many languages and populations, no version of the ZBI has been validated in COPD, nor compared across countries [36]. Informal caregivers of individuals with COPD have reported several disease specific challenges, including managing breathlessness and transitioning between stable and unstable disease-states [7,8], which are not observed in other chronic diseases such as diabetes, end-stage kidney disease, and Parkinson's, which tend to have a more stable and linear decline. It is unclear whether these experiences are captured by a scale developed for a different population (content validity). Additionally, caregiving may be experienced differently across cultures [16,17], which would impact the validity of between country comparisons. The purpose of this study was to assess the content validity of the most used version of the ZBI in COPD, the original 22 item ZBI, in Canadian and Portuguese informal caregivers of individuals with COPD.

Method

Design

Cognitive debriefing interviews were conducted with informal caregivers of individuals with COPD in Canada and Portugal. This study was approved by a hospital in Toronto, Canada (ref. 17-008-WP), and a hospital and university in Aveiro, Portugal (ref. 777636; UICISA, ref. 385-01/2017). All participants provided written informed consent prior to participation. All study procedures were performed in accordance with the ethical standards of the institutional review boards. This study followed the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines to assess content validity [37].

Participants & recruitment

In Canada, participants were recruited in-person during their family member's usual care respiratory clinic appointment at a hospital in Toronto. A healthcare practitioner identified individuals with COPD and caregivers to the researcher, who then explained the study to the individual and invited them to participate, if eligible. Informed consent was obtained from eligible caregivers and patients with COPD during the respiratory clinical appointment. In Portugal, individuals with COPD identified by their healthcare practitioner at a hospital and university in Aveiro were contacted by researchers who provided information about the study and asked if they could identify their informal caregiver. When the caregiver was identified, their contact was requested for participation. The researcher then contacted informal caregivers by telephone to inform them about the study, verified the eligibility criteria and asked about their willingness to participate. Data collection was scheduled on the days when patients had appointments at the units where they were identified, to avoid travel burden. Both caregivers and patients provided informed consent. Purposeful sampling was used to capture caregivers of individuals with moderate, severe, and very severe COPD [2]. Caregivers of individuals with mild COPD were not recruited as individuals with mild COPD often had few symptoms and required less assistance from a caregiver [38]. Informal caregivers were eligible to participate if they were: (1) 18 years or older; (2) the primary caregiver of an individual with COPD, i.e., the person who provide the largest amount of physical and/or emotional support without receiving any payment [5]; (3) able to understand the purpose of the study and agree to voluntarily participate. Participants were excluded if they had severe psychiatric conditions or cognitive impairment that profoundly affected their ability to understand and co-operate. In Canada, participants received remuneration for costs incurred to attend research-specific appointments.

Procedures

Data collection occurred at a location most convenient to participants (home or academic institution). Participants self-reported demographic information: age, sex, education level, employment status, marital status, and chronic health conditions; and information on the caregiving context: relationship with the care-receiver, cohabitation, type of care provided, number of years providing care, and amount of caring hours per week. Characteristics of the care-receiver (i.e., individual with COPD) were collected from medical records: age, sex, forced expiratory volume in 1 s (FEV_1) % predicted, FEV_1/FVC ratio. Cognitive debriefing interviews were conducted in-person by a researcher experienced in qualitative research and in working with patients and families living with chronic illness. Semi-structured interviews assessed participants' understanding of the ZBI and its relevance to their own experience as an informal caregiver. Interviews were conducted until data saturation was reached, i.e., the point where no valuable information was elicited from the interviews [21,39]. The interviews were audio-recorded and transcribed verbatim.

The Zarit Burden Interview (ZBI) [20]

The English (Canada/English – version of 11 December 2006) and Portuguese (version of 17 April 2007) original versions of the Zarit-Burden Interview (ZBI, Mapi Research Trust, Copyright 1983, 1990, Steven H. Zarit & Judy M. Zarit) [20,40,41] were used. This version of the ZBI has a total of 22 items, which assess the impact of caregiving on caregivers' health, psychological well-being, finances, social life, and relationship between the caregiver and care-receiver on a 5-point Likert scale [20]. The items scores are summed to give a total score ranging from 0 to 88, with high scores indicating greater impact/burden. This questionnaire has been found to be valid and reliable in informal caregivers of community dwelling people with Alzheimer's disease [20]. In the current study, Cronbach's Alpha for the total sample was very good (Total = .94; Canada = .89; Portugal = .76).

Cognitive debriefing interviews

In-person cognitive debriefing interviews were conducted using the concurrent probing technique, in which participants were asked to read the questions of the instrument and verbalize their thinking process – "think-aloud interviews" [42]. The concurrent probing technique has been widely used in content validity research as it allows for retrieval of information while it is fresh in participants' minds [42]. The cognitive debriefing interview explicitly focuses on the cognitive processes that caregivers use to understand and answer questions (e.g., "What do you think the question is asking?" "What do specific term(s) in the question mean to you?") [42]. Caregivers were asked to complete the questionnaire while verbalizing their thinking process. At the end of the interview, caregivers were asked if there were any aspects of caregiving that were not addressed in the instrument, and if so, how important these were to the concept of interest. The interviews followed the international recommendations [21,39,42]. The interview guide is available in the Supplementary material.

Analysis

A deductive content analysis was used to analyze the audio-recorded cognitive debriefing interviews [39,43]. A categorization matrix was developed based on the semi-structured interview guide, after which, two authors read the transcripts several times, coding and segmenting responses by hand into seven pre-defined categories generated by the authors: opinion of item clarity (i.e., "well understood, "not well understood"), reasons items were "not well understood," suggestions to improve "not well understood items," opinion of item relevance (i.e., "relevant," "could be relevant," "not at all relevant"), reasons items were considered "could be relevant," or "not at all relevant," suggestions to improve "not at all relevant items," opinion of questionnaire features (e.g., instructions, response choices). Frequency counts were tallied to capture participants' opinion of item clarity and item relevance for each ZBI item. Direct quotations from participants were used to support and describe the categories. To ensure reflexivity, researchers held regular meetings to reflect on and discuss the results. IBM SPSS Statistics 24 (IBM, Armonk, USA) was used to calculate descriptive statistics for sociodemographic characteristics and ZBI items, as well as inferential statistics comparing the Canadian and Portuguese samples on sociodemographic characteristics. Independent samples *t*-tests were computed for continuous outcomes and χ^2 for dichotomous or categorical outcomes.

Results

Participant characteristics

A total of 22 participants completed the study, 9 from Canada and 13 from Portugal. The average age of participants was 69 ± 8 (Canada = 67 ± 8; Portugal = 69 ± 7) years old, 18 were female (Canada = 7; Portugal = 11), 19 were a spouse of the individual with COPD (Canada = 7; Portugal = 12), 12 had been providing care for more than 4 years (Canada = 5; Portugal = 7), and 19 were not employed (Canada = 8; Portugal = 11). The average age of individuals with COPD was 75 ± 5 (Canada = 76 ± 5; Portugal = 74 ± 6) years old, and the average FEV$_1$ was 46 ± 19% predicted (Canada = 39 ± 20; Portugal = 50 ± 18). Across the total sample of caregivers, 46% had a college or university degree (Canada = 88%; Portugal = 15%). Table 1 displays the characteristics of informal caregivers, Table 2 the characteristics of

Table 1. Characteristics of informal caregivers of individuals with COPD for the total sample and by country.

	Total (*n* = 22)	Canada (*n* = 9)	Portugal (*n* = 13)
Age, years mean ±*SD*	69 ± 8	67 ± 8	69.3 ± 7.0
Sex (female), *n* (%)	18 (82%)	7 (78%)	11 (85%)
Highest Education Achieved, *n* (%)			
Primary School	9 (41%)	0 (%)	9 (69%)
Secondary school	3 (14%)	1 (11%)	2 (15%)
College certificate or diploma	4 (18%)	4 (44%)	0 (0%)
Undergraduate degree	5 (23%)	3 (33%)	2 (15%)
Graduate degree	1 (5%)	1 (11%)	0 (0%)
Current occupation, *n* (%)			
Employed	3 (14%)	1 (11%)	2 (15%)
Unpaid or domestic work	2 (9%)	1 (11%)	1 (8%)
Retired	16 (73%)	6 (67%)	10 (77%)
On disability	1 (5%)	1 (11%)	0 (0%)
Civil status, *n* (%)			
Married	19 (86%)	8 (89%)	11 (85%)
Widowed	1 (5%)	1 (11%)	0 (0%)
Common law	2 (9%)	0 (0%)	2 (15%)
Comorbidities, *n* (%)			
Hypertension	10 (46%)	2 (22%)	8 (62%)
Diabetes	1 (5%)	1 (11%)	0 (0%)
Dyslipidemia	9 (41%)	4 (44%)	5 (39%)
Osteoarthritis	3 (14%)	2 (22%)	1 (8%)
Rheumatoid Arthritis	1 (5%)	0 (0%)	1 (8%)
Depression	4 (18%)	2 (22%)	2 (15%)
Anxiety	2 (9%)	2 (22%)	0 (0%)
Osteoporosis	4 (18%)	4 (44%)	0 (0%)
Current smoker, *n* (%)	2 (9%)	1 (11%)	1 (8%)

Table 2. Characteristics of individuals with COPD for the total sample and by country.

	Total (*n* = 22)	Canada (*n* = 9)	Portugal (*n* = 13)
Age, years	74.5 ± 5.4	75.9 ± 5.2	73.5 ± 5.5
Sex (male), *n* (%)	16 (73%)	5 (56%)	11 (85%)
FEV$_1$, % predicted	45.9 ± 19.2	38.5 ± 19.7	50.4 ± 18.3
GOLD grade, *n* (%)			
Moderate	9 (41%)	2 (22%)	7 (54%)
Severe	8 (36%)	4 (44%)	4 (31%)
Very severe	5 (23%)	3 (33%)	2 (15%)

Note. Results are expressed as mean ±*SD* unless otherwise stated. FEV$_1$: forced expiratory volume in 1 s; GOLD: global initiative for obstructive lung disease.

Table 3. Characteristics of the caregiving context for the total sample and by country.

	Total sample ($n = 22$)	Canada ($n = 9$)	Portugal ($n = 13$)
Relationship with the individual with COPD, *n* (%)			
Spouse	19 (86%)	7 (78%)	12 (92%)
Child	3 (14%)	2 (22%)	1 (8%)
Cohabitation, *n* (%)			
Yes	19 (86%)	7 (78%)	12 (92%)
No	3 (14%)	2 (22%)	1 (8%)
Type of care provided, *n* (%)			
Personal care	8 (36%)	4 (44%)	4 (31%)
Mobility	5 (23%)	5 (56%)	0 (0%)
Domestic work	19 (86%)	9 (100%)	10 (77%)
Medication management	9 (41%)	6 (67%)	3 (23%)
Therapeutic care	4 (18%)	4 (44%)	0 (0%)
Financial management	7 (32%)	4 (44%)	3 (23%)
Shopping	14 (64%)	8 (89%)	6 (46%)
Bureaucratic duties	12 (55%)	8 (89%)	4 (31%)
Accompaniment to medical and/or other appointments	16 (73%)	9 (100%)	7 (54%)
Transportation	12 (55%)	7 (78%)	5 (39%)
Caregiving period (years), *n* (%)			
<1 year	2 (9%)	1 (11%)	1 (8%)
2–4 years	6 (27%)	3 (33%)	3 (23%)
≥4 years	12 (55%)	5 (56%)	7 (54%)
Caregiving hours/week, *n* (%)			
<8	6 (27%)	1 (11%)	5 (39%)
8–20	5 (23%)	2 (22%)	3 (23%)
21–40	4 (18%)	2 (22%)	2 (15%)
≥40	7 (32%)	4 (44%)	3 (23%)

individuals with COPD, and Table 3 the characteristics of the caregiving relationship.

Cognitive debriefing interviews

Item clarity

Figure 1(a) displays the percentage of participants who "understood" each item by country and Table 4 includes quotations for items that were not well-understood by at least a third of the sample by country.

Most participants had a good understanding of the ZBI items, although there were several items where difficulties in understanding were expressed. Participants expressed that item 4, "Do you feel embarrassed about your relative's behaviour?", ($n = 10$, 45%) was confusing and found the use of the term "behaviour" to be vague. They also expressed that item 19, "Do you feel uncertain about what to do about your relative?", ($n = 10$, 45%) was too vague and several participants suggested that including a timeframe in this question would improve clarity.

From the Canadian sample, seven participants (78%) expressed difficulty interpreting the term "privacy" from item 11, "Do you feel that, because of your relative, you don't have as much privacy as you would like?". Participants questioned whether "privacy" meant "time to yourself" or if it insinuated that secrecy was needed. The remaining items were understood by at least 78% (7/9) of Canadian participants.

From the Portuguese sample, 3–4 participants (23–31%) expressed difficulty understanding the items 3, 5, 7, 14, 15 and 21: "Do you feel stressed when you are around your relative?", "Do you feel angry with your relative when you are around him or her?", "Are you afraid of what the future holds for your relative?", "Do you feel that your relative expects you to take care of him or her, as if you were the only one that he or she could depend on?", "Do you feel you don't have enough money to care for your relative, in addition to the rest of your expenses?", and "'Do you feel that you could provide higher quality care for your relative?". Most difficulties were related to understanding the meaning of some expressions (e.g., what to be angry about, feeling stressed, what "the future holds" means in their specific context). One participant suggested changing item 5 to "Do you feel angry with your relative because he/she is sick?". In item 15 related to expenses, participants expressed difficulty in choosing the most appropriate score. Some participants also showed difficulties in differentiating item 20 ("doing more for your relative") from item 21 ("provide higher quality care").

Item relevance

Figure 1(b) displays the percentage of participants who considered each item "relevant" by Country and Table 4 provides quotations from participants of the reason they considered the items not relevant to them, when indicated by at least 1/3 of the sample.

Overall, the Canadian sample found more ZBI items relevant to their experience as an informal caregiver than the Portuguese sample. In the Canadian sample, 8 items were found to be "not relevant" to at least 1/3 of the sample (items 4, 5, 6, 11, 13, 15, 17, 19), while in the Portuguese sample, 20 items were "not relevant" to at least 1/3 of the sample (items 2–6, 8–22).

In terms of agreement between the samples, at least 2/3 of participants agreed that item 1, "Do you feel that your relative asks for more help than he or she needs?" and item 7, "'Are you afraid of what the future holds for your relative?" were relevant to their caregiving experience. Both samples agreed that items 4, "Do you feel embarrassed about your relative's behaviour?" and 13, "Do you feel uncomfortable about having friends over because of your relative?", were "not relevant at all" and more related to one's temperament and personality rather than a characteristic of COPD. For the former item, participants expressed that it seemed more appropriate for caregivers of patients with dementia and many suggested removing it. For the latter item, participants suggested replacing the term "uncomfortable" with "restricted" or "impeded" to improve the relevance. Similarly, both samples agreed that item 15 related to financial concerns was not relevant to their caregiving experience but that it may be for others and should remain in the questionnaire.

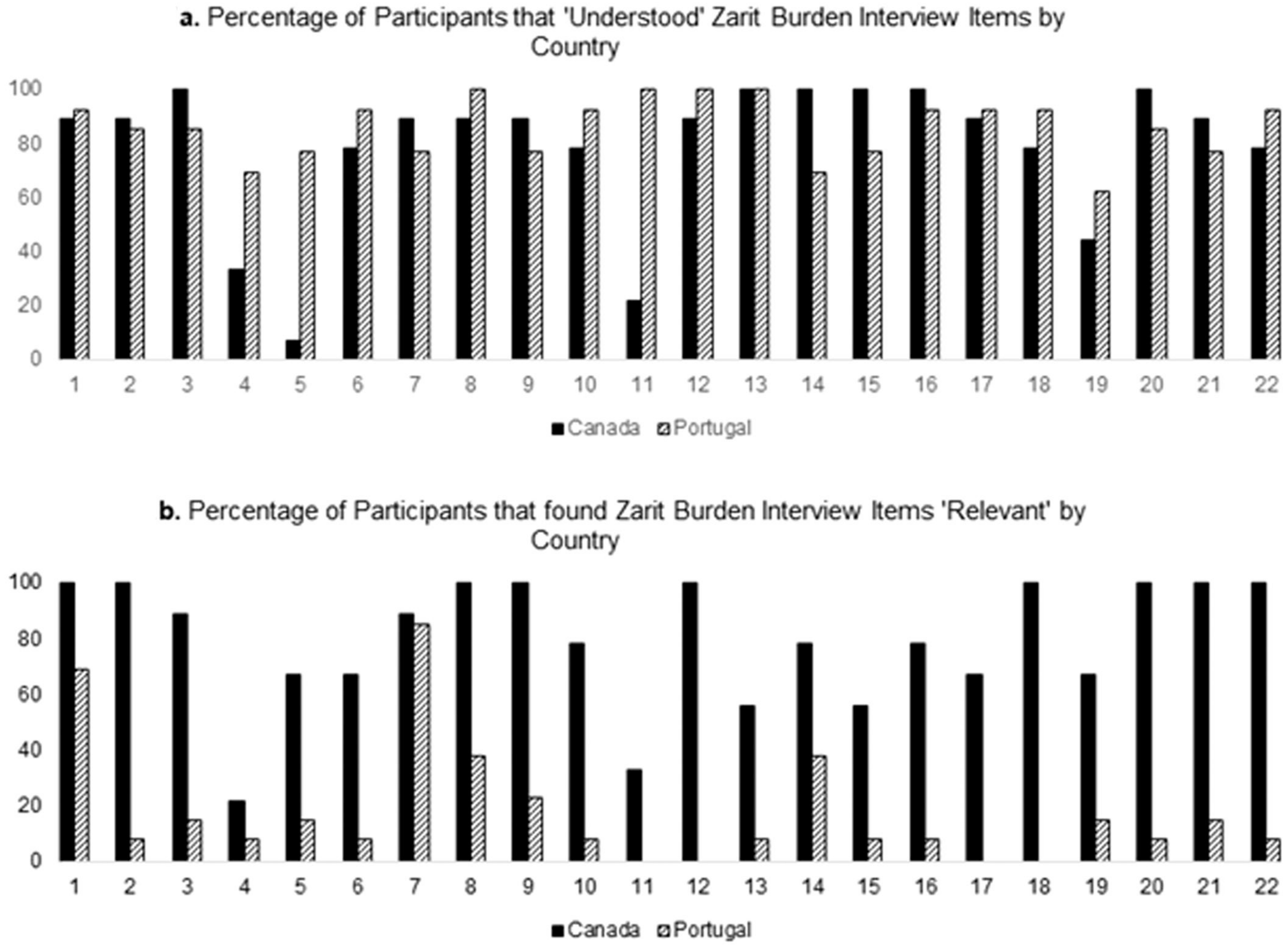


Figure 1. (a) The *x*-axis denotes the item number of the Zarit Burden Interview. In Figure 1(a) the *y*-axis denotes percentage of participants who "understood" the items. (b) The *x*-axis denotes the item number of the Zarit Burden Interview. In Figure 1(b) the *y*-axis denotes percentage of participants who found the items "relevant."

There were many disagreements between the samples regarding the relevancy of items. There were 12 items categorized as "not relevant" to the Portuguese sample but "relevant" to the Canadian sample. These items related to feelings of stress and burden from providing care (items 3, 9, 20, 21, 22), expectations and responsibility of care (items 8, 14, 18), impacts on social life and leisure (items 2, 12), and negative health effects and ability to provide care (items 10, 16).

While both samples agreed that some items may become more relevant to them as COPD progresses in the individual they are caring for, there were differences between the samples in the items they categorized this way. In the Canadian sample, items 17, "Do you feel you have lost control of your life since your relative's illness began?", and 19, "'Do you feel uncertain about what to do about your relative?'" were categorized to be more relevant as COPD progresses, whereas in the Portuguese sample items 12 "Do you feel that your social life has suffered because you're caring for your relative?" and 16 "Do you feel that you will be unable to take care of your relative for much longer?" were categorized this way.

Questionnaire features

Although overall the participants found the instructions and formatting of the ZBI clear, they had difficulties deciding which score to choose when the items were not relevant to them. The items that participants had the most difficulty with were items 1–5, 7, 8, 14–16 and 19. To improve the scoring system, 6 participants suggested to change the score "Never" to "No" ($n = 5$) or "Does not apply" ($n = 1$).

Summary statistics for ZBI

Descriptive statistics for the ZBI are provided in Supplementary table 1, with the distribution of scores by item and sample displayed in Figure 2. In the Canadian sample, responses were distributed across the scoring options for most of the ZBI items, except for items 4, 8, 13–15, 19–21. In the Portuguese sample, most participants selected the first scoring option ("Never"/"Not at all") for the majority of the ZBI items. The scoring distribution differences between the two samples was not explained by disease severity (Supplementary figure 1).

Discussion

This study investigated the content validity of the ZBI among caregivers of patients with COPD. Most items were well understood, although many items (8 from Canadian sample and 20 from Portuguese sample), especially those relating to patient behaviour and personality, were not relevant to at least 1/3 of the sample. The ZBI items were better understood and more relevant

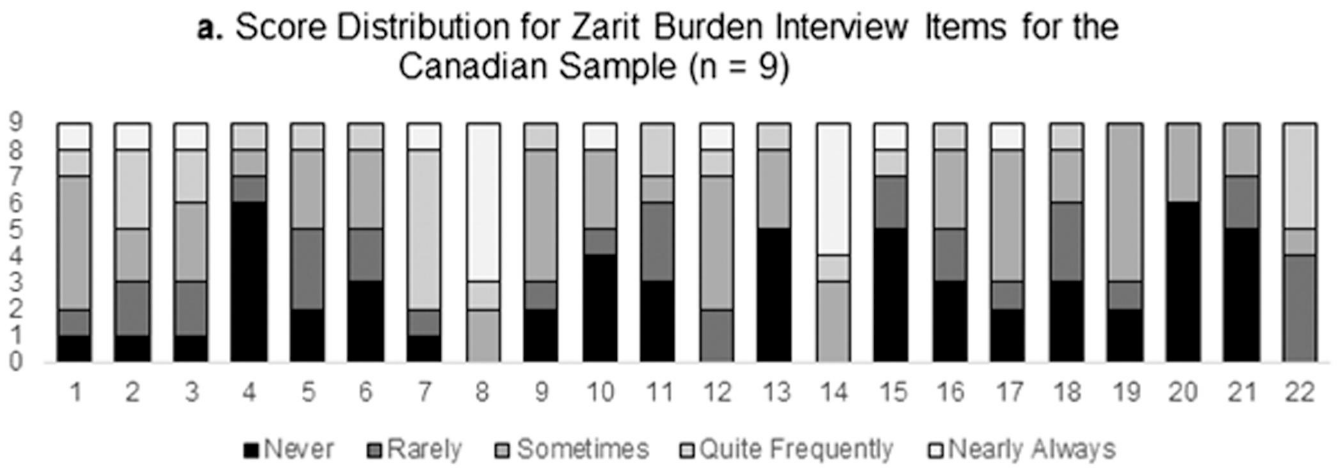
Table 4. Zarit Burden Interview Items with Issues Identified by at Least 1/3 of Sample by Country.

	Canada		Portugal	
Item	Issue (frequency)	Quotations (ID #: GOLD stage of COPD care recipient)	Issue (frequency)	Quotations (ID #: GOLD stage of COPD care recipient)
2. "Do you feel that, because of the time you spend with your relative, you don't have enough time for yourself?"			Not relevant (9/13)	"No, I don't feel like I don't have enough time for myself because he actually doesn't need it yet, he doesn't need me much. He can still do [things]." (#1: moderate) "Never, I always have time for myself." (#3: moderate) "I don't dedicate almost any time to her … " (#12: moderate)
3. "Do you feel stressed about caring for your relative and trying to fulfill other responsibilities for your family or work?"			Not relevant (7/13)	"Not for now. Sometimes I'm stressed but for other reasons." (#1: moderate) "I don't think it's right because I don't take care of her." (#12: moderate)
4. 'Do you feel embarrassed about your relative's behaviour?"	Not understood (6/9)	"Which behaviour? General, specific!" (#8: moderate) "And what do they mean by behaviour?" (#6: very severe)		
	Not relevant (7/9)	"I guess that implies more to people, like for Alzheimer's and things. She has COPD, she's sound of mind, she's the same person that we always had. She can't do the things she likes to do." (#2: severe) "He doesn't behave any better or worse than he ever did." (#6: very severe)	Not relevant (9/13)	"feeling embarrassed here has to do with cases of dementia or so." (#5: moderate) "I don't think it should be here (…) I don't think this question makes sense" (#10: very severe)
5. "Do you feel angry with your relative when you are around him or her?"	Not relevant (3/9)	"Um, no. I'm going to say not angry, sometimes very frustrated. How do you answer with that?" (#5: severe)	Not relevant (6/13)	"The question does not fit well (…) It could be: 'do you feel tired when you are with your relative?'" (#12: moderate)
6. "Do you feel your relative currently affects your relationship with other family members or friends in a negative way?"	Not relevant (3/9)	"They're all supportive. I don't know why anyone would be negative." (#4: severe)	Not relevant (10/13)	"I would never get upset with my husband because of friends or because of other family members." (#11: severe) "No, because everything is based on the principle of respect. Mutual respect. Because I cannot impose my way of thinking on others. I have to accept others as they are." (#13: moderate)
8. "Do you feel that your relative is dependent on you?"			Not relevant (6/13)	"My wife is not dependent on me." (#12: moderate) "She is not dependent on me. She has her autonomy and independence." (#13: moderate)
9. "Do you feel stressed when you are around your relative?"			Not relevant (8/13)	"I may feel more nervous when he is more distressed, I get more anxious." (#10: very severe)
10. "Do you feel that your health has suffered because of your involvement with your relative?"			Not relevant (11/13)	"The problems that I had were not because of him, it was some health issues that appeared." (#6: very severe) "No, it's the opposite, he cares a lot about me." (#7: severe) "I don't feel that my health has been affected by my relationship (…) the question should be asking: "Has your health been damaged or have you had some benefit … ?" because we often focus only on the negative aspect and after all we also have positive aspects." (#13: moderate)

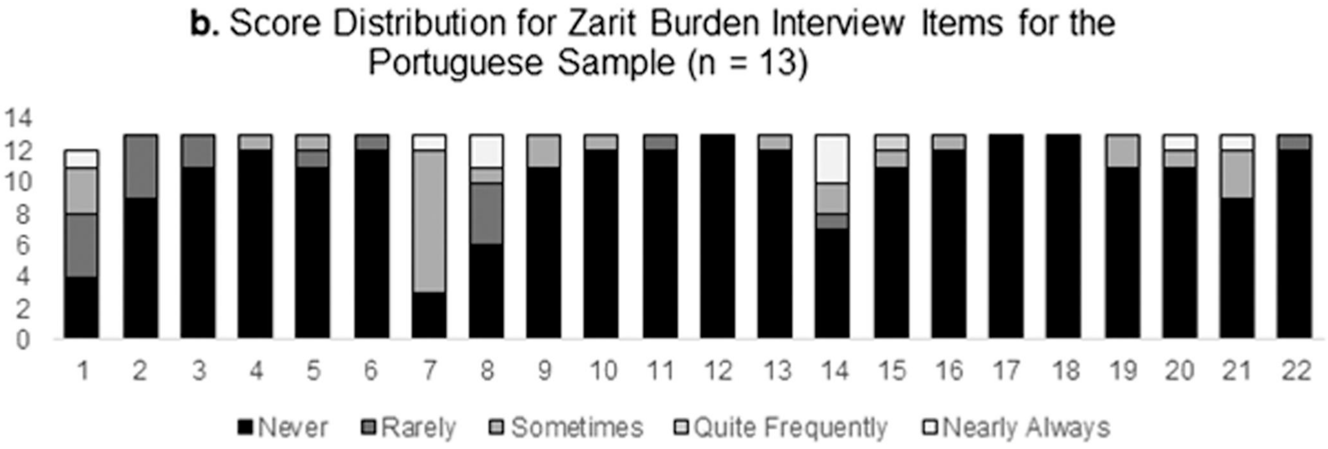
(*continued*)

Table 4. Continued.

Item	Canada		Portugal	
	Issue (frequency)	Quotations (ID #: GOLD stage of COPD care recipient)	Issue (frequency)	Quotations (ID #: GOLD stage of COPD care recipient)
11. "Do you feel that, because of your relative, you don't have as much privacy as you would like?"	Not understood (7/9)	"Privacy would mean what?" (#1: very severe) "Mental space, physical privacy. I don't really know. That could be broken down too … Like it could be all kinds of things. Privacy's a big word." (#7: severe)		
	Not relevant (6/9)	"It's not relevant to me. Like I said, I do my own things, and he does his own things. And we're fine." (#4: severe) "I don't need more privacy. Not from my husband." (#9: very severe)	Not relevant (7/13)	"No, because whatever I have to do, I do it anyway." (#2: severe)
12. "Do you feel that your social life has suffered because you're caring for your relative?"			Not relevant (10/13)	"It doesn't make any sense to me because I don't have to take care of her yet." (#12: moderate)
13. "Do you feel uncomfortable about having friends over because of your relative with COPD, your husband?"	Not relevant (4/9)	"I don't feel uncomfortable, it's just there's a limited time that we can do that." (#2: severe)	Not relevant (9/13)	"I don't feel uncomfortable because friends who go there, they are friends of both." (#2: severe)
14. "Do you feel that your relative expects you to take care of him or her, as if you were the only one that he or she could depend on?"			Not relevant (5/13)	"Right now the answer is no. Tomorrow circumstances may change, our way of being can change." (#13: moderate)
15. "Do you feel you don't have enough money to care for your relative, in addition to the rest of your expenses?"	Not relevant (4/9)	"Well, I mean I don't really have any special expenses for her right now. That may change, obviously, as time goes by." (#2: severe)	Not relevant (5/13)	"Not yet because of the disease. I don't know what to answer here." (#1: moderate) "Well, I have it [money] for now, but in the future I don't know. Right now, I have [money]." (#2: severe)
16. "Do you feel that you will be unable to take care of your relative for much longer?"			Not relevant (6/13)	"No, then, as long as I am healthy, I take care [of him]." (#3: moderate) "It does not apply - because here there may be 'it does not apply', but as there is never … but it is never one thing, it does not apply it is another, right?" (#5: moderate) "I am not taking care of her, that question is not yet relevant." (#13: moderate)
17. "Do you feel you have lost control of your life since your relative's illness began?"	Not relevant (3/9)	"Well, it oscillates every now and then. But I never had control over life, so how can I lose it!" (#8: moderate)	Not relevant (8/13)	"No, I have never lost control of my life because of my wife, nor did she because of me." (#12: moderate)
18. "Do you wish that you could just leave the care of your relative to someone else?"			Not relevant (5/13)	"This is something important to me because I am against putting people in a care home … " (#12: moderate)
19. "Do you feel uncertain about what to do about your relative?"	Not understood (4/9)	"Uncertain, what does that indicate?" (#1: very severe) "I mean what do you mean – physically what to do with them, put them in a home? Or mentally? What do you mean?" (#7: severe)	Not understood (5/13)	"What to do about what? (…) It seems that it has to do with whether I take him to a care home or not, but there are other questions before [that may be related], if he embarrassed me with his presence with friends, what I would do, or other questions about money for example … (…) if so, I have no indecisions at all." (#5: moderate)
	Not relevant (3/9)	"For now we're managing." (#9: very severe)	Not relevant (6/13)	"For now, I don't feel the need for anything, so far I haven't had any problems." (#10: very severe)
20. "Do you feel like you should be doing more for your relative?"			Not relevant (10/13)	"No, because I can't do more than what I do." (#3: moderate)
21. "Do you feel that you could provide higher quality care for your relative?"			Not relevant (8/13)	"I think that the amount of help I give is enough, I can't do better or worse." (#12: moderate) "I think I'm not doing anything more or less [than I should]." (#7: severe)
22. "Overall, how burdened do you feel about caring for your relative?"			Not relevant (7/13)	"Maybe it fits well, but I say no, that I don't feel this overload." (#12: moderate)



a. Score Distribution for Zarit Burden Interview Items for the Canadian Sample (n = 9)



b. Score Distribution for Zarit Burden Interview Items for the Portuguese Sample (n = 13)

Figure 2. (a) The *Y*-axis represents the number of responses and the *X*-axis represents the item number. The response choices for item 22 were different from the other items: 1= not at all, 2= a little, 3= moderately, 4= quite a bit, 5= extremely. (b) The *Y*-axis represents the number of responses and the *X*-axis represents the item number. The response choices for item 22 were different from the other items: 1= not at all, 2= a little, 3= moderately, 4= quite a bit, 5= extremely.

to the Canadian than to the Portuguese participants. Several factors may contribute to the differences between the Canadian and Portuguese samples, including education levels and translation of the ZBI to Portuguese. Given that participants found several items of the ZBI irrelevant to their experience as caregivers, and the floor effects observed for participants responses to ZBI items, we question whether the ZBI provides a valid assessment of caregiver burden among COPD caregivers in Canada or in Portugal. We suggest that some items require clarification and further testing of such changes, to improve the measure's value to the COPD caregiver population.

While most ZBI items were well understood, some were not, suggesting that the wording of certain items should be improved before further use in COPD caregivers. In the Canadian and Portuguese versions of the ZBI, clarity of items 4 ("feel embarrassed about your relative's behaviour") and 19 ("feel uncertain about what to do about your relative") is needed. For item 4, we suggest considering a wording change to clarify what is meant by "behaviour." Examples, such as reduced social participation or angry outbursts, could be considered for inclusion in this question. For item 19, participants sought clarity about the meaning of this item and the type of care that was implied. As such, we suggest considering a wording change, such as "feel uncertain about how to physically care for your relative." In the Portuguese version of the ZBI, the translation of several items should be reconsidered, as many participants were unsure of the meaning of some expressions (e.g., what to be angry about, feeling stressed). Additionally, the verbatim translation of items 20 and 21 are "doing more" and "doing better," were interpreted by Portuguese participants as having a similar meaning. Given that understanding precedes a determination of relevance, the wording of the ZBI items should be carefully considered. Overall, there is a dearth of studies assessing the content validity of instruments to assess informal caregiving in COPD. A previous systematic review found that only 1 [19] of 50 studies reported on the content validity of one single instrument, which was the Caregiver Reaction Assessment [36]. The findings of this study highlight the need to assess the content validity of caregiver burden tools designed for populations other than COPD, and to test them in the country where they will be applied to ensure their suitability and relevance.

Participants expressed that some items were not relevant to them, especially those related to temperament and personality (e.g., feel embarrassed about relative's behavior, being uncomfortable having friends over because of relative), which may be more relevant to informal caregivers of patients with Alzheimer's disease for whom the scale was originally developed [20]. People with Alzheimer's disease present behavioral and psychological symptoms of dementia (BPSD) such as psychoses, agitation, aggressiveness [44], which are not a characteristic of COPD. Rephrasing questions related to manifestations of behavior and personality should be considered in a version for COPD caregivers, as described previously.

Participants acknowledged that although some items were not personally relevant to them, they could be to someone else or to them at another point in time. For example, financial items were not relevant if they presently had adequate resources to accommodate costs associated with COPD management, whereas for others it was a concern [45]. The items pertaining to finances and caregiver health were perceived to become more relevant as the severity of the patient's disease increased, a finding previously reported among caregivers of those with traumatic brain injury [46], liver disease [47], and Alzheimer disease [48]. In this study, the frequency of item relevance did not increase across COPD GOLD stages.

Interestingly, some participants expressed that they did not "take care" of the recipient with COPD, although they agreed that they were the primary person providing physical and/or emotional support to the individual with COPD and were not paid for such support. It may be that participants do not associate the acts of support they provide with the word "care." Perhaps another term, such as "support" might be more appropriate than "care." Further consideration and exploration of this2

terminology may be important to increase the implacability of the ZBI to COPD caregivers.

Education, cultural background, and language translation could have contributed to the differences in understanding between the two samples examined. The linguistic validation of the Canadian and Portuguese samples was conducted [20,40,41]. Without access to the process of the translation and linguistic validation we cannot comment on the matter. Cultural differences in the caregiving experience have been observed in caregivers of people with dementia [49,50]; but were not evaluated in the COPD caregiver population. It is also possible that domains of care might be prioritized differently and that not all were addressed.

Limitations

The size and characteristics of the sample limit the strength of conclusions and generalizability of the results. Most participants were female and a spouse of the individual with COPD. However, given that women and spouses are common caregivers [46–48] at present, our sample was representative. The interviews in Canada and Portugal were conducted by different researchers. We minimized this limitation by utilizing the same semi-structured interview guide at both centres and having systematic and transparent procedures for processing data to establish trustworthiness of data and obtain valid and reliable inferences. Difficulties with item interpretation and translation of the ZBI, along with the small sample size could contribute to the unclear association between COPD disease severity and caregiver experience in the present study. Additionally, the amount of exacerbations and symptoms experienced by individuals with COPDs could contribute to the association between disease severity and caregiver experience, which was not collected in the present study. Longitudinal studies assessing caregiver experience and disease progression are needed to understand this relationship more fully.

Conclusion

This study investigated the suitability of the ZBI to assess caregiver experience among caregivers of individuals with COPD and found that, in its current form, the ZBI may not be a valid assessment tool of caregiver experience in this population. We suggest that some items require clarification and further testing of such changes to improve the value of this measure to the COPD caregiver population.

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