

Impact of caring for persons with schizophrenia

Review of burden assessment measures

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>>> Jain, M., Girardi, A., Ridley, M., Rudell, K., Gold, A.

Background

Schizophrenia is highly burdensome, both to the patients and caregivers (care partners of patients with schizophrenia), largely due to the chronic, relapsing nature of the condition. However, caregiver burden imposed by such chronic conditions is often overlooked, and carer perspectives are underrepresented in Health Technology Assessment (HTA) appraisals (Pennington et al., 2022). In the context of schizophrenia, few studies have focused on its humanistic burden which not only concerns patients but also the caregivers (Millier et al., 2014).

The impact of caregiving for a person with schizophrenia is a multidimensional concept consisting of social, functional, behavioral and economic dimensions (Awad & Voruganti, 2008). Different instruments are available to evaluate caregivers' burden, which vary in their length, domains and population of interests. Therefore, the aim of this study is to define how caregiver's burden is currently assessed within the context of schizophrenia.

Methods

A three-phase targeted search was conducted:

- Phase 1: the first search was conducted on ePROVIDE in December 2023 to identify relevant scales used to assess caregiver burden in schizophrenia. Results of this search were integrated with a search of electronic databases.
 - Phase 2: identification and review of primary research studies concerning caregiver's burden evaluation. The following search terms were combined with Boolean operators and entered in PubMed, Medline, Embase, Global Health and PsychInfo : caregiver burden, burden of caregivers, family burden, schizophrenia, questionnaire.
 - Phase 3: identification of published reviews/metanalysis. The search strategy used in the second phase was expanded to include reviews and metanalysis articles.
- No limits were placed on the time of publication. Articles with both abstracts and full texts available, written in English, specific to caregivers of patients with schizophrenia and describing caregiver burden using scales or questionnaires were retained. The extracted information included the scale used to assess caregiver burden, number of items, concepts measured and whether it was developed or validated for the specific condition.

Conclusions

Of the identified scales, only two were developed specifically for caregivers of patients with schizophrenia, while the majority (85.7%) were developed for other conditions or non-condition specific. The identified scales largely differ in relation to their focus, length and with evidence on development identified only for 50% of the assessments. Given that the diversity of scales limits uniformity of how caregiver burden is currently assessed in the context of schizophrenia, the findings suggest the need for improved harmonization of caregiver's burden assessment.

Objectives

- To identify relevant scales on ePROVIDE used to assess caregiver burden in schizophrenia.
- To combine the findings from ePROVIDE with results obtained from the primary research studies and review articles.
- Extract relevant information from ePROVIDE and the selected articles

Results

- 43 primary research studies and 4 reviews were retained after removing duplicates, screening for titles/ abstracts and full text eligibility. The primary research studies identified 8 additional scales used to assess caregiver burden in schizophrenia. Reviews/ metanalyses identified 4 additional scales used to evaluate caregiver burden in schizophrenia.
- Overall, taking into account findings from ePROVIDE, reviews and primary research studies, 14 burden scales were identified to assess caregiver's burden (Table 1), with the Burden Assessment Schedule being the most frequently used (34.7%) (Figure 1).
- The number of items in the scales varied largely (range:13 to 66) with recall periods ranging from 2 weeks to 12 months (Table 1).
- Of the 14 scales identified, only two scales (14.3%) were developed specifically for caregivers of patients with schizophrenia: Schizophrenia Caregiver Questionnaire and Involvement Evaluation Questionnaire. Of the remaining 12 (85.7%), one was developed for caregivers of patients with dementia, while the others were non-disease specific (n = 11/14; 78.6%). Validation development evidence was identified in 50% of the scales (n = 6).
- Seven scales (7/14; 50%) focused on evaluating caregiver's burden; one scale (7.1%) was used to assess caregiver's adjustment, two (14.2%) for caregivers' expressed emotions and one (7.1%) was used to evaluate the overall caregiving experience in general. No information was available for the three remaining scales.

Table 1: Scales extracted for assessing caregiver burden in schizophrenia

Scales	Authors	No. of items	Concepts measured	Developed for the condition	Validated for the condition
Zarit Burden Interview (ZBI)	Zarit SH (1980)	Long form: 22; Short form: 12	Psychological functioning Social functioning		✓
Burden Assessment Schedule (BAS)	Thara, R., et al. (1998)	40	Psychological functioning Social functioning		✓
Caregiver Burden Assessment Checklist (CBAC)	Thara, R., et al. (1998)	No information	No information		
Family Burden Interview Schedule (FBIS)	Pai S; Kapur RL (1981)	24	Psychological functioning Social functioning		✓
Involvement Evaluation Questionnaire (IEQ)	van Wijngaarden B; Schene AH (1992)	31	Psychological functioning	✓	
Schizophrenia Caregiver Questionnaire (SCQ)	Zarit SH (2013)	30	Psychological functioning Social functioning	✓	
Family Problems Questionnaire (FPQ)	Morosini et al. (1991)	29	Social functioning		✓
Social Behaviour Assessment Schedule (SBAS)	S Platt., et al (1980)	No information	Social functioning		
Camberwell Family Interview (CFI)	Van Humbeeck G., (1976)	No information	Psychological functioning		✓
Camberwell High Contact Survey (CHCS)	Brugha, T.S., et al. (1988)	No information	No information		
Social Adjustment Scale II (SR)	Weissman M.M., (1976)	54	Social functioning		
Experience of Caregiving Inventory (ECI)	Szmukler GJ., et al (1996)	66	Psychological functioning Social functioning		✓
Modified Caregiving Strain Index (MCSI)	Thornton M; Travis SS (2003)	13	Psychological functioning		
Caregiver Burden Inventory (CBI)	Novak M; Guest C (1989)	24	Psychological functioning		

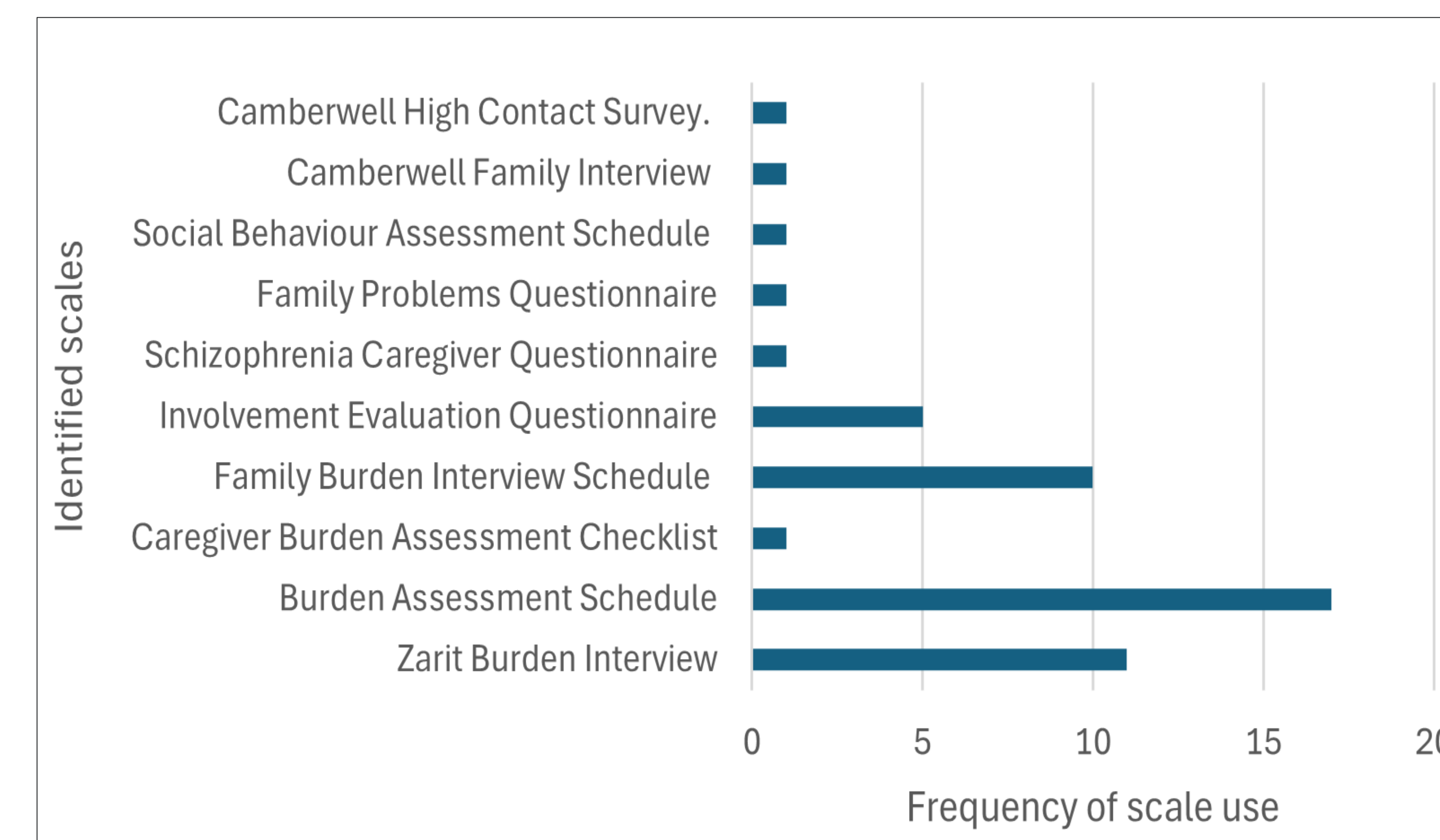


Figure 1: Frequency of use of caregiver burden assessment scales in primary research studies (n=43)

References

