

The Advantages of a Centralized Dissemination Strategy for Health Outcomes Instruments and Their Translations: A Case Study using the Zarit Burden Interview (ZBI)

Anfray C, MA¹, Emery MP, MSc¹ and Zarit SH, PhD²

¹MAPI Research Trust, Lyon, France; ²Penn State University, University Park, USA

Objective

- Since December 2007 the Zarit Burden Interview (ZBI), 22-item and 12-item versions, has been centrally distributed by MAPI Research Trust in close collaboration with, and on behalf of, Dr. Zarit, developer and copyright owner of the instrument. Our objective was to compare information retrieved through a classic literature search regarding the instrument's translations to that obtained from the centralized distribution center (MAPI Research Trust).

Methods

- Literature search in Medline, Embase and PsychInfo with the following keywords: Zarit, caregiver, burden, interview, translation, language, and validation. The articles were organized into a table according to the language used in the study, the country of reference, and the number of teams in each country using the ZBI.
- Request to the distribution center to obtain information about the available ZBI translations.

Results

Literature Search

106 articles were retrieved of which 13 concerned a modified ZBI, 9 the original US version, and 3 the validation of a new questionnaire derived from the ZBI (see Table 1). We identified 20 countries, representing 12 languages with possible variations in Chinese (3 - Mainland China, Hong Kong, Taiwan), English (4 - Australia, Ireland, UK, US), French (2 - Canada, France), and Spanish (3 - Argentina, Mexico, Spain), representing 71 different local teams. Only one article enabled us to identify the author of the official Japanese version. There was no information about who to contact to use the translations.

For each country, there was no way to identify whether one version was the same one used by all teams, increasing the doubt of having multiple translations for one country and language (e.g. Spain - n=7 teams).

Request to Distribution Center

In contrast, the request to the center led to the immediate identification of 34 translations of the ZBI 22-item version and 14 translations of ZBI 12-item version, officially approved by the author (see Table 2). Information about copyright, conditions of use and methodology of translation was provided for each official translation.

Table 1: Translations of the Zarit Burden Interview

Results of a literature search: Medline, Embase, Psych info - N=106 articles (Data Star report)

Version/country	Number of articles	Comments	Number of teams using version	Article # (in search)	Type of study
Chinese (mainland China)	1	Simplified Chinese? Mandarin?	1	1	Validation (PV)
Chinese (HK)	1	Simplified Chinese? Cantonese?	1	43	Validation (PV)
Chinese (Taiwan)	1		1	16	Validation (PV)
English Australia	3		3	2; 38; 102	Others
Spanish Spain	11		7	3, 11; 5, 17, 33; 54, 67; 57, 58; 69; 81	Others
Spanish Mexico	1		1	75	Other
Canada English	4		3	47; 62; 72, 96	Others
Canada French	3		2	6 ; 78, 92	Other study, Validation (PV)
Canada Zarit short version 12 items	1	Language not specified, EN probably	1	91	Devt of a short version
Canada Zarit modified version	1	No details about version	1	93	Other study
Canada abridged version	2	Probably 12-item version by Hebert	1	61, 82	Review, PV
Japanese	31	Several articles specify team who has developed the official Japanese version	17	4, 12, 34, 42, 51; 10; 21, 60, 64, 68, 86, 87, 95, 100; 24; 25; 29; 30; 36; 39, 85; 44; 49, 77; 52; 80; 83; 84; 89, 90; 99	Others, Development JP
Japanese short version	6		4	13; 23; 32, 56; 65, 74	Others, Review Validation JP
English US SOURCE	9		8	7; 19; 45; 48, 79; 88; 98; 104; 106	Others
English US modified Zarit	1		1	26	Other
Russian	1		1	9	Other
Portuguese (Brazil)	5		4	8; 27; 50, 55; 66	Others, Validation (PV)
Malaysian	1		1	73	Other
Malaysian short version	1		1	14	Other
English UK	2		2	15; 18	Other
Dutch	1		1	22	Other
Hebrew	1		1	28	Other
Nigerian modified Zarit	1		1	31	Other
Spanish Argentina	2		1	35, 37	Others
French France	6		3	40, 46; 53; 63, 71, 97	Others
Korean	1		1	41	Other
Finnish	1		1	94	Other
English Ireland	1		1	101	Other
Total	100		71 teams		

+1 article Canada (review of instruments - #20) +1 article Argentina (not about Zarit - #103), 2 articles NL (not about Zarit - #59, #76), 1 article about study in India, China, South East Asia, Latin America, Caribbean, Africa #70, 1 article country not specified (Dellasega - #105).

Table 2: Official Translations of the Zarit Burden Interview (22-items and 12-items) (updated August 2009)

Quest.	Country	Language	Methodology	Mother Language
ZBI-12	ARGENTINA	Spanish	Formatting/Update/Proof-reading	
ZBI-12	AUSTRALIA	English	Adaptation/Clinician Review/Proof-reading	eng-US
ZBI-22	AUSTRALIA	English	Adaptation/Clinician Review/Proof-reading	eng-US
ZBI-22	AUSTRIA	German	Adaptation/Clinician Review/Cognitive Debriefing/ International Harmonization	ger-DE
ZBI-22	BELGIUM	Dutch	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonization	
ZBI-22	BELGIUM	French	Adaptation/Clinician Review/Cognitive Debriefing/International Harmonization	fre-FR
ZBI-22	BULGARIA	Bulgarian	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonization	
ZBI-12	CANADA	English	Formatting/Update/Proof-reading	
ZBI-12	CANADA	French	Formatting/Update/Proof-reading	
ZBI-22	CANADA	English	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonization	eng-US
ZBI-22	CANADA	French	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonization	
ZBI-22	CZECH REPUBLIC	Czech	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonization	
ZBI-22	DENMARK	Danish	2 forward/1 backward/Cognitive Debriefing/Proof-reading	
ZBI-22	FINLAND	Finnish	2 forward/1 backward/Clinician Review/Cognitive Debriefing	
ZBI-22	FINLAND	Swedish	Adaptation/Clinician Review/Cognitive Debriefing	swe-SE
ZBI-12	FRANCE	French	Formatting/Update/Proof-reading	
ZBI-22	FRANCE	French	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonization	
ZBI-12	GERMANY	German	Formatting/Update/Proof-reading	
ZBI-22	GERMANY	German	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonization	
ZBI-22	GREECE	Greek	2 forward/1 backward/Clinician Review/Cognitive Debriefing	
ZBI-22	HUNGARY	Hungarian	2 forward/1 backward/Clinician Review/Cognitive Debriefing/Proof-reading	
ZBI-22	INDIA	Hindi	2 forward/1 backward/Cognitive Debriefing	
ZBI-22	ISRAEL	Arabic	2 forward/1 backward/Cognitive debriefing/Proof-reading	
ZBI-22	ISRAEL	Hebrew	2 forward/1 backward/Clinician Review/Cognitive Debriefing/Proof-reading	
ZBI-22	ISRAEL	Russian	Adaptation/Clinician Review/Cognitive Debriefing/Proof-reading	rus-RU
ZBI-12	ITALY	Italian	Formatting/Update/Proof-reading	
ZBI-22	ITALY	Italian	2 forward/1 backward/Clinician Review/Cognitive Debriefing	
ZBI-12	MEXICO	Spanish	Formatting/Update/Proof-reading	
ZBI-22	MEXICO	Spanish	Adaptation/Clinician Review/Proof-reading	spa-AR
ZBI-22	NETHERLANDS	Dutch	Adaptation/Clinician Review/Cognitive Debriefing	dut-BE
ZBI-22	NORWAY	Norwegian	2 forward/1 backward/Cognitive Debriefing	
ZBI-12	POLAND	Polish	Formatting/Update/Proof-reading	
ZBI-22	POLAND	Polish	2 forward/1 backward/Clinician Review/Cognitive Debriefing	
ZBI-22	PORTUGAL	Portuguese	2 forward/1 backward/Clinician Review/Cognitive Debriefing	
ZBI-12	ROMANIA	Romanian	Formatting/Update/Proof-reading	
ZBI-22	ROMANIA	Romanian	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonisation	
ZBI-22	RUSSIA	Russian	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonisation	
ZBI-12	SLOVAKIA	Slovak	Formatting/Update/Proof-reading	
ZBI-22	SLOVAKIA	Slovak	2 forward/1 backward/Clinician Review/Proof-reading	
ZBI-12	SPAIN	Spanish	Formatting/Update/Proof-reading	
ZBI-22	SPAIN	Spanish	1 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonisation	
ZBI-22	SWEDEN	Swedish	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonisation	
ZBI-22	THAILAND	Thai	2 forward/1 backward/Cognitive Debriefing/Proof-reading	
ZBI-22	UKRAINE	Ukrainian	2 forward/1 backward/Cognitive Debriefing	
ZBI-12	UNITED KINGDOM	English	Formatting/Update/Proof-reading	
ZBI-22	UNITED KINGDOM	English	Adaptation/Clinician Review/Cognitive Debriefing/International Harmonisation	
ZBI-12	USA	Spanish	Formatting/Update/Proof-reading	
ZBI-22	USA	Spanish	2 forward/1 backward/Clinician Review/Cognitive Debriefing/International Harmonisation	

Conclusion

Findings indicate that information retrieved through a centralized distribution center is more reliable and less time consuming than a search using traditional methods. Promoting a controlled centralized system with the instrument developers' input facilitates access to reliable, comprehensive and updated information, and contributes to meeting health authorities' requirements of evidence-based information.