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<https://doi.org/10.1177/2333721420920424>

PUBLISHER

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VERSION

VoR (Version of Record)

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Maltby, John, Eef Hogervorst, Blossom Stephan, Xu Sun, Pinyan Tang, Effie Law, and Elizabeta B Mukaetova-Ladinska. 2020. "The Development of a Quality of Life Scale for Informal Carers for Older Adults". Loughborough University. <https://hdl.handle.net/2134/12654476.v1>.

The Development of a Quality of Life Scale for Informal Carers for Older Adults

Gerontology & Geriatric Medicine
Volume 6: 1–6
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sagepub.com/journals-permissions
DOI: 10.1177/2333721420920424
journals.sagepub.com/home/ggm



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Abstract

Background: The aim of the study was to develop a multidimensional quality of life instrument suitable for use among individuals across cultures who have an informal care role for older persons. **Methods:** Participants were informal carers of older adults in the United Kingdom ($n = 308$), United States ($n = 164$), and China ($n = 131$). We carried out exploratory and confirmatory factor analyses of 61 items derived from the eight-factor Adult Carers Quality of Life Questionnaire with newly added items to define both traditional and nontraditional informal care roles. **Results:** Findings suggest a 24-item quality of life scale with a six-factor structure to caring for older adults that assesses (a) exhaustion, (b) adoption of a traditional carer role, (c) personal growth, (d) management and performance, (e) level of support, and (f) financial matters. **Conclusion:** We present a new scale to assess the multidimensional aspects of quality of life among those caring for older adults.

Keywords

caregiving, well-being, support, measurement

Manuscript received: January 23, 2020; **final revision received:** March 11, 2020; **accepted:** March 23, 2020.

Introduction

With population aging, there are emerging gaps in services which place increased pressure on family members to care for dependent older people (Zhu & Walker, 2018). Subsequently, this has an effect on carers' quality of life, both positively and negatively (Joseph et al., 2012; Lawrence et al., 2008). One avenue of research is to adopt a multidimensional model of carer experience moving away from assessing primarily the general symptoms of well-being (e.g., by assessing depressive symptoms; Joseph et al., 2012). The Adult Carers Quality of Life Questionnaire (Joseph et al., 2012) focuses on both positive and negative outcomes across eight domains: caring support, caring choice, caring stress, financial implications, personal growth, sense of value, ability to care, and carer satisfaction. Similarly, the Carer Experience Scale (Goranitis et al., 2014) comprises the following six attributes: activities, informal support, formal support, fulfillment, control, and quality of the relationship with the care recipient. The current study seeks to expand the multiperspective approach taken in these questionnaires (Goranitis et al., 2014; Joseph et al., 2012) to focus on caring for people in their old age.

There is a need to shift focus from a general caring for-an-adult role to a specific measure for those caring for older adults. The number of informal carers for older aged individuals is increasing with the rapidly aging population, resulting in caregivers providing for aging individuals with usually more complex care needs related to both physical and mental dependency due to dementia, psychiatric, and physical comorbidities (Kingston et al., 2018). Therefore, given the burden of adapting to the complex care needs (Mortazavi et al., 2015), the mostly qualitative evidence (Cross et al., 2018) suggests that caregiving for older adults is associated with isolation and a departure from the carer's usual or expected lifestyles. Consequently, the stress of meeting these changing needs can affect the

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mental health of caregivers, leading to people abandoning their caregiving altogether (Del-Pino-Casado et al., 2017). Caring for older adults presents specific challenges and development of measures that accurately capture or identify specific issues related to this form of caring are needed. A review of qualitative accounts suggest that elements that need to be accounted for include the role of the person (and the challenges therein) in being a carer, their ability to cope, the potential rewards of caring, and the caregivers' experience of formal and informal support (Cross et al., 2018; Lawrence et al., 2008).

There is also a need to understand the cultural variations surrounding caring for older adults in terms of the "traditional" and "nontraditional" roles (Lawrence et al., 2008). Typically, within a cultural context, a traditional caregiving role for an older person is where caregiving is an expectation, natural, and virtuous, in which the needs of the person cared for are prioritized, with the role often shaped by a culturally normative process and cultural tradition and justification (Cross et al., 2018; Dilworth-Anderson et al., 2005; Haley et al., 1996; Lawrence et al., 2008). Within a cultural context, a nontraditional care role is unexpected, unnatural, and seen by the carer as lacking virtue and reflects a deviation from a caregiver's life plans with no perceived rewards (Lawrence et al., 2008). Cultural variations are thought to exist within these two roles. For example, in the United Kingdom, South Asian carers tend toward a traditional approach, while Caucasian carers tend to follow a nontraditional approach, while Black Caribbean carers are split between the two (Lawrence et al., 2008). These two accounts of caregiving for older persons are important elements which need to be accounted for when considering the quality of life of a caregiver, with individual experience of caregiving influencing both the caregiver and those cared for (Spector et al., 2016), and the adoption of a traditional caregiving role mediating higher levels of caregiver stress within particular cultural groups (Lawton et al., 1992).

Knowing the quality of life of someone who has adopted an informal care role for an older aged person will have important implications in terms of recognizing the support and additional care needed across this population. Therefore, the aim of this study was to develop a quality of life scale for those caring for older adults seeking to explore the multidimensional aspects of quality of life, while considering both the traditional and nontraditional roles of caregiving.

Method

Research Design

The study employed survey and correlational techniques.

Samples

Three samples were recruited via online survey data recruitment platforms including Prolific (UK), MTurk

(USA), and Wenjuanxing (China). All participants self-identified as caring for an individual aged ≥ 55 years. Sample 1 comprised 308 (89 men, 219 women; $M = 40.64$ years, $SD = 13.29$) U.K. respondents. Sample 2 comprised 164 (68 men, 96 women; $M = 37.77$ years, $SD = 12.00$) U.S. respondents. Sample 3 comprised 131 (59 men, 72 women; $M = 32.71$ years, $SD = 7.57$) Chinese respondents. Further details of these samples are provided in Supplementary Material 1.

Measures

Adult carers for older adults quality of life. Sixty-one items (see Supplementary Material 2) were used to assess quality of life for carers of older adults. All 40 items were taken from the Adult Carers Quality of Life Questionnaire (Elwick et al., 2010; Joseph et al., 2012) that comprises eight subscales including caring support, caring choice, caring stress, financial matters, personal growth, sense of value, the ability to care, and carer satisfaction. A further 21 items were developed from the descriptions of traditional and nontraditional roles of Lawrence et al. (2008) by the authors who have expertise in psychometric test development, old age psychiatry, and dementia research. The items were written to cover the themes identified as present in the general literature on caregivers to older adults, including the caregiver role (and the challenges thereof), coping strategies, rewards, and caregivers' experience of formal and informal support. Wording was revised by the authors until there was agreement. All respondents were asked to answer all statements about the individual to whom they provided the most care (or most cared for if they cared for more than one person). Responses were scored using the 4-point scale from the Adult Carers Quality of Life Questionnaire: 1 = "Never," 2 = "Some of the time," 3 = "A lot of the time," or 4 = "Always." The 61 items were administered to the U.K. sample, with a suggested 24 items, following the first stage of the analysis, being given to the U.S. and China samples (see Supplementary Material 2 for the Chinese translation).

Ethical Consent

The study procedures received ethical approval from the <blinded> School of Psychology's Ethics Board (22061-jm148-ls:neuroscience,psychology&behavior). All participants provided written informed consent.

Results

Factor Analysis

Exploratory factor analysis (EFA) (Sample 1). As we were introducing new items to an existing scale in a new context, to explore the number of latent dimensions to the 61 items and determine where each item belonged on each of those latent dimensions, we used EFA. The ratio

of the number of participants (308) to variables (61) exceeded the recommended minimum ratio needed for EFA of 5 to 1 (with a minimum number of 100 participants; Gorsuch & Hillsdale, 1983). In terms of the number of factors to extract, a parallel analysis, calculated from 1,000 randomly generated data sets with 308 cases and 61 variables, suggested a six-factor solution, because the seventh eigenvalue value from the extraction (15.92, 8.26, 3.27, 2.77, 2.09, 1.91, and 1.50) did not exceed the seventh eigenvalue at the 99th percentile from the randomly generated datasets (2.14, 2.01, 1.93, 1.87, 1.80, 1.75, and 1.69).

Six of the items showed skewness statistics greater than ± 1 , therefore not meeting the criteria of a normal distribution. Consequently, a principal-axis EFA with Promax rotation with delta set to 0 was conducted. Table 1 shows a shortened illustration of the six-factor solution for the items used to develop the Adult Carers for Older Adults Quality of Life Questionnaire. A full table of this solution is presented in Supplementary Material 2.

Meaningful loadings were assessed using the criteria of .32 (“poor”), .45 (“fair”), .55 (“good”), .63 (“very good”), and .71 (“excellent”) (Tabachnick & Fidell, 2013). The first factor comprises items from the caring stress and caring choice subscales of the Adult Carers Quality of Life Questionnaire, with the highest loading items representing *exhaustion* and *lack of choice*. Furthermore, items derived to represent a nontraditional caregiver ideology also loaded on this factor, albeit not as high. The second factor comprises items derived from reflecting a *traditional care role* and loaded highest for this factor. The third to sixth factors comprise items from the *ability to care*, *personal growth*, *caring support*, and *financial matters* subscales of the Adult Carers Quality of Life Questionnaire, respectively. Overall, the EFA analysis suggests a six-factor solution to the quality of life among those who care for older adults.

Confirmatory factor analysis (CFA) (Samples 2 and 3). CFA was used to examine whether the proposed six-factor model of the Adult Carers for Older Adults Quality of Life could be replicated in the U.S. and China samples. Also, we proposed the development of a shorter scale than the original 61 items to facilitate efficient and comfortable use among carer populations, thereby reducing burden on respondents. We proposed four items to measure each facet, as the financial matters factor only comprised four items, and the loadings on these factors represent a “good” or better assessment. Proposing a scale of four items exceeds the minimum criteria of three items to identify a factor (Little et al., 1999; Velicer & Fava, 1998). Developing a scale of 24 items is within the optimal range of 20 to 30 items suggested by P. Kline (1986) for a questionnaire, and having 24 items keeps the questionnaire response time to optimal (i.e., no longer than 10 min) for minimizing nonresponses (Revilla & Ochoa, 2017), allowing 25 s for each question. Using

equivalent number of items per scale facilitates direct comparison between subscales scores, without having to consider the effects of some subscales being longer than others. Finally, using four items per subscale meant the number of participants (164/131) to variables (24) ratio exceeded the recommended minimum ratio needed for CFA of 5 to 1 (with a minimum number of participants of 100; Hair et al., 2010; Hu & Bentler, 1999).

Therefore, we examined whether the six-factor model presented a good fit to the data. To assess each of the proposed models, we used criteria for adequate goodness-of-fit indices: confirmatory fit index (CFI), non-normed fit index (NNFI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR). Statistics that represent an “acceptable” fit are indicated by CFI and NNFI $\geq .90$, and RMSEA and SRMR of less than .08 (R. B. Kline, 2005). Also, the incremental value of the proposed CFA models is indicated by a change in CFI (Δ CFI) greater than .01. We compare three models across both samples. The first two were (a) a unidimensional model, proposing that all 24 items formed an underlying latent factor of caring quality of life, and (b) a six-factor model (based on the EFA) comprising exhaustion and lack of choice, the traditional caring roles, the ability to care, personal growth, caring support, and financial matters. However, there is also increasing attention to bifactor models. With a bifactor model, the explained variance between the items is simultaneously considered between both the general (general quality of life) and group factors, for example, exhaustion, traditional caring roles, the ability to care, personal growth, caring support, and financial matters.

The goodness-of-fit statistics for the three models for each sample are presented in Table 2. While the six-factor model demonstrates an acceptable fit for some statistics, the bifactor model shows acceptable and improved (Δ CFI $> .01$) goodness-of-fit overall. For both the U.S. and Chinese samples, the general factor in this model was 6.5% and 14.3%, with the group factors explaining higher levels of variance, respectively, with the United States 93.5% (exhaustion, 18.9%; traditional, 9.9%; ability to care, 10.6%; growth, 9.8%; support, 14.5%; financial matters, 22.1%) and China 83.7% (exhaustion, 12.4%; traditional, 18.4%; ability to care, 16.9%; growth, 14.6%; support, 15.6%; financial matters, 15.6%). The findings suggest that the group factors accounted for most of the variance, and therefore the six factors should be scored separately.

Further information on mean scores and correlations with demographic variables for the six subscales for each of the countries is provided in Supplementary Material 3.

Discussion

The aim of this study was to develop a quality of life scale for those caring for older adults. We adopted an

Table 1. Maximum Likelihood Extraction of the With Promax Rotation of the 61 Items From the Adult Carers Quality of Life Questionnaire (Elwick et al., 2010; Joseph et al., 2012) and 21 Items Written From the Definition of Traditional and Nontraditional Roles Provided by Lawrence et al. (2008).

Item	1	2	3	4	5	6
Exhaustion						
1. I am mentally exhausted by caring	.869	-.034	-.092	.313	-.102	.047
2. I feel I have less choice about my future due to caring	.863	.096	.095	-.079	-.058	.033
3. I feel stressed as a result of caring	.837	.031	-.094	.139	-.053	.028
4. I feel worn out as a result of caring	.831	.012	-.009	.246	-.097	.045
Traditional care role						
5. The person I care for and I both get something out of my caring for them [†]	-.059	.728	.079	-.018	-.026	.067
6. I get a sense of reward from caring for this person [†]	-.017	.766	-.136	.206	.033	-.077
7. My caregiving of this person is the natural thing to do [†]	-.008	.705	.134	-.190	-.092	.020
8. I don't get anything from caring for this person (Reversed) [†]	.158	-.623	.196	-.188	.153	.023
Ability to care						
9. I can manage most situations with the person I care for	.072	.007	.881	-.073	-.080	.063
10. I feel I am able to make the life of the person I am looking after better	.069	.031	.808	.016	-.001	-.111
11. I am able to deal with a difficult situation	-.018	-.136	.780	.062	-.019	.038
12. I am satisfied with my performance as a carer	-.011	-.096	.762	.080	.072	-.025
Personal growth						
13. Because of caring, I feel that I have grown as a person	.108	-.054	.013	.861	.018	-.007
14. Because of caring, I have learnt a lot about myself	.202	-.048	.065	.797	.005	.021
15. I feel that I have become a better person by caring	.043	.113	.029	.747	.059	-.008
16. I have become a more tolerant person through my caring role	.119	-.028	.132	.681	.017	.052
Caring support						
17. I am happy with the professional support that is provided to me	-.067	-.016	.029	-.117	.835	.010
18. My needs as a carer are considered by professionals	.056	-.097	.002	.058	.681	-.040
19. I feel able to get the help and information I need	-.153	-.086	.062	.122	.639	.021
20. I have all the practical support I need	-.254	.000	-.004	.035	.621	.049
Financial matters						
21. I am able to save for a rainy day	.135	.059	-.137	.091	.073	.860
22. I feel satisfied with my financial situation	.035	-.037	.072	.065	.034	.842
23. There is enough money in our house to pay for the things we need	.000	.043	.091	.005	-.041	.707
24. I worry about money (Reversed)	.159	-.200	.060	.161	.103	-.608

Note. Items for the 24-item scale administered to the U.S. and China samples (Samples 2 and 3). All items from Adult Carers Quality of Life Questionnaire (Elwick et al., 2010; Joseph et al., 2012) except new items marked † which were written from Lawrence et al. (2008). Bold values represent the factor loadings.

approach that emphasizes both positive and negative outcomes, while seeking to explore the multidimensional aspects of quality of life caring (Elwick et al., 2010; Joseph et al., 2012), and also considering both the traditional and nontraditional roles related to different cultural backgrounds (Lawrence et al., 2008).

Among samples from the United Kingdom, United States, and China, we found a replicable six-factor structure related to caring older adults that included the following six separate constructs: feelings of exhaustion, adoption of a traditional role, personal growth, management and performance, level of support, and financial matters. This model is heavily reliant on the eight-factor model presented in the Adult Carers Quality of Life (Elwick et al., 2010; Joseph et al., 2012), with five of the scales reflecting assessments contained within that scale. However, the current findings suggest that the quality of life associated with caring for older adults can be represented through six rather than eight elements. Also, our findings add a new component, which is the extent to

which an individual adopts a traditional role, reflecting a quality of life focused on the carer receiving some sort of reward and/or something from the caring relationship. This is a valuable addition, given the emphasis on cultural variations around adopting this type of care role (Lawrence et al., 2008). Furthermore, following the suggestion of there being a nontraditional care role (Lawrence et al., 2008), the items we developed to assess an individual's fears about their care role and deviation from their life expectations load on an exhaustion factor. This suggests that the items loading on the exhaustion factor encompass the traditional care role.

There are two main limitations of the study. First, there are a number of factors that could have influence reported quality of life including socioeconomic status, income, ethnicity, wider family, and social support (Haley et al., 1996; Lawton et al., 1992). However, our analysis was restricted to samples from the United Kingdom, United States, and China, and therefore more research is required to examine the relevant

Table 2. Confirmatory Factor Analysis Fit Statistics for the Different Models Proposed for the Adult Carers for the Older Adults Quality of Life for the U.S. and China Samples.

Item	χ^2	df	$p \leq$	CMIN/DF	CFI	NNFI	RMSEA	SRMR
USA (n = 164)								
Unidimensional	1,570.94	252	.000	6.23	.375	.315	.179	.160
Six-factor	424.91	237	.000	1.79	.911	.896	.070	.065
Bifactor	325.09	213	.000	1.53	.947	.931	.057	.053
China (n = 131)								
Unidimensional	690.52	252	.000	2.74	.493	.446	.116	.118
Six-factor	350.18	237	.000	1.48	.869	.848	.061	.078
Bifactor	267.14	213	.007	1.25	.937	.919	.044	.059

Note. We also provide chi-square (χ^2), degree of freedom (df), significance (p), and relative chi-square (CMIN/DF). CFI = confirmatory fit index; NNFI = non-normed fit index; RMSEA = root mean square error of approximation; SRMR = standardized root mean square residual.

influence and interaction between sociodemographic variables on scores on the subscales of Adult Carers for Older Adults Quality of Life. Second, while the current factor structure is different from the Adult Carers Quality of Life Questionnaire (Elwick et al., 2010; Joseph et al., 2012), there is no clear evidence to suggest this scale or structure of the scale is specific to caring for older people. Further consideration to what extent the current scale might be distinguishable from other caring scales or might be used with other populations is warranted. Notwithstanding this consideration, the current findings suggest a shorter scale to measure quality of life among informal carers of older persons that integrates the consideration of traditional and nontraditional care roles.

Together, these findings have enabled us to present the Adult Carers for Older Adults Quality of Life Questionnaire. The factor analyses demonstrate structural validity for a measure to assess the multidimensional aspects of quality of life among those caring for older adults. Being able to assess the quality of life among those who adopt an informal care role for an older aged person will inform the type of support needed across this population.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Ethical Approval

Ethical approval for the study was gained from the University of Leicester School of Psychology Ethics Board under Ethics Code (22061). Written informed consent was gained from participants.

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Open Data

Data reported in this study are available at the University of Leicester data repository: <https://leicester.figshare.com/>.

Supplemental Material

Supplemental material for this article is available online.

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