

A qualitative interview study into the experiences of fatigue and depression in chronic hepatitis B.

Authors and affiliations

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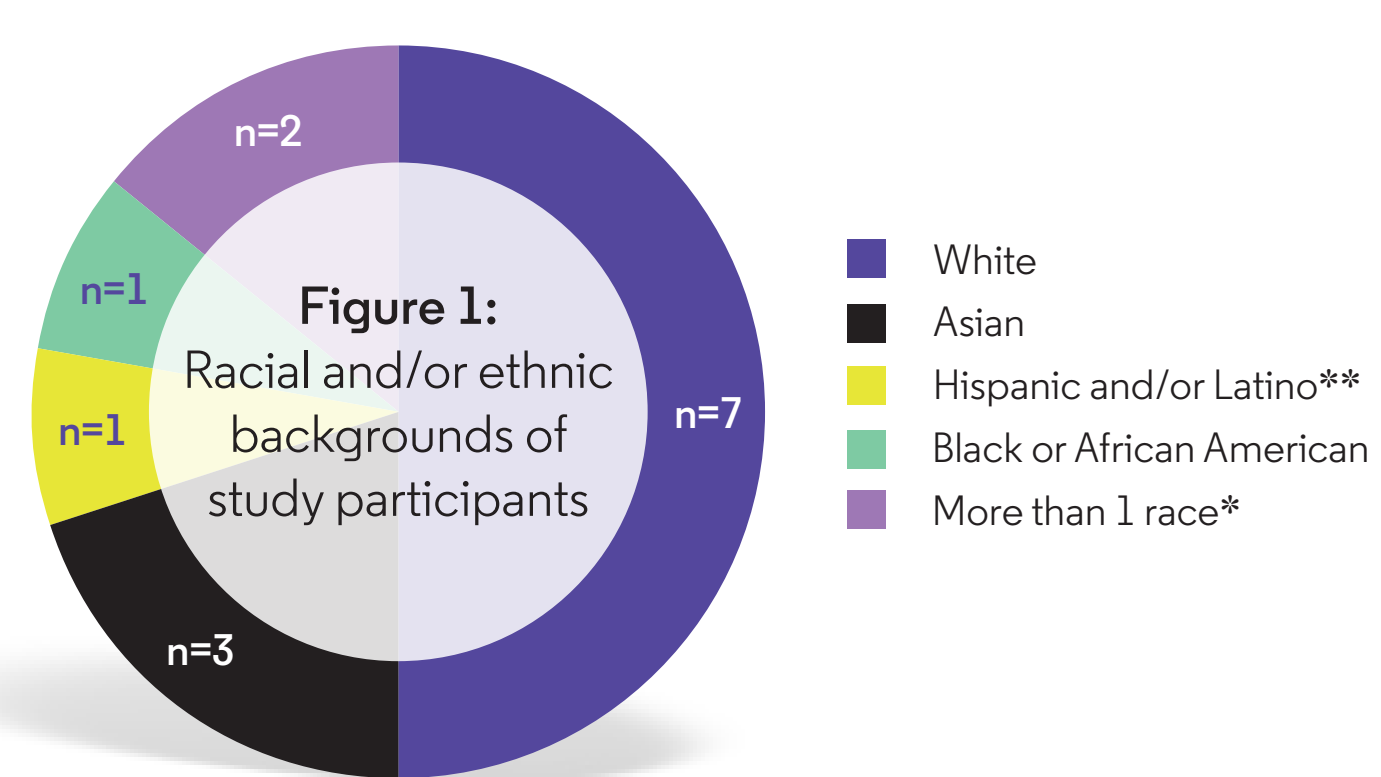
Introduction and objective

- A recent modelling study (comprising a literature review and interviews with clinical experts) estimated that the global prevalence of Hepatitis B corresponded to 292 million people worldwide¹.
- Chronic Hepatitis B (CHB) is the term used to describe an infection that lasts for ≥ 6 months². CHB is often asymptomatic and has an impact on people's health-related quality of life (HRQoL). A recently developed conceptual model³ highlighted the potential importance of fatigue and depression to patients with CHB.
- This study aimed to explore the patient experience of fatigue and depression including development of two conceptual models for the selection of appropriate patient-reported outcome (PRO) measure to assess these experiences.

Methods

- Sample:** Inclusion criteria required participants to have a clinically confirmed diagnosis of CHB (or coinfection of Hepatitis B and D) and self-reported feelings of fatigue and/or depression within the past three months. Efforts were made to target participants from racial/ethnic backgrounds representing the diversity present at the population level.
- Interview procedure:** Concept elicitation interviews lasting approx. 45-minutes were conducted with adults living with CHB in the United States (US). Experienced qualitative interviewers used a semi-structured interview guide to explore CHB-associated fatigue and/or depression experiences, including symptoms and impacts. Participants rated each symptom and impact that they experienced on a scale of 0–10 based on "bothersomeness" (i.e., how much the symptom/impact bothered them when at its worst) and provided additional qualitative explanations for these ratings.
- Analysis:** Data were analyzed using qualitative directed content analysis techniques^{4,5}. Two conceptual models of CHB-associated fatigue and depression were developed. Saliency graphs were developed to illustrate the most bothersome and common ("salient") symptoms and impacts. Salient concepts were defined as those that were a) experienced by ≥50% of participants, and b) rated on average as ≥5 on the 0-10 scale.

Results



*n=1 participant identified as white and American Indian, n=1 participant identified as white and Middle Eastern.

**Note that 'Hispanic and/or Latino' has been included here as one participant self-reported their race as Hispanic/Latino.

Interviews were conducted with n=14 participants (n=11 male, n=3 female) with CHB including:

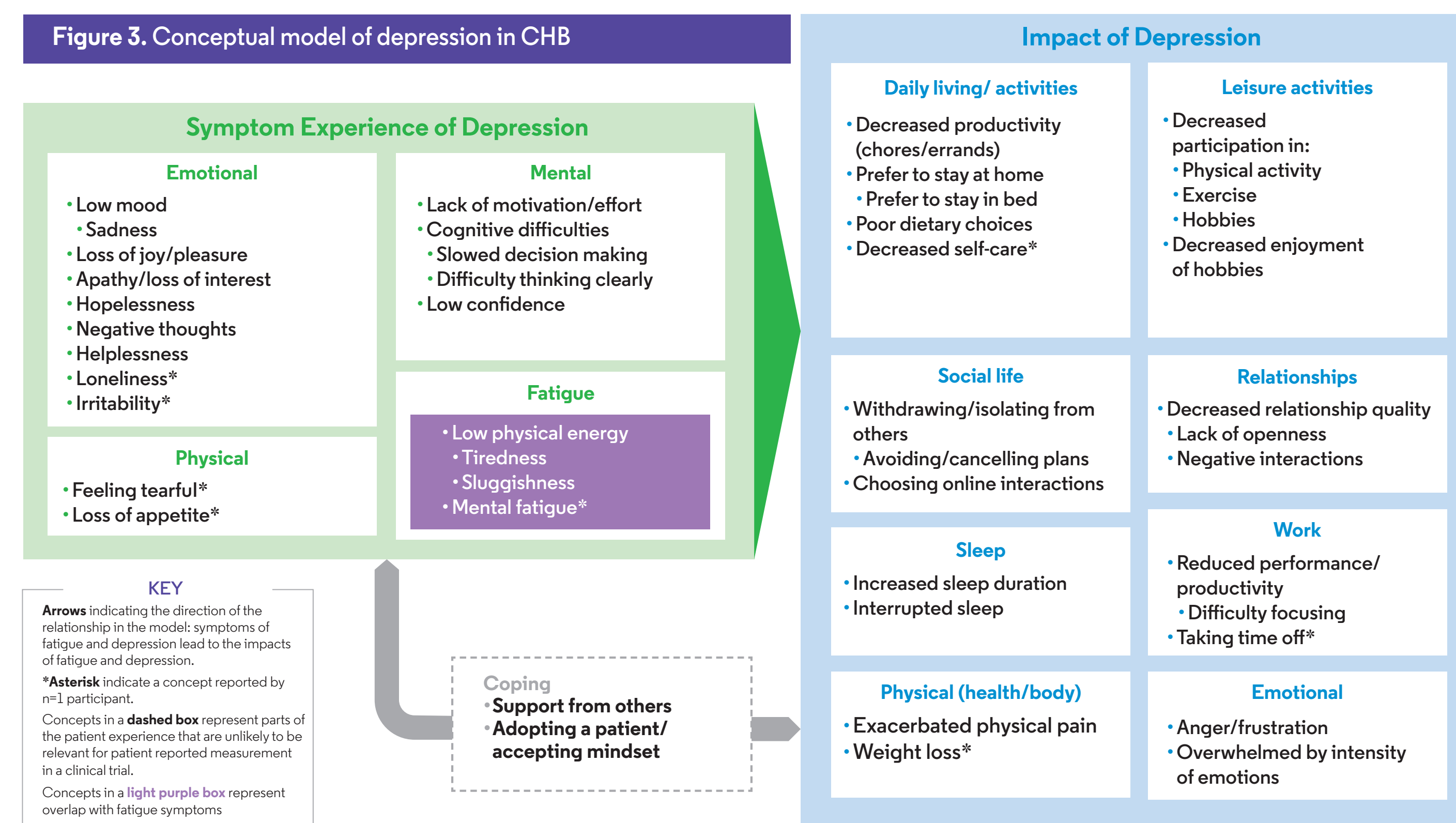
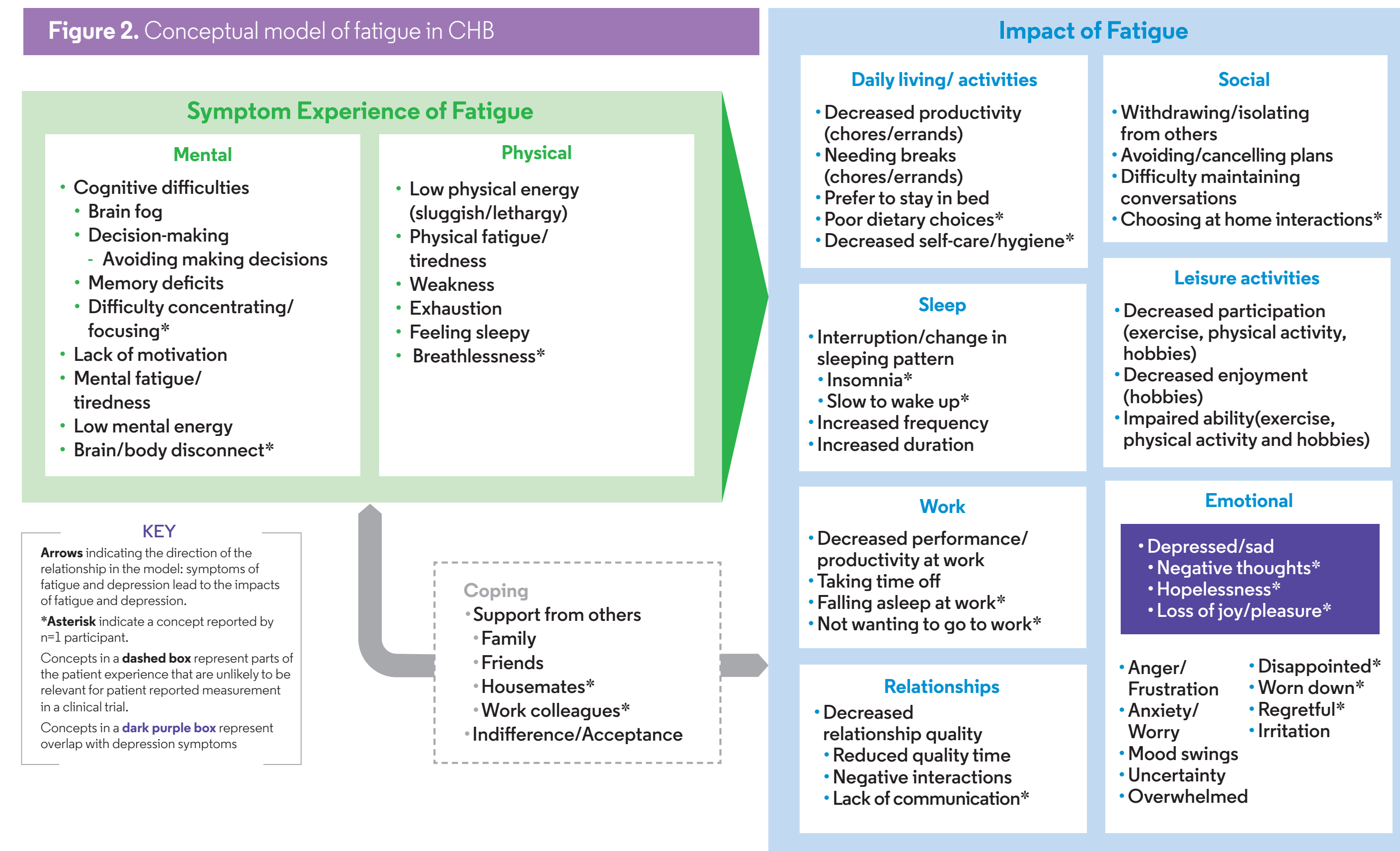
- n=12 participants living with fatigue (n=5 mild, n=6 moderate, n=1 severe), aged 36-70 years (mean 41, standard deviation [SD] 11.1)
- n=10 participants living with depression (n=5 mild, n=4 moderate, n=1 severe), aged 26-70 years (mean 47, SD 13.1)
- n=8 participants who had reported experiencing both fatigue and depression

Additionally, within the sample:

- No participants had Hepatitis D coinfection.
- n=6 participants were receiving treatment for CHB at the time of the study.
- Efforts made to recruit participants from diverse racial and/or ethnic backgrounds resulted in n=7 (50%) participants who were Asian, Black, Hispanic and/or Latino, or more than 1 race (Figure 1).
- Participants had attained a range of education levels including high school diploma level or lower (n=4).

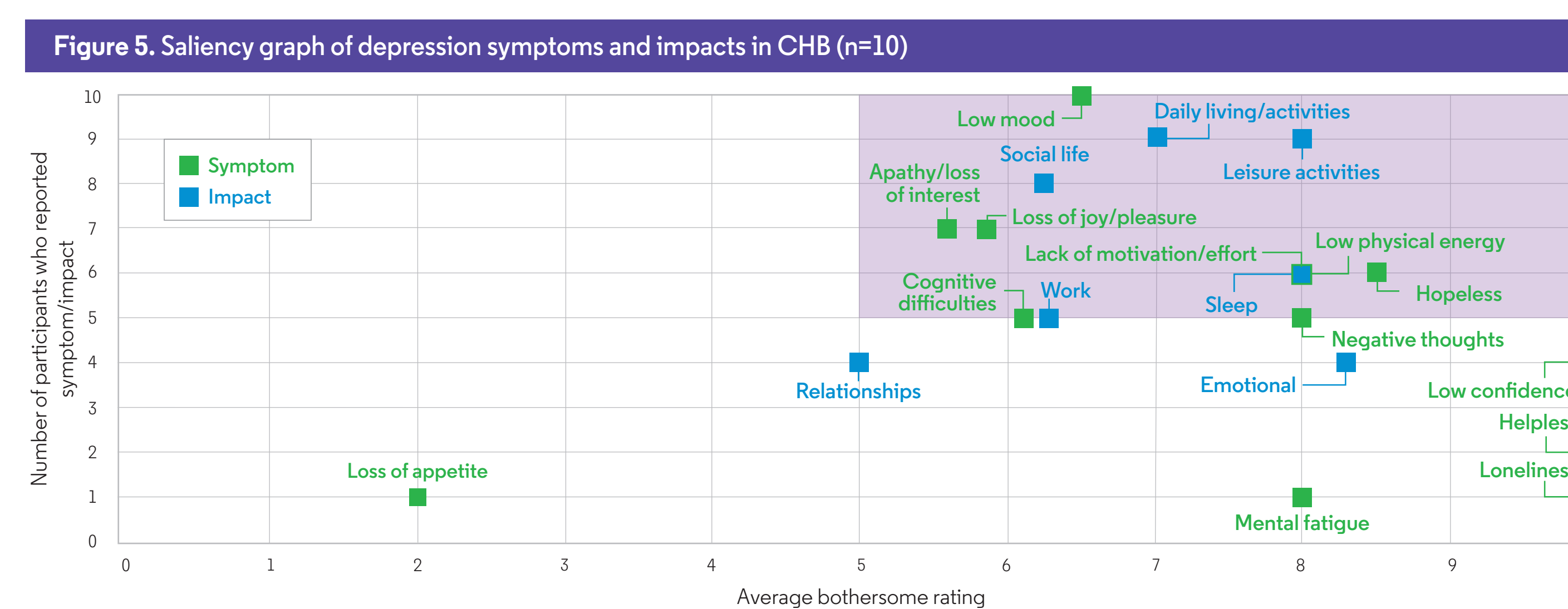
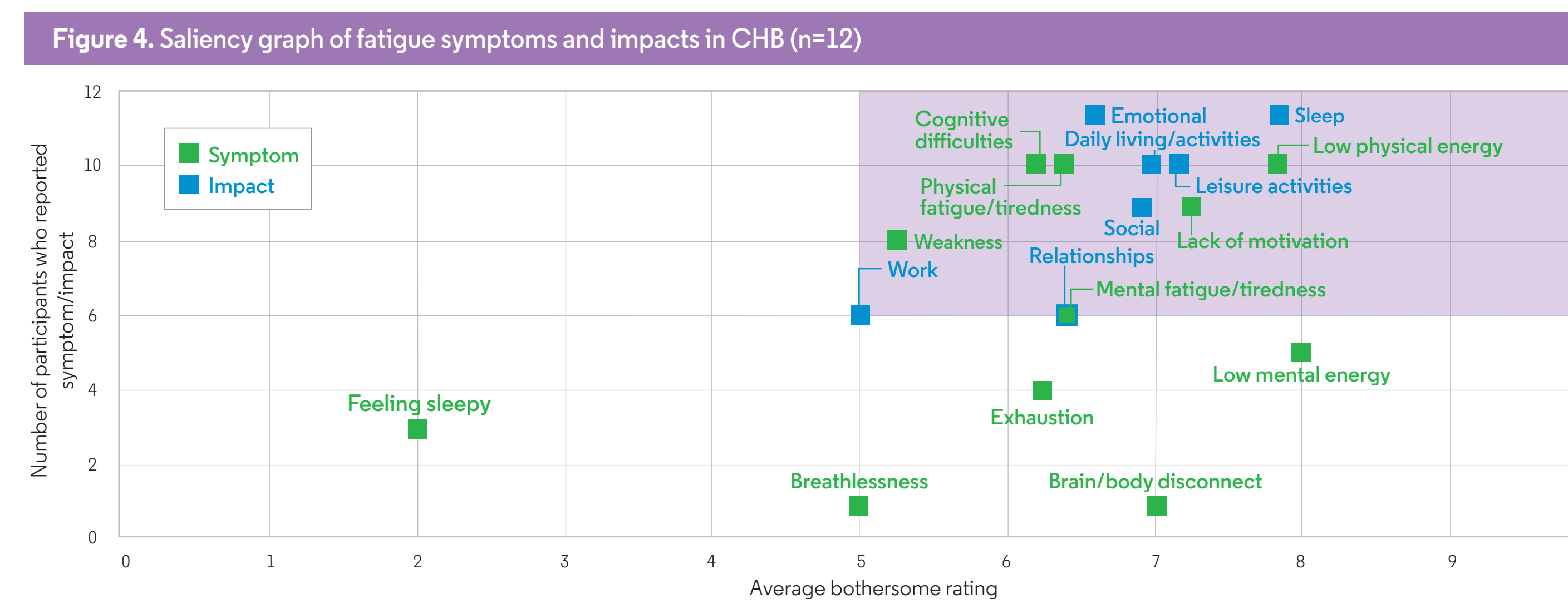
Conceptual models

- Figure 2 and Figure 3 present the conceptual models developed to illustrate the patient experience of fatigue and depression in CHB.
- While several aspects of depression and fatigue were unique, there was notable overlap. Several symptoms associated with fatigue were reported by participants with depression, including low physical energy.
- Several participants with fatigue reported feeling sad/depressed due to fatigue.



Salient concepts

- Salient concepts are displayed in Figure 4 (fatigue) and Figure 5 (depression). Note that not all symptoms and impacts are included as not all participants provided ratings for each concept, although all participants rated at least three concepts each. The most salient concepts are indicated by purple boxes. Example descriptive quotes are provided in Figure 6 (fatigue) and Figure 7 (depression).



Discussion

- The most common symptoms of fatigue were low physical energy, physical fatigue/tiredness, and cognitive difficulties (such as memory deficits and brain fog). Fatigue also impacted daily living/activities, social life, relationships, leisure activities, work, sleep, and emotions.
- The most common symptoms of depression were a low mood/sadness, loss of joy/pleasure, and apathy/loss of interest. Depression also impacted daily living/activities, social life, relationships, leisure activities, work, sleep, emotions, and impacts on their physical health/body.
- Fatigue and depression are two distinct experiences, and patients with CHB may experience only one or the other. Therefore, separate PRO measures should be used to assess the multifaceted aspects of each. However, some commonalities were observed across the physical, mental and emotional components of both experiences. Participants experiencing fatigue may report symptoms of depression, and vice versa.

Figure 6. Quotes of key salient concepts of fatigue in CHB

Low physical energy
"When you sit down on the couch and you're just so lethargic you can't physically and mentally get in the space to get up." (01-F)

"It's always the both - most bothersome, 'cause I'm always been - I've always been a person that's, um, pretty active and on the go and that - and this can almost, like, stop you in your tracks if it gets to that point" (09-F)

Physical fatigue/tiredness
"I've felt little more fatigued than usual when I'm - I like - you know, I like to exercise a lot and work out, um, so the most part, err, when I'm running, I've felt a little more fatigued, a little more tired, at times." (14-FD)

"Well, I don't get, err, many things accomplished, err, that I should in an eight-hour day. I probably, get about [laughs] less than four, err, hours' worth of work done." (10-F)

Daily living/activities impacts
"Just being, um, too fatigued, either mentally or physically, to start anything, to start the chores, or if I start something, I have to stop and, like, continue maybe in the next couple hours or tomorrow, or something like that." (05-FD)

Sleep impacts
"Surprisingly, sometimes I suffer from insomnia, I'm so, I'm so, I'm so tired that I can't even go to sleep." (02-FD)

Cognitive difficulties
"I'm not mentally as sharp. Err, even sometimes when I'm really fatigued, I have short-term memory lapses, you know, I think that all plays a part in it" (02-FD)

Emotional impacts
"If I'm, um, I'm feeling really fatigued and I'm not in a good headspace, then I might think about other things and err, might feel a little bit more sad or, or weepy, than I would on a normal day." (01-F)

Leisure activities impacts
"Basically, my exercise program is based off, err, nothing, you know, a-as far as activities, as, you know, actually physically working out have gone to working out maybe three times a week, to absolutely nothing." (07-F)

Figure 7. Quotes of key salient concepts of depression in CHB

Loss of joy/pleasure
"I struggle to find things to - even things I, I used to enjoy, I err - everything seems dull-dulled down, like it's, sort of like, err, muted." (08-FD)

"Even things that should normally make me excited, don't. Like, um, make it harder for me to, like my day-to-day." (04-D)

Leisure activities impacts
"When, err, when I feel more depressed or low, I feel less like engaging in physical activity." (06-FD)

Low mood
"How I would describe it? Being down in the dumps." (02-FD)

Daily living/activities impacts
"I just don't have the energy to, like, err, do the dishes or do my laundry, so I'll procrastinate and put it off." (05-FD)

Apathy/loss of interest
"Um, like, being apathetic, being, um, like, not excited to things." (05-FD)

Social life impacts
"When I'm feeling depressed, I feel less like being around other people." (06-FD)

Conclusion

People with CHB living with fatigue and/or depression have multifaceted experiences which impact diverse aspects of day-to-day life. The conceptual models developed in this study may be used to select appropriate PROs to measure these important experiences in future clinical research.