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Depression, sleep problems, and perceived stress among informal caregivers in 58 low-, middle-, and high-income countries: A cross-sectional analysis of community-based surveys

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ABSTRACT

Caregiving has been associated with adverse health outcomes. However, there is a paucity of multi-country, population-based studies on mental health outcomes of caregivers especially from low- and middle-income countries (LMICs). Thus, we assessed the association of caregiving with depression, sleep problems, and perceived stress in 10 high-, 27 middle-, and 21 low-income countries. Cross-sectional community-based data of the World Health Survey including 258,793 adults aged ≥18 years were analyzed. Multivariable logistic and linear regression analyses were conducted to explore the association of past 12-month caregiving with past 12-month DSM-IV depression, and past 30-day perceived stress [range 0 (low)-100 (high)] and severe/extreme sleep problems. Nearly 20% of the individuals were engaged in caregiving with particularly high rates observed in high-income countries (HICs) (e.g., Finland 43.3%). Across the entire sample, after adjustment for potential confounders, caregivers had a significantly higher likelihood of having depression (OR = 1.54; 95%CI = 1.37–1.73), sleep problems (OR = 1.37; 95%CI = 1.25–1.50), while their mean perceived stress score was 3.15 (95%CI = 2.46–3.84) points higher. These associations tended to be stronger in HICs. A greater number of caregiving activities was associated with a greater likelihood of depression, sleep problems, and perceived stress regardless of country income levels. In conclusion, caregiving has a negative impact on mental health worldwide with possibly greater effects in HICs. Given the growing contribution of caregivers in long-term care, interventions and policies to alleviate the mental health burden of caregivers are urgently needed to maintain sustainable and effective care practices.

1. Introduction

Population aging is occurring at an unprecedented speed globally as a result of increasing life expectancy and decreasing fertility (Lutz et al., 2008). Between 2015 and 2050, the population of older adults is expected to more than double in size, reaching nearly 2.1 billion. The older population is expanding particularly rapidly in developing regions where two thirds of the world's older people reside (United Nations, 2015).

While people now live longer, they are also living for more years with disability (GBD 2015 DALYs and HALE Collaborators, 2016). This is expected to drastically increase the number of individuals in need of care, which requires a substantial increase in the quantity of caregivers. This increasing need for care is not only for the older population.

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Children with complex disabilities also now live longer as the result of medical advances, and may even outlive their parents (Talley and Crews, 2007). Although the growing need for long-term care (LTC) policies has generally been considered in the context of industrialized countries, the LTC needs in the developing world are increasing at a much faster rate, while this need is emerging in a much more socioeconomically disadvantaged context (World Health Organization, 2003). Therefore, the establishment of sustainable and effective LTC policies is one of the most pressing issues facing modern society globally.

Worldwide, the vast majority of individuals living with disabilities due to long-term illness or old age are provided unpaid support and assistance from relatives or friends (informal care) (World Health Organization, 2003). At any given time, one out of four people acts as an informal caregiver, and half of these are likely to provide over 20 h of care per week at some point in their life (Hirst, 2002). Informal care is a crucial alternative to otherwise expensive health care services and institutional care. For example, in the UK, the value of informal adult care in 2010 was £61.7 billion (Office for National Statistics, 2013), while the financial contribution of informal caregivers is estimated to be 50%–90% of the overall LTC costs in Europe (Athens/Vienna: European Commission, 2010). However, the supply of informal caregivers is decreasing due to factors such as low fertility and smaller families, migration, and more female employment (Heitmueller and Inglis, 2007; Lamura et al., 2008). Governmental budget decreases in health care are also imposing a large burden on the decreasing number of informal caregivers (Morris, 2004). In developing countries, where health and welfare services are scant, it is likely that there is a particularly heavy reliance on informal care (Prince, 2004).

The health of the caregiver is vital to sustain informal care provision. For example, depression in caregivers often leads to the institutionalization of the care recipient (Colerick and George, 1986), which is costly at both individual and societal levels. In addition, poorer physical and mental health of the caregiver has been associated with harmful informal caregiver behavior (Beach et al., 2005; Lin and Giles, 2013). However, studies conducted mainly in high-income countries (HICs) have demonstrated that caregivers are more likely to have physical diseases and, in particular, mental health problems. Caregiving strain has been associated with a 1.63 times higher risk of caregiver death (Schulz and Beach, 1999).

Stress-related conditions and depression are the most frequent mental health problems reported among caregivers (Pinquart and Sörensen, 2003), while sleep problems are also common (McCurry et al., 2015). Chronic sleep problems and depression in the context of stressful long-term caregiving responsibilities may also increase risk for physical health problems (McCurry et al., 2015; Xiang and An, 2015). Stress may arise not only from the act of caregiving but also from the costs associated with providing care and financial cost of lost working hours (Carter, 2008). A previous study has shown that a substantially higher proportion of income may be lost as a result of caregiving in low- and middle-income countries (LMICs) compared to HICs (Viana et al., 2013).

Despite this, very little is known about dispensation of LTC and its impact on mental health in LMICs. Furthermore, multicountry studies including LMICs are scarce (Shahly et al., 2013) despite potentially different circumstances surrounding caregivers between countries (e.g., quality of social service, family size, underlying disease of the care recipient). Community-based data is also sparse and most previous studies have focused on caregiving for patients affected by a particular disease (e.g., cancer, dementia), thereby limiting generalizability. To our knowledge, two previous multicountry, general population studies of the World Mental Health Surveys examining family burden related to caregiving included data on 9–10 LMICs (Shahly et al., 2013; Viana et al., 2013). However, the only mental health outcome assessed was psychological distress.

Thus, given the complete lack of studies on the association of caregiving with depression, sleep problems, and perceived stress from a global perspective, we used data on 258,793 adults aged ≥18 years from predominantly nationally representative samples of 10 HICs, 27 middle-income countries (MICs), and 21 low-income countries (LICs) which participated in the World Health Survey (WHS), to obtain a worldwide understanding on the prevalence of caregiving, and its associated mental health burden.

2. Methods

2.1. The survey

The WHS was a cross-sectional survey conducted in 70 countries in 2002–2004. Survey details are available from the WHO (http://www.who.int/healthinfo/survey/en/). Briefly, single-stage random sampling was carried out in 10 countries, while the remaining 60 countries used stratified multi-stage random cluster sampling. All adults aged ≥18 years with a valid home address were assigned a non-zero chance of inclusion. Standard translation procedures for the survey questionnaire were followed to ensure comparability across countries. Face-to-face interviews and telephone interviews were conducted by trained interviewers. Individual level response rates were over 82%. Post-stratification corrections were made to sampling weights to adjust for non-response and the population distribution reported by the United Nations Statistical Division.

Data from 69 countries were publicly available but we excluded 11 countries for a lack of sampling information or data on caregiving. Thus, 58 countries constituted the final analytical sample (n = 258,793). According to the World Bank classification in 2003 (at the time of the survey), 10 (n = 15,841), 27 (n = 137,666), and 21 (n = 105,286) countries were HICs, MICs, and LICs, respectively. The list of the countries included in the current study is provided in Table 1. The data were nationally representative for all countries with the exception of China, Comoros, the Republic of Congo, Ivory Coast, India, and Russia.

Ethical boards at each study site provided approval for the survey with informed consent being obtained from all participants after the nature of the procedure has been fully explained. The investigation was carried out in accordance with the latest version of the Declaration of Helsinki.

2.2. Variables

2.2.1. Caregiving (exposure variable)

Those who answered affirmatively to the question “During the past year, did you provide help to a relative or friend (adult or child), because this person has a long-term physical or mental illness or disability, or is getting old and weak?” were considered to be caregivers (Hosseinpoor et al., 2013). This question is comparable to those used in previous surveys to identify caregivers (Smith et al., 2014). Furthermore, questions on five types of caregiving activities (personal care, medical care, household activities, supervision, transport/mobility) with “Yes” and “No” options were asked to caregivers (See eTable 1 of the Appendix for actual questions). The number of caregiving activities was summed. Non-caregivers were assigned a score of 0.

2.2.2. Depression (outcome variable)

Depression was assessed with the DSM-IV algorithm based on duration and persistence of depressive symptoms in the past 12 months (Cifuentes et al., 2008; Loerbroks et al., 2012). The algorithms used are provided in eTable 2 (Appendix).

2.2.3. Sleep problems (outcome variable)

Sleep problems were assessed by the question “Overall in the last 30 days, how much of a problem did you have with sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning?” with answer options none, mild, moderate, severe, and extreme. As in previous WHS publications, those who answered severe