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Assessing caregiver burden following an acute hospitalization of the heart failure patient: A feasibility study

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Purpose

The purpose of this study is to evaluate the feasibility of the administering the Zarit Caregiver Burden Interview (ZBI) using cognitive interviewing and probing questions to explore caregiver burden after discharge following an acute hospitalization of a heart failure (HF) patient.



Background

- Hospitalization of heart failure (HF) patients often results in many changes related to pharmacologic and non-pharmacologic regimens that make caregiving more challenging and increase perceived burden.¹
- There is a critical need to prepare and support HF caregivers for the caregiving role after hospital discharge.²
- HF caregiver burden is not always conceptually defined and previously captured using only quantitative measures which fail to include the contextual features relevant to outcomes.³
- One-third of heart failure caregivers are affected by burden, which directly affects the HF patient by decreasing the quality of delivered care and quality of life for the patient.⁴



GAPS

- Perceived caregiver burden following an acute exacerbation hospitalization of the HF patient has not been studied in HF in the literature.
- Studies examining relationships between caregiver characteristics/behaviors and patient outcomes are limited for HF. ²
- HF dyad relationship-level factors that affect burden have been understudied in HF population.²



Zarit Burden Interview

- Unidimensional measure of burden
 - Consequences of caregiving
 - Guilt/self-criticism
 - Personal strain
 - Role strain
- 22 item Likert scale tool
 - 0-20= no burden
 - 21-40 mild to moderate burden
 - 41-60 = moderate to severe burden
 - 61-88= severe burden



Zarit Burden Interview

- ZBI shown to be reliable and valid for caregivers of cancer and dementia patients. ⁵
- The ZBI found to be reliable and valid in HF caregivers in 2016. ⁵
- Cronbach's alpha for ZBI was .921⁵



Methods

- The feasibility study employed a mixed methods design.
- Quantitative data collected by the Zarit Burden Interview scores and descriptive statistics.
- Qualitative data collected via semi-structured interview with cognitive interviews and probing for those questions answered with >3 or 4 answer on ZBI
- Thematic analysis completed on interviews.



Methods

- HF caregivers were consented in the inpatient setting OR at the 1-week hospital follow up appointment in the clinic.
- HF caregivers completed the ZBI via oral administration by the PI.
- ZBI scored by the PI.
- If HF caregivers answered with a 3 “quite frequently” or 4 “nearly always” on the burden tool, probing questions were asked.



Methods

- Cognitive interviews with probing questions were audio-taped and transcribed verbatim for the purpose of qualitative analysis.
- Interview transcripts were analyzed using a thematic approach focusing on common quotes from the HF caregivers by two separate authors and themes coded.



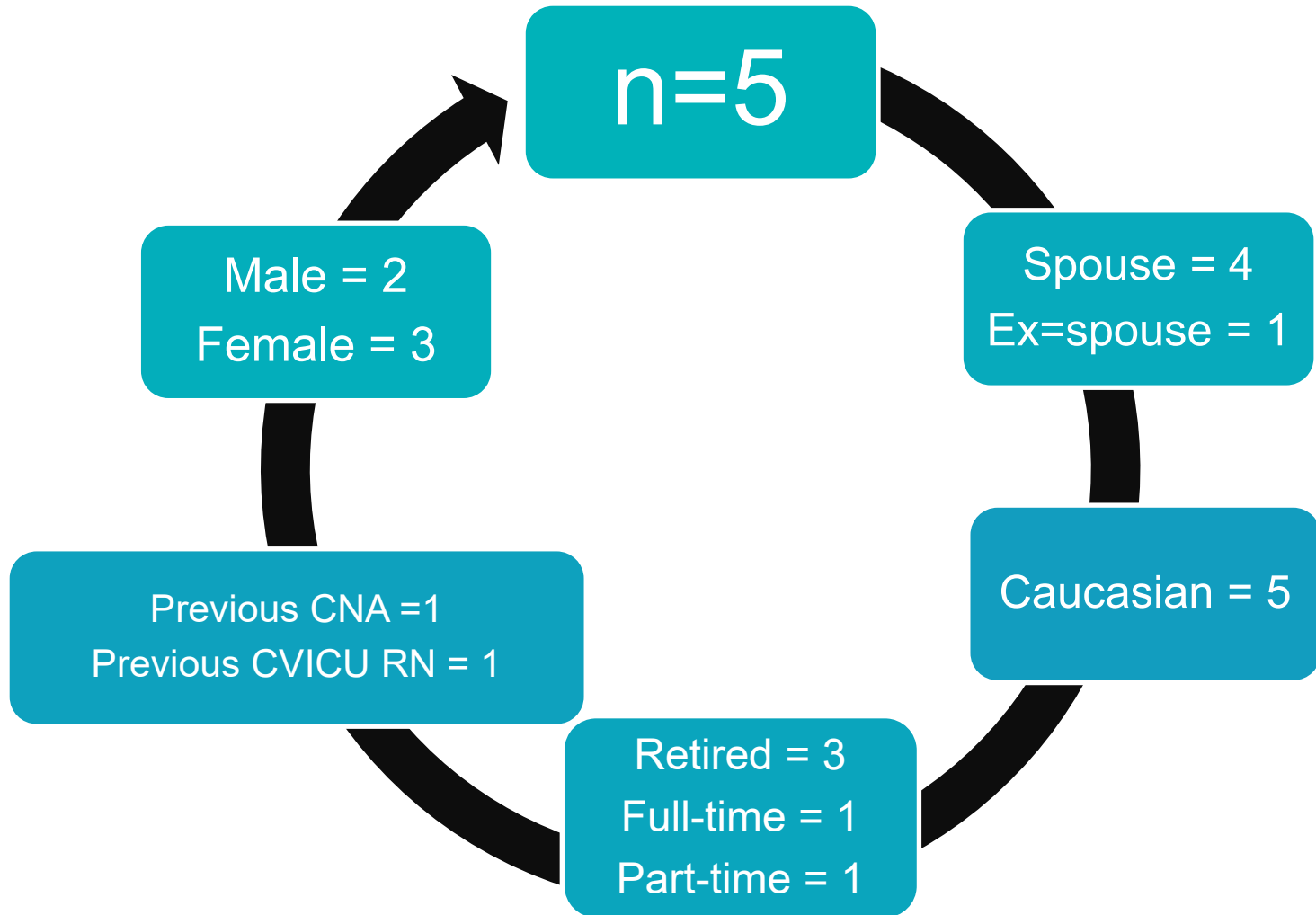
Example of probing questions

Question 14: Do you feel your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?

Female caregiver answered “Quite frequently”
When I prompted to explain further: “I am the only one that is even remotely available. My first career was as a CAN. I also took care of my siter and both parents prior to them dying. I honestly am the ONLY one. He would do it for me. We have been married for 25 years. It is what you do”.



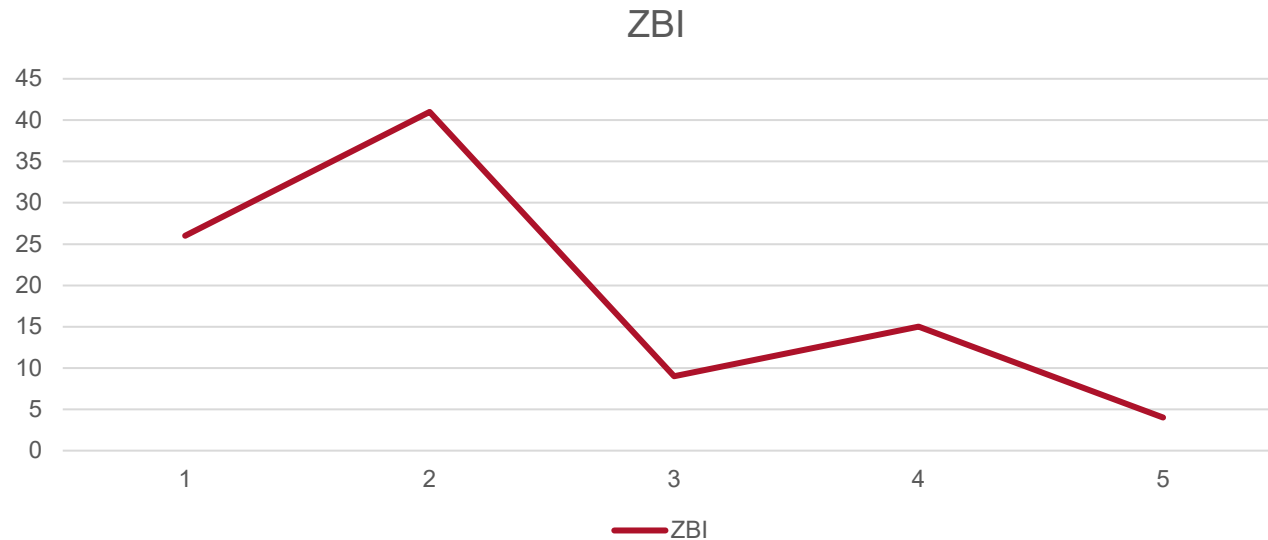
Demographics of Caregivers





Quantitative

- ZBI scores ranged from 4 to 41
- Little to no burden → moderate to severe burden
- Male caregivers (n=2) had low ZBI scores (4,9)
- Female caregiver scores: 15, 26, 41
- High score came from a fulltime employed ex-wife who did not live with the HF patient



Qualitative themes from interviews



HF patient
Challenges

Caregiver
Challenges

Social Challenges

Discharge
Challenges

Fears



Discussion

- Male caregivers reported less burden.
- Ex-spouse reported highest burden.
- Social isolation from COVID-19 reported in 4 caregivers.
- Hospitalization caused more burden per interview for 4 of the 5 caregivers.
- Medication changes at discharge the biggest challenge for caregivers.



Conclusion

- The ZBI is a feasible tool to measure caregiver burden with cognitive interviews and probing questions.
- Themes of cognitive interview (probing questions) matched original ZBI questions.



Future directions

- Enrollment of more diverse caregivers, such as non-married, non cohabitating caregivers.
- Extra probing questions to closed ended answers in future interviews.
- Transfer knowledge learned to current working dissertation dyad study.



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