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Reliability and validity of the COPE Index among caregivers of disabled people

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ABSTRACT

Aim: To study the reliability and validity of the Carers of Older People in Europe (COPE) Index among caregivers of disabled people of different ages.
Methods: A cross-sectional design of Finnish caregivers ($n = 1117$). Exploratory factor analysis (EFA) was performed separately on samples of three different age groups, and the internal consistencies of the subscales were investigated.
Results: Three factors were identified; Cronbach's alpha was 0.83–0.86 for negative impact and 0.77–0.78 for quality of support, indicating good internal consistency. The third factor, positive value, was less consistent across the age groups ($\alpha < 0.66$).
Conclusions: The COPE Index is a valid and reliable screening tool to measure negative impact and quality of support of caregivers of disabled people. Further research is needed to develop the COPE Index to more precisely measure positive value of the caregiving process.

1. Introduction

Informal caregivers' helping hands enable many disabled persons to live in their homes rather than in an institution, and increasing importance of this assistance is evident due to the aging population and limited resources of welfare societies in Western countries. For example, it has been estimated that 6.4% of whole population in Finland serve as family caregivers (Vilkko, Muuri, Saarikalle, Noro, & Finne-Soveri, 2014) - but not, however, without personal cost. Several population-based studies have revealed that the caregiving process can have a negative impact (Kim & Schulz, 2008; Pinquart & Sorensen, 2007), including depressive symptoms, anxiety or distress as outcome measures of mental health (Mohamed, Rosenbeck, Lyketsos, & Schneider, 2010; Smith et al., 2014). Moreover, the burden of caregiving is associated with cardiovascular illness (Haley, Roth, Howard, & Safford, 2010; Ji, Zoller, Sundquist, & Sundquist, 2012; Mausbach, Patterson, Rabinowitz, Grant, & Schulz, 2007; von Kanel et al., 2008).

Caregiving stress is an outcome of a process which comprises caregiver's background characteristics, primary and secondary stressors, and mediators of stress (Pearlin, Mullan, Semple, & Skaff, 1990). Risk factors for higher stress in a caregiver's background are female gender, low education and cohabitation with the care recipient (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). In particular, multiple caregiving tasks and extended amounts of time spent on caregiving, and challenges caused by the behaviour of the recipient seem to stress caregivers (Savundranayagam & Kosloski, 2011). On the other hand, higher personal mastery (van der Lee, Bakker, Duivenvoorden, & Dröes, 2014), social support (Rodakowski, Skidmore, Rogers, & Schulz, 2012) as well as increased use of positive coping strategies (Harmell, Chattillion, Roepke, & Mausbach, 2011) have a protective effect on health outcomes whereas the use of avoidance coping strategies is associated with higher caregiver strain (del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011).

Similarly, parents who are caring for children with disabilities experience a great level of stress (Hayes & Watson, 2013; Lee, 2013; Pousada et al., 2013), attributable to various causes, such as behavioural problems and the disability level of the care recipient, ineffective coping strategies, family functioning and poor social support (Isa et al., 2016; Plant & Sanders, 2007). These findings are comparable with those reported by caregivers of older adults and with the outcomes of parental stress processes, which also lead to psychological and physical health problems (Isa et al., 2016; Murphy, Christian, Caplin, & Young, 2007). In fact, the main differences in between findings on caregivers of children with disabilities and those on caregivers of persons in other age groups derive more from the concepts used by different researchers than from the actual effects on carers of caregiving. Since the factors of caregiver strain seem to be similar across the different age groups of

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care recipients, it might be possible and useful for the clinicians to use the same measurement to identify strain with caregivers regardless of whom they care for. This screening can enable to find those who can most benefit of supportive interventions. Accordingly, it can help planning carefully focused and better targeted new clinical interventions.

Caregiving research has been criticized for focusing mainly on the negative effects of caregiving with the result that the positive aspects have been either neglected or underreported (Nolan, Grant, & Keady, 1996; O'Reilly, Connolly, Rosato, & Patterson, 2008; Roth, Fredman, & Haley, 2015). One stressed caregiver may leave him—/herself out of caregiving if not knowing about form of support such as possibility to have a break from caregiving. Moreover, there are positive aspects in caregiving such as an improved relationship with the care recipient, the feeling of appreciation, and a perception of personal satisfaction (Li & Loke, 2013; Nolan et al., 1996). The various tools that have been developed to assess the impact of caregiving, have mostly been confined to the negative rather than both negative and positive aspects of caregiving (Van Durme, Macq, Jeanmart, & Gobert, 2012; Whalen & Buchholz, 2009). Of these instruments, the most studied and clinically used is the Zarit Burden Inventory, which mainly evaluates caregiver strain and was developed for caregivers of persons with dementia (Van Durme et al., 2012).

One of the multidimensional scales identified by Whalen and Buchholz (2009) is the COPE Index (Caregivers of Older People in Europe Index). It was developed in collaboration with several European countries as a brief first-stage assessment tool to identify caregivers who may need supportive interventions of any kind (Balducci et al., 2008; McKee et al., 2003). In the COPE Index, a caregiver is seen as a partner and expert rather than a resource, and this holistic view of caregiving includes both perceived positive and negative aspects of caregiving in light of existing support (Nolan & Philp, 1999). Highlighting positive aspects of caregiving can give experiences of empowerment for caregivers, and pointing out negative impacts can help targeting their supportive actions more accurately. To date, Cope Index has been utilized as part of social and health care services among caregivers of elderly people. In addition, it has been utilized among caregivers of other than elderly care recipients (Jönsson, Wijk, Danielson, & Skärsäter, 2011; Salminen, Hämäläinen, Karhula, Kanelisto, & Ruutiainen, 2014). However, the validity and reliability of the scale among caregivers of disabled people at different age have not been investigated.

The aim of this study is to investigate and compare the validity and reliability of the Finnish version of the COPE Index among caregivers of care recipients in different age groups.

2. Methods

2.1. Study design and participants

This study is a part of a large cross-sectional research project, the Caregiver Research Project of the Social Insurance Institution of Finland (Tillman, Kalliomaa-Puha, & Mikkola, 2014). Ethical approval for the research project was obtained from the research department of the Social Insurance Institution of Finland. The population studied, the caregivers, was defined utilizing the administrative data of income taxes. In detail, people, who had received the caregiver's allowance in 2012 and lived in mainland in Finland at the end of 2012, belonged to the studied population. However, people, who had died, lived abroad or were in institutional care at the time of the sample was drawn, were excluded. The size of the population was 40,591 caregivers. A simple random sample of 4000 caregivers was drawn from the population in the spring of 2014. The 80-item questionnaire was mailed via the Finnish postal service in May and June 2014. The response rate was 59.7% ($n = 2388$). The missing value analysis, adjusted for gender, region and age, showed that those who answered were slightly more likely over 60 years of age than those did not participate in the inquiry. Only those ($n = 1343$) who were still caregivers at the data collection point were included. Participants for whom any of the data from the 15-item COPE Index scale or care recipient's age was missing were excluded. After exclusions, 1117 participants were included in the exploratory factor analysis. The mean age of the caregivers and care recipients were higher ($p < 0.001$) in the excluded data than in the included data, and consequently the excluded participants included a larger proportion of spousal caregivers ($p < 0.001$). However, no gender ($p = 0.402$), hours of caregiving ($p = 0.102$) or duration of caregiving ($p = 0.264$) differences were observed between the excluded and included participants.

2.2. Measures

From the 80-item questionnaire were included for the purposes of this study 15-item COPE Index, which consists of three subscales for caregiving: negative impact (seven items: Do you find caregiving too demanding? Does caregiving cause difficulties in your relationships with friends?, Does caregiving have a negative effect on your physical health?, Does caregiving cause difficulties in your relationship with your family? Does caregiving cause you financial difficulties?, Do you feel trapped in your role as a caregiver?, and Does caregiving have a negative effect on your emotional wellbeing?), positive value (four items: Do you feel you cope well as a caregiver?, Do you find caregiving worthwhile?, Do you have a good relationship with the person you care for?, and Do you feel that anyone appreciates you as a caregiver?) and quality of support (four items: Do you feel well supported by your friends and/or neighbours?, Do you feel well supported by your family?, Do you feel well supported by health and social services? Overall, and Do you feel well supported in your role of caregiver?). In addition we included questions on the caregiving arrangement and the caregiver/care recipient characteristics (the caregiver's gender, relationship to the care recipient, cohabitation with the recipient, the age of the caregiver and care-recipient, the caregiver's occupational status, length of time in the caregiving measured in years, and hours of caregiving per day).

A validation study of the 15-item version of the COPE Index among nearly 6000 caregivers of elderly people from six European countries (Germany, Greece, Italy, Poland, Sweden and United Kingdom) revealed three subscales for caregiving with internal consistencies (Cronbach's α) varying from 0.64 to 0.83 (Balducci et al., 2008). Statistically significant correlations between the COPE Index subscales, especially negative impact, and criterion measurements have been as expected and have provided evidence on criterion validity (Balducci et al., 2008; Roud, Keeling, & Sainsbury, 2006). The COPE Index has been translated into Finnish, reviewed and translated back into English according to the protocol (Sousa & Rojjanasrirat, 2011). It has been piloted with the caregivers of disabled adults ($n = 63$) and published in 2011 in Finnish (Juntunen & Salminen, 2011).

2.3. Data analysis

The data were divided into three subgroups based on care recipients´ age: a) care recipients aged 65 years or over (COA); b) care recipients aged over 18 and <65 (CA); and c) care recipients aged 18 years or under (CY). For the analysis, the negative impact subscale was reversed, so that higher score indicates a higher positive experience of caregiving. This made it possible to investigate the internal consistency of the entire scale. Exploratory factor analysis (EFA) was used to explore whether the three-factor structure is replicable in the datasets of the different caregiver groups. The analyses were completed using Mplus software version 6 (Muthén & Muthén, 1998–2010). Goodness of Fit (GF) was evaluated using the root mean square error of approximation (RMSEA), the standardized root mean square residual (SRMR), and comparative fit index (CFI) based on the recommendation of Bentler (2007). It is recommended that the RMSEA would be no >0.06, the SRMR <0.08 and the CFI value close to 0.95 or greater (Hu & Bentler,