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Care recipient self-perceived burden: Perspectives of individuals with chronic health conditions or personal experiences with caregiving on caregiver burden in the US

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ABSTRACT

Introduction: Self-perceived burden refers to the perceived impact of a care recipients' illness and care needs on their caregiver(s). This study aimed to: 1) examine the components of caregiver burden from a perspective of people with chronic health conditions, 2) explore the extent to which people consider caregiver burden important in their healthcare decision-making, and 3) develop a global item to capture the essential elements of self-perceived burden.

Methods: Semi-structured interviews using cognitive debriefing were conducted with US-based individuals with chronic conditions, informal caregivers and social care users between October and December 2018. Components of caregiver burden were organized within a concept analysis framework. The preferred wording for a global self-perceived burden item was explored for face and content validity using five candidate items. Interviews were transcribed verbatim and analyzed using thematic analysis.

Results: Total of 19 participants, aged 23–76, completed the interviews. Study identified three main antecedents of caregiver burden: caregiving situation, financial resources, and sociocultural environment. Attributes included physical, emotional, financial, and social aspects. Consequences were financial hardship and decreased health-related quality of life. Most participants distinguished "burden" from related concepts such as "bother" and "stress". "I feel like a burden to my family/friends" with a severity response option scale, was perceived to broadly encompass the construct.

Conclusion: Self-perceived burden was identified as a highly relevant concept in healthcare decision-making for US participants. A global self-perceived burden item can provide a valuable summary measure to inform medical decision-making and potentially capture spillover effects of patient care on family and caregivers.

1. Background

People who are cared for by their loved ones often experience feelings of being a burden to their families, referred to as "self-perceived burden" (SPB) (Oeki & Takase, 2020). SPB is a construct that stems from the burden care recipients feel they have imposed on others due to their health limitations – physically, socially, emotionally, and financially (Chiò, Gauthier, Calvo, Ghiglione, & Mutani, 2005; McPherson, Wilson, Chyurlia, & Leclerc, 2010; Natalie Cousineau et al., 2003; Oeki et al., 2012; Simmons, 2007) and is shaped by cultural and sociopolitical structures (Bigger & Vo, 2022). SPB is commonly reported in advanced diseases, among patients receiving palliative care for cancer (Tang et al., 2017; Wilson, Curran, & McPherson, 2005), stroke survivors (McPherson, Wilson, Chyurlia, & Leclerc, 2010; Ren et al., 2016), and chronic pain patients (Kowal, Wilson, McWilliams, Péloquin, & Duong, 2012). SPB can negatively impact patients' sense of dignity and well-being, as

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well as that of their caregivers (Chochinov et al., 2007; Rodríguez-Prat et al., 2019; Xiaodan et al., 2022), and may impact decision-making about treatments and end of life care (Ganzini et al., 2008; Gudat et al., 2019; Kelley et al., 2015; Lee et al., 2015; Rodríguez-Prat et al., 2019; Sullivan, Hedberg, & Hopkins, 2001; Tang et al., 2017; Wilson et al., 2007).

Informal caregivers are an essential part of the healthcare system, with over one in five Americans reportedly providing care to an adult or child with special needs at some time in the past 12 months (Brenda C. Spillman; Control & Prevention, 2020). They play a significant role, accounting for 75–80% of the total care hours given to older Americans (Spillman, 2009). However, these caregivers face additional challenges navigating the complexities of the healthcare system, compounded by financial barriers that affect many patients. In the United States (US), financial barriers to healthcare are widespread across all age demographics and significantly impact access to services and the affordability of essential care, such as medications and healthcare services, irrespective of insurance status (Jacobson et al., 2021; Montero, Kearney, Hamel, & Brodie, 2022). While Medicare provides some relief to older adults, healthcare barriers remain, particularly in comparison with other high-income countries (Osborn, Doty, Moulds, Sarnak, & Shah, 2017). These healthcare barriers can affect the use of health services and increase the burden placed on informal caregivers.

SPB and caregiver burden are defining features of care relationships that have been insufficiently studied together. Additionally, SPB may be an underrecognized factor impacting the families of caregivers and offers an additional source of information in relationship to caregiver health and well-being. In a scoping review of the literature, one patient-reported outcome measure (PROM) was identified as a measure of SPB that was developed in Canada: the 10-item Self-perceived Burden Scale (N. Cousineau et al., 2003). Despite limited use, this scale has some evidence of psychometric properties (Natalie Cousineau et al., 2003; Oeki et al., 2012; Simmons, 2007). However, routine clinical management often prioritizes lower patient respondent burden (Aiyegbusi et al., 2022), including brief single-item assessments that allow individuals to provide an overall rating (Verster et al., 2021). Since cultural perceptions of SPB vary worldwide (Oeki et al., 2012), it is important to examine the concept of SPB from the perspective of US individuals with chronic health conditions and/or personal experiences with caregiving. To date, no qualitative studies have explored SPB in the US (Saji et al., 2022). The aims of this study were to 1) characterize elements that constitute caregiver burden from the perspective of individuals with chronic health conditions and/or personal experiences with caregiving, 2) examine the extent to which individuals with chronic health conditions and/or personal experiences with caregiving consider burden to their family relevant in their management and healthcare decision-making, and 3) develop a global item that captures the essential elements of SPB. A clearer understanding of SPB as a concept, as well as a global SPB item, could be instrumental in providing better support services for care recipients and their families in the US.

2. Methods

2.1. Study population and recruitment

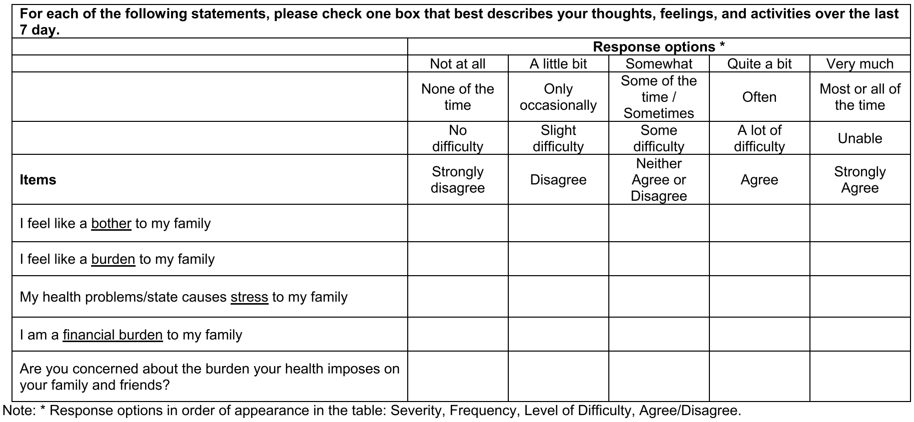
To ensure a diverse range of participants with lived experiences of managing health conditions, the study employed purposive recruitment, targeting individuals across a spectrum of demographics (age, gender, race and ethnicity), social backgrounds, and health conditions, including both acute and chronic physical or mental health conditions. We specifically sought individuals aged 18+ with personal experience navigating the challenges and burdens associated with managing their own health or that of loved ones as informal caregivers. Individuals unable to provide informed consent, or with limited English proficiency were not included in the study. Recruitment was done in two ways. First, informative flyers were strategically placed in clinics at the University of Illinois Hospital & Health Sciences. Through this method, we recruited 11 individuals. To further broaden our search, we utilized Research Match, a national health volunteer registry supported by the U.S. National Institutes of Health (Harris et al., 2012). We employed targeted search filters on the platform to identify individuals with chronic health conditions and personal experiences of caregiving in the Chicagoland area, which then informed participants via e-mail about a potential study they might be eligible. This resulted in the recruitment of 8 individuals. All participants were briefed on the purpose of the study and provided informed consent. Two female research assistants and co-authors (A.L.M, M.K.) with formal training in qualitative research conducted the in-person interviews between October and December 2018 at the University of Illinois Chicago, College of Pharmacy. The interviews were audio-recorded, and each participant was compensated 60$ for their time and travel cost. Study data were collected as a subcomponent of a large international project which aimed to develop a new measure the EQ Health and Wellbeing for evaluating interventions in health, public health, and social care including the impact on patients, social care users, and caregivers (Brazier et al., 2022; Carlton et al., 2022; Peasgood et al., 2022). The University of Illinois Chicago institutional review board approved the study (#20180817). All participants signed informed consent.

2.2. Candidate items

We performed a scoping literature review (Munn et al., 2018; Peters et al., 2015) to identify existing measures of SPB and to understand how the concept was operationalized. The primary measure identified was the Self-perceived Burden Scale (SPB-Scale) (Cousineau et al., 2003; Oeki et al., 2012). In addition, the literature review revealed that concepts such as “bother” (Cahill et al., 2009) and “stress” (Cahill et al., 2009; Liu et al., 2020) were identified as burden-related (Walker & Avant, 2005). We aimed to explore these related concepts to identify the most appropriately phrased item for US respondents. For response options, we included frequency and severity (Peasgood et al., 2021). We also included level of agreement and agree/disagree options, as some respondents may find these simpler options. A 5-point ordered response scale with a default position was adopted, based on existing, commonly used measures (Cella et al., 2010; Herdman et al., 2011) and a default recall period of 7 days (Bradburn et al., 2004). A total of 5 candidate items were drafted (Fig. 1).

2.3. Interviews

Interviews were based on a semi-structured interview guide (Table S1) using cognitive debriefing (Willis, 1999). Before launching, the interview script was pre-tested with 2 graduate students and pilot-tested with the first 2 participants. The interview started with general questions on the impact of the participants’ health problems on their family and friends, and their healthcare decision-making in relation to the financial impact of their health situation on their family. The questions were open-ended and supplemented with probes (Beatty & Willis, 2007), to allow the participants to answer in their own words and uncover different perspectives. In the second part of the interview, we explored the face and content validity of the candidate SPB items to determine the preferred wording and which item most accurately measured the concept of interest (Fitzpatrick et al., 1998; Patrick et al., 2011). Participants were probed on the written draft items based on four areas of the cognitive response model developed by Tourangeau (Willis, 1999): 1) Comprehension (*i.e.*, understanding of the concept); 2) Retrieval (*i.e.*, ability of the respondent to recall the information from memory given the recall period (Johnson, 2014)); 3) Judgment (*i.e.*, how the information is combined, supplemented, and extrapolated from the information retrieved); and 4) Response (*i.e.*, how the respondent mapped their desired response onto the preferred response scale (Johnson, 2014)). At the end of the interview, participants were asked to



For each of the following statements, please check one box that best describes your thoughts, feelings, and activities over the last 7 day.					
	Response options *				
	Not at all	A little bit	Somewhat	Quite a bit	Very much
	None of the time	Only occasionally	Some of the time / Sometimes	Often	Most or all of the time
	No difficulty	Slight difficulty	Some difficulty	A lot of difficulty	Unable
Items	Strongly disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
I feel like a bother to my family					
I feel like a burden to my family					
My health problems/state causes stress to my family					
I am a financial burden to my family					
Are you concerned about the burden your health imposes on your family and friends?					

Note: * Response options in order of appearance in the table: Severity, Frequency, Level of Difficulty, Agree/Disagree.

Fig. 1. Care Recipient self-perceived burden candidate items and response option sets. Note: * Response options in order of appearance in the table: Severity, Frequency, Level of Difficulty, Agree/Disagree.

indicate a preference for one item and a response option scale. One researcher (A.L.M) led the discussion while the other (M.K.) took notes and provided additional probes. All interviews were audio recorded.

2.4. Analysis

Interviews were transcribed verbatim by two study team members (M.K., C.E.R.), who subsequently conducted the coding analysis using NVivo, Version 12 (QSR International) (NVivo, 2000). Thematic analysis was performed on the transcripts using the Framework Method (Gale et al., 2013; Ritchie et al., 2013), which enables a combination of deductive (from *a priori* themes found in the literature) and inductive (eliciting new themes from participants) qualitative analysis (Goldsmith, 2021). Coders independently reviewed 5 randomly selected transcripts before meeting to develop an initial set of codes. For exploring participant's perspectives on caregiver burden, the concept analysis framework (Rodgers, 2000; Walker & Avant, 2005) was used to organize findings into antecedents (events preceding caregiver burden from patient's perspective), attributes (underlying meanings of caregiver burden), and consequences (events resulting from caregiver burden). For exploring SPB candidate items, the codes were aligned with Tourangeau's response model. The coders independently coded the next 5 transcripts and discussed any further refinements needed. The remaining interviews were coded, and any discrepancies were resolved through consensus discussion. The sample size was determined by reaching theoretical saturation when no new information was obtained from the interviews (Miller et al., 2014). This was determined when additional interviews consistently yielded no new themes or insights relevant to our research questions. The research team conducted regular reviews after every three interviews, ensuring a systematic approach to achieve saturation. The study followed established practices for Consolidated Criteria for Reporting Qualitative Research (COREQ) in collecting and analyzing data (Tong et al., 2007) (Table S2) and best practices for developing and validating scales for health, social, and behavioral research in developing a global SPB item (Boateng et al., 2018).

3. Results

3.1. Study sample

A total of 19 participants with chronic health conditions and/or personal experiences with caregiving gave their consent and participated in the interviews, which lasted an average of 20 min. One participant declined to participate in the study during recruitment when informed that the interview would be audio-recorded. The ages of the participants ranged from 23 to 76 years with a mean (SD) of 53.8 (13.8). The sample comprised 47.4% male participants. As detailed in Table 1, the participants' racial/ethnic composition was: 52.6% identified as White/Caucasian, 47.4% as Black/African American, and 10.5% as Hispanic. A majority of the participants (73.8%) reported having at least one chronic condition, including severe respiratory diseases, arthritis, or cancer. Additionally, 15.5% of the participants identified themselves as informal caregivers.

3.2. Interview results: caregiver burden from the perspective of individuals with chronic health conditions and/or personal experiences with caregiving

Several themes contributing to caregiver burden from the perspective of individuals with chronic health conditions and/or personal experience with caregiving were identified within the concept analysis framework, as shown in Fig. 2. These themes are further illustrated with exemplary quotes in Tables 2–4 highlighting the real-world impact of these factors on the patient's lives.

3.2.1. Antecedents of caregiver burden

From the participant's perspective, several key antecedents contribute to the experience of caregiver burden. These antecedents can be categorized into three main areas: caregiving situation, sociocultural environment, and accumulation of roles (Table 2).

The participants recognized that caregiving situation itself presents challenges. They were aware of how their own health and lifestyle choices, such as diet or managing chronic conditions, could financially and emotionally impose additional demands on their families and contribute to caregiver burden. For instance, one participant stated:

> "*It's indicative of a culture in the US that young people who do not take care of themselves end up relying heavily on family for basic needs like groceries or medical appointments*" (Participant 17, Male, 62 years).

Participants discussed how health status of care recipients, encompassing disease severity and disability, significantly influences the need for caregiving. For example, participants spoke about the physical demands of assisting with daily activities and the emotional toll of witnessing a loved one's struggles. An example comes from a participant who shared:

> "*After my chemotherapy, I was left unable to manage even basic tasks, necessitating considerable support from my family*" (Participant 12, Female, 58 years).

The sociocultural environment surrounding caregiving was also a focal point of how people may perceive their role and impact within the caregiver-care recipient dynamic. The availability of family members to share caregiving responsibilities was identified as an important factor, with lack of support significantly increasing the burden on primary

Table 1
Participant’s demographic and clinical characteristics.

Characteristic	N = 19	%
Age		
Age, mean/SD	53.8 (13.8)	
18-39	4	21.1%
40-59	8	42.1%
60+	7	36.8%
Age range	23–76	
Gender		
Male	9	47.4%
Female	10	52.6%
Race		
White/Caucasian	10	52.6%
Black/African American	9	47.4%
Ethnicity		
Hispanic	2	10.5%
Non-Hispanic	17	89.5%
Insurance status		
Medicare	5	26.3%
Medicaid	3	15.8%
Private insurance	8	42.1%
No health insurance	1	5.3%
Medicare and Medicaid	2	10.5%
Education		
No high school	1	5.3%
High school	4	21.1%
Bachelor’s Degree	8	42.1%
Graduate Degree	6	31.6%
Conditions		
Asthma, emphysema, or chronic bronchitis	7	36.8%
Arthritis or rheumatism	6	31.6%
Cancer diagnosed in last 3 years	3	15.8%
Diabetes	2	10.5%
Digestive problems (such as ulcer, colitis, or gallbladder disease)		0.0%
Heart trouble (such as angina, congestive heart failure, or coronary artery disease)	2	10.5%
Do you have any long-standing physical or mental impairment, illness, or disability?	14	73.7%
How difficult is it for you to meet the monthly payments on your bills?		
Not difficult at all	12	63.2%
Slightly difficult	3	15.8%
Somewhat difficult	3	15.8%
Very difficult	1	5.23%
Extremely difficult	0	0.0%
Is there anyone, either living with you or not living with you, who is sick, disabled or elderly whom you look after or give special help to?	3	15.8%
Quality of Life		
Overall, how satisfied are you with your life nowadays? Mean (SD) Range (1–10)	8	1.29
EQ-5D-5L[a]	0.84	0.20
EQ VAS	77.3	14.78

[a] US value set, based on Pickard et al. (Pickard et al., 2019).

caregivers. The stress and conflict arising from these situations are internalized by individuals, who then may perceive themselves as a cause or added burden to their caregivers. Building a network of social support outside the family was seen as vital in reducing caregiver burden and mitigating emotional strain. Participants expressed differing cultural perspectives on caregiving, highlighting individual and family expectations that could influence the perceived burden. The dynamics between care recipient and caregiver emerged as a factor, with close relationships potentially experiencing additional emotional burden compared to distant ones. Additionally, the struggle of balancing multiple roles, such as managing childcare while caring for aging parents, was identified as a significant source of stress and conflict. A participant highlighted:

> *“We assume that everyone is self-sufficient and people who are not, they need a great deal of help. When someone is sick, that only amplifies. My sister, who worked, had to reschedule her classes to be with me for surgery and stay with me. And she took a leave of absence. Not a lot of people can do that. But I am aware many people in my cancer support group have no support, no family here, and they have to go to work”* (Participant 12, Female, 58 years).

3.2.2. *Attributes*

Antecedents contribute to different attributes of caregiver burden, as identified by participants (Table 3). Financial burden was a major concern, encompassing direct and indirect costs associated with care. Participants listed medical bills, medication costs, transportation expenses, and lost income due to caregiving as major financial hardship. These objective financial burdens are subjectively appraised by individuals and may lead to financial distress, with worries about their current and future financial situation and the unpredictability of the disease’s trajectory. This was captured by a participant who noted:

> *“My health condition impacts my family because I am constantly begging them for money”* (Participant 3, Male, 67 years).

Emotional burden was described as emotional stress, worry, and grief associated with loved ones’ illnesses. Caregiving was seen as potentially straining family dynamics, leading to conflict and resentment, especially when responsibilities and finances were not shared equitably. Providing physical assistance with daily activities and managing the recipient’s needs was described as a physically demanding aspect of caregiving, while social burden stems from isolation, changes in relationships, and potential conflict within the family due to caregiving responsibilities.

> *“With a family member, there are emotional, the finances, the planning, where they are going to live if they need to be taken care of. There are lots of variables that make it complicated. A financial component can lead to more emotional. It’s a cycle.”* (Participant 13, Female, 33 years).

3.2.3. *Consequences*

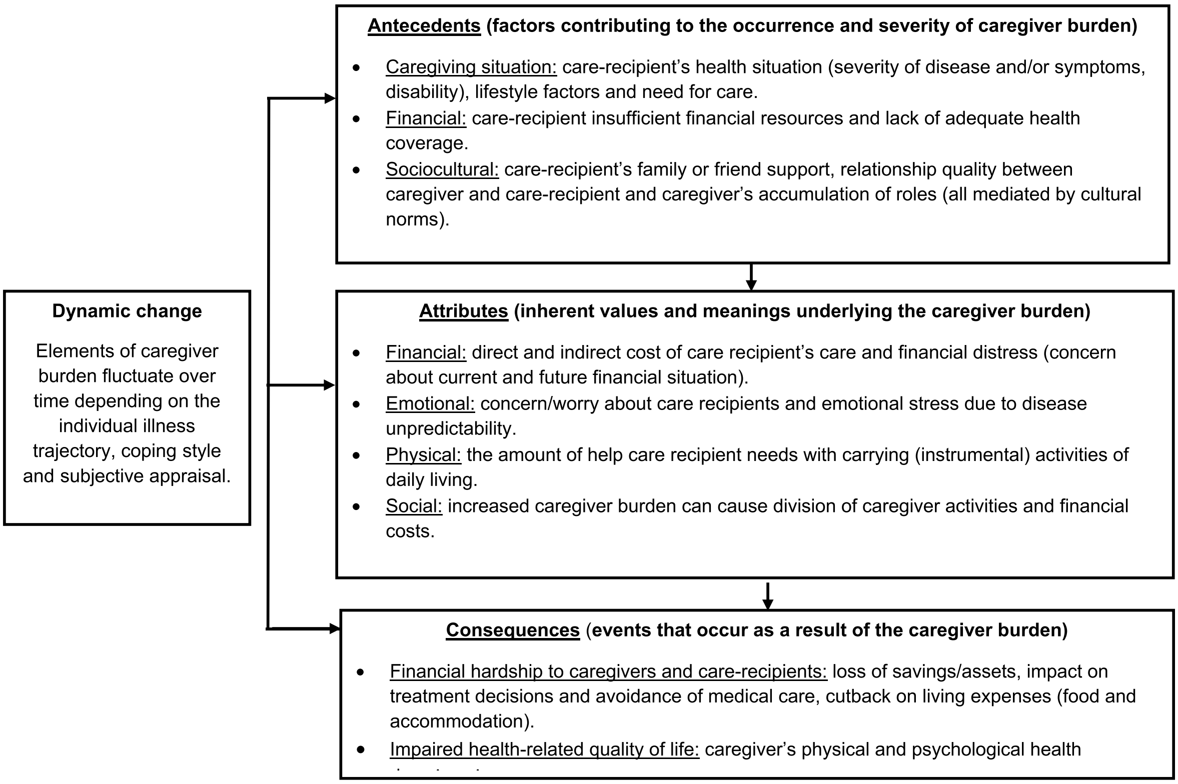
The consequences of caregiver burden had impacts on both the care recipient and the caregiver (Table 4). Financial hardship was frequently mentioned by participants, affecting not only their treatment decisions but also their broader financial stability. Participants provided insights into difficult choices faced due to financial constraints, such as deciding between purchasing food or medication — a decision that not only affects patients personally but also places a tangible strain on family resources. Our study participants went beyond sharing their personal experiences; they frequently offered observations from their surrounding communities. Their broader perspective, often woven into their personal narratives, highlighted patterns they witnessed in others facing similar challenges. Such insights enriched our understanding of how widespread these challenges are within the community. As one participant noted:

> *“Some older people have to think about whether they are going to eat over medicine or go to the doctor. And that is a hard choice because they have to eat, and they have to go to the doctor. But if they do not have money or insurance, what are they going to do?”* (Participant 6, Female, 56 years).

Lastly, the decreased health-related quality of life for caregivers was a consequential theme, emphasizing the physical and emotional toll on those providing care. As one participant reflected:

> *“Caring for my sick family member has meant my own health needs often come second”*’ (Participant 19, Female, 44 years).

Such statements were echoed by others, highlighting the challenging balance caregivers face between their own well-being and their



Antecedents (factors contributing to the occurrence and severity of caregiver burden)

- Caregiving situation: care-recipient's health situation (severity of disease and/or symptoms, disability), lifestyle factors and need for care.
- Financial: care-recipient insufficient financial resources and lack of adequate health coverage.
- Sociocultural: care-recipient's family or friend support, relationship quality between caregiver and care-recipient and caregiver's accumulation of roles (all mediated by cultural norms).

Dynamic change

Elements of caregiver burden fluctuate over time depending on the individual illness trajectory, coping style and subjective appraisal.

Attributes (inherent values and meanings underlying the caregiver burden)

- Financial: direct and indirect cost of care recipient's care and financial distress (concern about current and future financial situation).
- Emotional: concern/worry about care recipients and emotional stress due to disease unpredictability.
- Physical: the amount of help care recipient needs with carrying (instrumental) activities of daily living.
- Social: increased caregiver burden can cause division of caregiver activities and financial costs.

Consequences (events that occur as a result of the caregiver burden)

- Financial hardship to caregivers and care-recipients: loss of savings/assets, impact on treatment decisions and avoidance of medical care, cutback on living expenses (food and accommodation).
- Impaired health-related quality of life: caregiver's physical and psychological health

Fig. 2. Conceptual components of caregiver burden from the perspective of of individuals with chronic health conditions or personal experiences with caregiving.

caregiving responsibilities.

> "*That is one thing I think about, how do you take care of yourself when you have to take care of someone else"* (Participant 9, Female 64 years).

Furthermore, participants frequently observed a dynamic relationship between the caregiver burden and care recipient's SPB. This dynamic evolves with the progression of chronic condition, highlighting the ever-changing nature of caregiving. A participant noted:

> *"As my mother's condition worsened, the emotional and physical demands on me increased significantly. It's a constantly shifting situation that we, as a family, have to adapt to"* (Participant 8, Male, 48 years).

3.3. Care recipient self-perceived burden candidate items: importance and face/content validity findings

All participants placed high relevance and importance on measuring SPB, viewing it as a crucial aspect of understanding their experiences and impact on families. This highlighted the multifaceted nature of SPB and its relevance in understanding not just individual experiences but also family dynamics. A participant summarized this:

> "*It gives the sense of how they see their illness, relation to their family and what their home situation is like."* (Participant 6, Female, 56 years).

While our initial candidate items were informed by existing measures and a scoping literature review, the face and content validity testing through interviews provided invaluable insights into how participants understood and experienced SPB (Table 5 and 6). Among the tested candidate items, "*I feel like a burden to my family/friends*" with a severity response scale (ranging from "Not at all" to "Very much") effectively encompassed the construct of interest. Participants acknowledged that "burden", as a concept, implied financial, social, physical, and emotional domains, without the need for further clarification of the concept. However, they also expressed the potential value of including specific examples to prompt wider consideration of various burden types and individual experiences. This feedback led to the inclusion of attributes in parenthesis.

Although the literature identified "bother" and "stress" as SPB-related, participants clearly differentiated them. The majority of participants did not perceive "bother" — often associated with annoyance or inconvenience — as directly related to health issues. As one participant pointed out, "*burden has a financial aspect, while bother does not.*" (Participant 2, Female, 67 years) Similarly, "stress" was primarily understood in an emotional context, and too vague to capture the broader scope of SPB. This quote summarizes the distinction:

> "*If I had three concepts: bother, stress, and burden. Bother, is kind of annoyance, stress is a little bit ongoing, they are more worried about it, it is more emotional and the burden is the thing nobody wants to be*." (Participant 18, Female, 63 years).

Interestingly, several participants like this one connected SPB to caregiver burden: *"Why would you think you are a burden to a family unless you are getting that feeling from someone" (Participant 9, Female, 64 years).* This highlighted the potential interdependence of these burdens, further underscoring the complexity of the construct.

4. Discussion

Using a qualitative approach, this study generated evidence for a greater understanding of caregiver burden from the perspective of individuals with chronic health conditions and/or personal experiences with caregiving in the US, leading to the creation of a global SPB-item. Participants often referred to their own experiences and the experiences of those close to them to illustrate the magnitude of the issue. In addition, all participants viewed the "burden of their health on friends and families" as critical to their own sense of well-being and an important consideration in healthcare decision-making.

Based on methods that drew upon current good practices for measure development (Boateng et al., 2018), this study identified the most preferred wording for the SPB-Global item: *"I feel like a burden (physical,*

Table 2
Antecedents' of caregiver burden from the perspective of individuals with chronic health conditions or personal experiences with caregiving: themes and exemplary quotes.

Themes	Sample Quotes
Caregiving situation	
Care recipient's lifestyle factors - Diet - Obesity - Physical activity - Prevention of chronic disease - Medication adherence - Receipt of preventive care and services - Prevention of disease complications	"There are a lot of circumstances when individuals who do not take care of themselves, they have to rely on their family to take them to store, to doctor, and they can be young. I see young people who have a stroke, and obese, I see it so often. It's indicative of a culture in the US" (Participant 19, Male, 62 years). "I am very active in managing my health and I want to be active in my kids' life like everybody else. I want to be independent. I don't want to die of things I can prevent, like diabetes and hypertension. I own it. I am concerned about it; I try to do all I can and manage my health to not come down with the preventable disease. I do not want to be a burden to my friends and family" (Participant 19, Male, 62 years).
Care recipient's health situation - Severity of disease and/or symptoms - Disease progression and complications - Degree of disability (increase in dependency on (instrumental) activities of daily living) or frailty - Accumulation of multiple conditions - Need for emotional encouragement	"I needed a lot of care, I could not drive after chemotherapy, I needed help after chemo. When I was at home, I could not take care of cooking my food and any of that. I could not drive of my chemo. Some days I could not even get out of bed, I was nauseated and tired" (Participant 12, Female, 58 years). "My mom has an issue with the esophagus, and she has to go to the Mayo clinic, so my sister has to take a day off and take her to the doctor and then wait and then take her back. It affects the whole family. Both my sisters constantly have to take her to doctor's appointments. It affects both of my sister's families. It has a great impact" (Participant 7, Female, 38 years).
Financial Resources	
Care recipient's (insufficient) financial resources - Savings - Retirement - Other assets - Benefits (e.g., long-term disability) - Loss of job or income - Access to other economic resources (e.g., family)	"I had a long-term disability. I had not worked in a year and was paid like I worked. A lot of people in my cancer support group do not have that. I am incredibly fortunate to have been able to actually save money when I was sick. I do not know how we expect people to take care of themselves and get better. People work in jobs that are extremely stressful and if they do not, they don't have income, and that is a horrible situation" (Participant 12, Female, 58 years). "Many diseases need chronic care. You need to hire help or find some relative to do it if you cannot pay for it" (Participant 11, Male, 69 years).
Care recipient's healthcare coverage - Lack of health insurance - Accessibility of healthcare - Underinsured - Health insurance literacy	"What is driving me crazy is people are not able to keep up with the changes in healthcare policy so that sometimes they do not know they have access to things they think they do not have" (Participant 2, Female, 67 years). "I take the US healthcare system is horrible. I often think about moving to Canada for many reasons. Everybody has problems of some size, but it's worse here than anywhere, and that is known fact. It is commonly known. Insurance is very big, and even if you have, it might not be good. More often than not it is not good" (Participant 11, Male, 69).
Sociocultural Environment	
Family support - Presence of family members that can share caregiving responsibilities - Ability of family members to support care-recipients	"We assume that everyone is self-sufficient and people who are not, they need a great deal of help. When someone is sick, that only amplifies. My sister who worked, she had to reschedule her classes to be with me for surgery and stay with me. And she took a leave of absence. Not a lot of people can do that. But I am aware many people in my cancer support group have no support, no family here, and they have to go to work" (Participant 12, Female, 58 years). "I have two older sisters, of whom one is retired. She had nothing else to do and helped me out a lot. I do not know what people who do not have someone who is retired to take care of them. That is what my sister did for me" (Participant 12, Female, 58 years).
Social support - Social participation - Care recipient's emotional support outside family help to reduce their family/caregiver's strain	"I think it's important to develop social relationships to augment or replace the family relationship. It is going to take off the pressure of the family, but you have to build support network around it" (Participant 9, Female, 64 years).
Cultural norms - Caregiver's cultural perspectives in caregiving	"I think about what if I get older, is there family who will care for me. My cousin has her dad with Parkinson's, and she is their primary caregiver, and I think I could not do that for my dad. She like changes his diapers, and I could not do that" (Participant 19, Female, 44 years).
Relationship quality - Relationship between care-recipient and caregiver.	"Stress is there probably with a significant other more than necessarily a relative or a friend" (Participant 2, Female, 67 years).
Accumulation of roles - Caregiver's multiple responsibility conflict (e.g., being a parent to a child at the same time as being a caregiver to parents)	"When parents are middle-aged, they have elderly parents that they have to take care of, make decisions for and take responsibility. That can impact finances and emotions, it can cause problems between sibling who take care of the brunt of it; the people who are younger than me, in their 40ties or 50ties they are torn apart because they have no life of their own" (Participant 8, Male, 48 years). "Whether there is a person who is ill is older or young as a child, and there are other children involved can influence caregiver burden" (Participant 13, Female, 33 years).

emotional, social, and financial) to my family/friends." Specifically, "burden" was selected as the primary concept of interest, incorporating attributes identified through our analysis, including financial, emotional, physical, and social burdens, as denoted in parentheses in the item. Financial burden, as expressed by our participants, covers a broad spectrum of economic challenges, ranging from the immediate costs of care to the overarching financial stress. Emotional burden emerges from concerns about the care recipient's well-being and the emotional ramifications of disease management. Physical burden involves the tangible demands of assisting with daily activities, and social burden reflects the impact on social interactions and relationships. By incorporating these specific attributes within the SPB-Global item, we aim to prompt participants to reflect on various dimensions of burden, thereby enabling them to ascertain their feelings of being a burden to their family.

Generally, our findings extend those originated by Cousineau et al.

Table 3

Attributes of caregiver burden from the perspective of individuals with chronic health conditions or personal experiences with caregiving: themes and exemplary quotes.

Themes	Sample Quotes
Financial burden	
Direct and indirect costs of care recipient's care • Medical bills • Health insurance and out of pocket costs • Medication costs • Care-related expenses • Extended care costs • Transportation costs • Time (taking time off work) • Loss of savings and/or other assets	"I'm fortunate to have savings to fall back on during my illness, but many aren't so lucky, and the financial strain can be overwhelming" (Participant 12, Female, 58 years). "Even if you are in extended care on your own, then there is a frustration in trying to make sure that you are safe in your home, that you are taking your medications and that you have help in your home in whatever help you need, and that is a financial drain to your resources or your family. Even in extended care, that is expensive, and it's a drain on your estate and everyone else" (Participant 2, Female, 67 years). "Sometimes people do not have insurance, and families have to take on their financial debt. And that can be very hard on the family because everybody does not have money to pay. So that sometimes would take a toll on the family member because they are trying to find a way to help them" (Participant 5, Female, 23 years).
Financial distress • Worry about being able to afford healthcare costs • Unpredictability of future costs • Concerns about current and future loss of savings and/or income • Difficulty paying monthly bills	"So financially, you do not know how to plan for some of the things. Planning for the disease is stressful due to unpredictability (Participant 2, Female, 67 years). "With a family member, there is emotional, the finances, the planning, where they are going to live if they need to be taken care of. So there are lots of variables that make it complicated. A financial component can lead to more emotional. It's a cycle" (Participant 12, Female, 58 years).
Emotional burden • Concerns/worries about care recipient's disease trajectory • Emotional stress • Caregivers having to face certain diseases of their loved ones	"Some health conditions, depends on how severe the problem is can cause caregiving problems that are a big deal, that are emotional problems that can be quite difficult. I've had to put one of my daughters in rehab, it was a big deal" (Participant 16, Male, 76 years). "Emotional burden is when you are sick or a family member is sick, it is a toll on loved ones; whenever you are going through, your family is taking it emotionally because they do not know which way is going to go" (Participant 6, Female, 56 years). "There is definitely emotional stress, I see it every time I see my mum; she is so emotional about everything and about how her medical problems are affecting us. And then they affect her" (Participant 7, Female, 38 years).
Physical burden • Care recipient's need for assistance with (instrumental) activities of daily living, such as dressing, help w/getting out of bed, walking, eating, groceries, help with prescription medication, meal preparation, housework, and taking someone to the doctor	"It can be like physically having to take care of a person that is ill" (Participant 13, Female, 33 years). "Burden can be physical because family have to help you" (Participant 6, Female, 56 years). "I can be bedridden; they can be terribly manageable, bathing me, washing me" (Participant 17, Male, 62 years).
Social burden	
Impact on family relationships • Family conflict due to disproportionate division of caregiver activities and financial costs • Change in family dynamics due to caregiving	"It's a lot of burden on somebody, and I have seen it cause problems in the siblings and who are doing their fair share, and who is not doing their fair share, and people not agreeing financially on what they should be doing" (Participant 18, Female, 63 years). "There are several siblings involved in responsibility and some are getting the brunt of everything, and the others are not. This causes the financial, emotional, and long-term relationship between siblings to form resentment" (Participant 9, Female, 64 years). "There are some problems I had that I think had detrimental effects on my family. That made me feel uncomfortable" (Participant 16, Male, 76 years).

suggesting SPB is a single construct that encompasses physical, emotional, and financial components (Natalie Cousineau et al., 2003). Interestingly, previous research by Zarit et al. author of a widely-used caregiver burden self-report measure The Zarit Burden Interview, described caregiver burden as "the extent to which caregivers perceive their emotional, physical health, social life, and financial status to be affected as a result of caring for their relative" (Zarit et al., 1980). Our results and the literature suggest that SPB and caregiver burden have similar components. This raises the possibility of using SPB as a proxy for caregiver burden. To be clear, we are not suggesting SPB is the same construct as a caregiver-reported burden, but the two may be closely related, and the extent to which SPB could substitute for caregiver-reported burden is highly relevant as it would only require a single respondent. More research is needed to quantify the agreement between caregiver burden as reported by caregivers and as perceived by care recipients. Additionally, building on this qualitative work, future research should aim to delineate individual differences and contributing factors in the perception of SPB. While this study focuses on the perspective of individuals with chronic health conditions and/or personal experiences with caregiving, it is important to acknowledge that the perception of burden by the care recipient may not always align with the caregiver's perspective. For instance, one person may not perceive any burden on their partner, viewing caregiving as an inherent role in their relationship, while the partner might disagree. Additionally, caregivers may underreport their burden, for example, due to reluctance to appear complaining. This subjectivity in caregiver and care recipient viewpoints highlight the need for considering both viewpoints and the value of incorporating care recipient' perspectives to understand the full scope of caregiver burden.

The newly constructed SPB-Global item could be further researched as: 1) a standalone single item measure and 2) a new multi-item PROM that consists of a single global item accompanied by additional items representing the individual components of SPB: physical, social, financial, and emotional burden. While multi-item PROMs may provide a more comprehensive evaluation, single-item assessments of overall SPB provide a useful summary measure. As a standalone instrument, the single SPB-Global item allows individuals to implicitly weigh various components of SPB that are important to them and assign an overall rating based on their individual rankings and experiences. While rankings and experiences will vary, it is likely that there is a common set of key components that make up overall SPB. Furthermore, the global item imposes a minimum burden on respondents and is more time-efficient. By using this concise measure of SPB, clinicians and other

Table 4
Consequences of caregiver burden from the perspective of individuals with chronic health conditions or personal experiences with caregiving: themes and exemplary quotes.

Themes	Sample Quotes
Financial Hardship • Alteration of care recipient's treatment decisions due to cost • Care recipient's avoidance of medical care (emergent or non-emergent) • Cutback on other expenses (food, living expenses, accommodation) to cover medical bills • Job-caregiving conflict (job status change or loss, reduction of working hours) • Financial sacrifices	"If I was a financial burden to my family it would bother me. It would affect the decisions I make to seek help, especially if you do not have anyone to help and you have to pay out of pocket, or private insurance, or co-pay" (Participant 4, Male, 58 years). "I can think of one example when I know someone did not go for care because of becoming a financial burden" (Participant 18, Female, 63 years). "Our healthcare it is totally broken. I hear it very often that people have to choose between buying their medication and paying bills because of disparities and income and access to healthcare. I hear it very often. It's very common. It is something that needs to be addressed aggressively in the US" (Participant 17, Male, 62 years). "Before Obamacare, before they expanded Medicare, people would not go to the doctor because they could not afford to go" (Participant 4, Male, 58 years). "Financial situation can compromise patient's health, no question about it. People think about financial problems before they seek health care" (Participant 16, Male, 76 years). "My friend in the nursing home, she had a situation with dental care. Her financial advisor said, "you cannot consider anything until 1st of the year". You are making yourself more ill, perhaps or putting yourself in a life-threatening position" (Participant 2, Female, 67 years). "I know a lot of people who if they can take care of themselves at home, they will do it. Other than broken bones, I knew people who glued their skin together because they did not want to get stitches. They could not afford it because they did not have insurance" (Participant 12, Female, 58 years). "Some people do not take medicine because they cannot afford it. They don't go to the doctor until it's too late. Then they go to ER, and they in the ER say it's too late" (Participant 11, Male, 69 years).
Decreased Health-related Quality of Life • Decrease in caregiver's physical and mental well-being • Caregiver's physical and psychological health deterioration (e.g. exhaustion) • Caregiver not having life of their own, loss of self and personal social life • Failure to address one's own problems (leads to more health deterioration) • Impact on finances	"If you have a family member that you are caring for, often your own mental and physical health takes a back seat. I think interventions both for patient and also for the families are really important" (Participant 19, Female, 44 years). "In the US healthcare system, health conditions have a huuuuge effect on family/caregiver's daily activities" (Participant 11, Male, 69 years). "I am thinking of my neighbor whole husband has Alzheimer. I am sure expenses are prohibited and her life and things she wants to do are on back burner and when I see her, she looks exhausted. That is one thing I think about, how do you take care of yourself when you have to take care of someone else. She has 3 sons, but none of them come to help. I think it causes animosity, estrangement in families, and resentment. Plus, the drain is financial and emotional" (Participant 9, Female, 64 years). "When people become middle-aged, they have elderly parents that they have to take care of, make decisions for and take responsibility. That can impact finances and emotions, it can cause problems between sibling who take care of the brunt of it; the people who are younger than me, in their 40ties or 50ties they are torn apart because they have no life of their own" (Participant 9, Female, 64 years).

professionals working with care recipients and their caregivers can determine if a further assessment is needed while minimizing the time, energy, and resources required. Future research should include psychometric testing of the proposed items alongside other instruments to inform their measurement characteristics and the contexts in which they have the potential to inform SPB (for example, alongside measures of health and social care). Additionally, the burden on caregivers and the care recipient's concerns about burden may factor into decision-making, especially when finances are involved in the US, and this area has yet to be studied.

Although SPB is commonly experienced in patient populations (Kowal, Wilson, McWilliams, Péloquin, & Duong, 2012; Ren et al., 2016; Wilson, Curran, & McPherson, 2005), family members and healthcare practitioners often fail to recognize this issue in their patients (Ching, 2007; Jones et al., 2011; Lofaso & Weigand, 2014). Furthermore, acknowledging SPB as a concern is crucial for informing clinical policies and fulfilling the moral obligation to provide humane care to all patients (Rodríguez-Prat et al., 2019). As the population ages and people with chronic illnesses live longer, dependence on care is expected to increase, leading to a shift from professional to informal care (Broese van Groenou & De Boer, 2016). Healthcare professionals should be aware of SPB and help reduce its impact, as it can influence patient decision-making in treatment and end-of-life care (Lee et al., 2015; Rodríguez-Prat et al., 2019; Tang et al., 2017). People living with illness, disease, or disability may struggle to effectively communicate their concerns to their informal caregivers (Caregiving, National Alliance for Caregiving National Alliance for Cargeiving, 2019). The SPB-Global item can facilitate communication and encourage individuals with chronic health conditions and family members to find solutions to reduce SPB and find positivity in the caregiving-receiving relationship. With a better understanding of SPB, health and social care can provide more effective support services to patients and their families.

While we recognize certain limitations of qualitative research like potential generalizability issues, our study's emphasis was on thoroughly exploring the diverse and personal experiences and range of perspectives on the perceived SPB by individuals with chronic health conditions and/or personal experiences with caregiving. Conducted in the Chicago, IL, area, the findings may not fully represent the diverse experiences across the US. In addition, our sample reported relatively few issues with healthcare bills and had a high health-related quality of life on EQ-5D-5L. Future studies should aim to include a wider range of participants to better understand SPB across broader socioeconomic spectrum and disease types. While the recruitment process was designed to target a diverse sample, the passive nature of flyer distribution and

Table 5
Care recipient self-perceived burden candidate item's face validity.

	Summary of Face Validity	Face Validity Sample Quotes
I am a bother to my family.	Comprehension: • Ambiguity in meaning (whether bother here relates to health) • Vague meaning (mostly unrelated to health) • False inference (people may not see themselves as a bother)	"Is this questionnaire only about healthcare? You could be a bother for a lot of reasons." (Participant 11, Male, 69 years) "It can be vague, but it can mean anything, that I am able to live to my responsibilities, maybe something of health situation when I am not able to work or you know, capable, bedridden, it could be anything. So vague." (Participant 17, Male, 62 years)
I am a burden to my family.	Comprehension: Ambiguity in meaning; participants recommended to provide some examples to give people options on which burden they may be and they "get a sense if they feel they are burdening at all."	"I find some people might not find it easy to answer because people do not always see themselves as other people see them." (Participant 3, Male, 67 years) "It is going to be uncomfortable for some people, but at the same time it is going to make them look at themselves." (Participant 3, Male, 67)
My health problems/state causes stress to my family.	Comprehension: Ambiguous interpretation, vague meaning. Some participants thought it is not helpful to ask and will provide no information.	"I'd recommend putting in parenthesis because stress can mean different things to people." (Participant 6, Female, 56 years) "You can be stressed about your problems, without being a burden." (Participant 7, Female, 38 years)
I am a financial burden to my family.	Some participants felt it might be uncomfortable to explicitly ask (only) about financial concerns, that some might find it offensive, intrusive, or a sensitive topic. The point was also raised on comprehension and not understanding the purpose of the question.	"I think it might be a little bit causing stress to ask people that. It is not worth asking that. I do not understand why you would ask that, why you need information that for. That might make people angry or uncomfortable." (Participant 5, Female, 23 years) "I think if you are going to do an intervention, including the financial component is important, but I do think just word burden captures the financial burden." (Participant 19, Female, 44 years)
Are you concerned about the burden your health imposes on your family and friends?	Some participants felt it might be uncomfortable for some, even aggressive. Having statements is preferred for consistency in framing with other questions.	"I am uncomfortable with this question. Because it implies, you are telling them they are a burden. I feel like I am a burden is a better way. "(Participant 16, Male, 76 years) Asking do you identify, concern as a burden, it feels a little aggressive." (Participant 5, Female, 23 years)

Table 6
Care recipient self-perceived burden candidate item's content validity.

	Summary of Content Validity	Content Validity Sample Quotes
I am a bother to my family.	Bother was interpreted as: "Annoying, "casual annoyance," "irritating," "something you deal with,", "not much of a problem," "nuisance to my family," "being an obligation," "being extra problem for your family," "inconvenience," "causing your family and friends to get tired of dealing with your problems"	"Bother means when people are annoyed, irritated with you." (Participant 4, Male, 58 years) "I don't think bother is the right word, it sounds like annoying." (Participant 19, Female, 44 years) "Bother is one thing, the burden is another. The burden is more financial, as well as time per caregiving. A bother is I think from the patient's point of view, they feel of that, that is upsetting to them, more occasional. Where sometimes, occasional bother is not going to be hard on family and friends. But it can quickly turn into a burden. Bother is a step lower than a burden." (Participant 2, Female, 67 years)
I am a burden to my family.	Burden was interpreted as: • Financial (paying for hospitalization, medication, professional care) • Time per caregiving (having to take time off work, or transportation, drive someone somewhere) • Physical (helping with (instrumental) activities of daily living such as washing, eating, help around the home, helping physically to take someone to doctor) • Emotional and mental burden • Frustration (by inability powerless to help) • Stress (of losing someone) • Energy • Sacrifice of the family	"Very similar to bother, but burden means financial, emotional and time, but you are not really worth you are causing more negative feelings than positive feelings. The burden is more serious than bother. You can be burden financially, emotionally, time and sacrifice to the rest of the family" (Participant 9, Female, 64 years) "Burden would be I am a big negative in their life. And it brings in more financial side, that bother did not bring. Burden is financial, time, energy." (Participant 18, Female, 63 years) "Burden means physically take my mum, or financially that we happen to pay for her hospitalization." (Participant 7, Female, 38 years) "You could be an emotional burden, a time burden, I worry about you, you are taking all my time, but you might have money, so you are not a financial burden to me, but you would think maybe you need help. You could also be a financial burden." (Participant 18, Female, 63 years)
My health problems/state causes stress to my family.	Stress was interpreted as: • Emotional • Worry about health problems by family members • Pain and suffering	"Um, you're kind of leaning the door on interpretation. If I would be thinking about it, if I had three bother, is kind of annoyance, stress is a little

(*continued on next page*)

Table 6 (*continued*)

	Summary of Content Validity	Content Validity Sample Quotes
	• Pressure to take care of a family member • Emotions "like anxiety" • Financial, physical and time (in one participant)	bit ongoing, they are more worried about it, it is more emotional and the burden is the thing nobody wants to be." (Participant 18, Female, 63 years) "Stress is mostly emotional to me at least. Burden could also be emotional but could be all those other things, but stress is focusing more on emotions. Like anxiety." (Participant 7, Female, 38 years)
I am a financial burden to my family.	Financial burden was interpreted as cost related to medical services and financial distress. It is only a subset of burden and does not capture the whole concept of interest.	"You could be a financial burden, but that is only a subset of burden." (Participant 18, Female, 63 years)
Are you concerned about the burden your health imposes on your family and friends?	Concern as a burden was interpreted more subjectively.	"It is the same thing as previous items. The difference is it's more how I am feeling as opposed to more like the previous two were more concrete." (Participant 6, Female, 56 years)

self-selection via Research Match may have introduced selection bias. The interview mode of administration could lead to social desirability bias, where the interviewer's behavior, personal appearance, or voice characteristics could potentially influence the participants (Miller et al., 2014). Despite these limitations, this is the first study in the US to provide a comprehensive understanding of SPB. A strength of the study is the use of cognitive debriefing as a method of interview, which allowed participants to provide a deeper understanding of SPB as a concept and how the SPB-Global item works, the type of phenomena it captures, and how it supports the scientific goal. Cognitive debriefing also provides opportunities to identify potential sources of response error (Altman, 2016; Willis, 2004).

5. Conclusion

SPB has been an underrecognized source of insight into the impact of illness on families that complements the caregiver(s) perspective on burden. By measuring SPB, a better understanding of the impact of illness on families and treatment decision-making surrounding care of individuals with chronic health conditions can be gained. Additionally, SPB can provide insight into caregiver health and well-being in outcomes research without having to administer measures to both the care recipient and caregiver dyad. Our results indicate that a SPB-Global item encompasses financial, social, physical, and emotional aspects of burden on caregivers. This item can be used as a standalone measure or as part of a larger instrument, depending on the research goals. Overall, the inclusion and assessment of SPB has the potential to improve support and quality of life for both care recipients and their caregivers.

CRediT authorship contribution statement

Maja Kuharic: Writing – original draft, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Lisa K. Sharp:** Writing – review & editing, Supervision, Methodology. **Robin S. Turpin:** Writing – review & editing, Supervision, Methodology. **Brendan Mulhern:** Writing – review & editing, Supervision, Methodology. **Todd A. Lee:** Writing – review & editing, Supervision, Methodology. **Chloe Elizabeth Grace Rose:** Writing – review & editing, Visualization, Formal analysis. **Andrea Monteiro:** Writing – review & editing, Project administration, Methodology, Funding acquisition, Data curation, Conceptualization. **A. Simon Pickard:** Writing – review & editing, Supervision, Methodology, Investigation, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Alan Simon Pickard and Brendan Mulhern are members of the EuroQol Group. Other authors declare that they have no competing interests.

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Appendix A. Supplementary data

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