



Burden and Support Needs of Informal Care Partners of People Living with Alzheimer's Disease in Three Countries

Tina Cartwright¹, Catherine Loveday¹, Lucy Doyle¹, Jannice Roeser², Nikki Bayliss³, Candida Halton⁴, Sally Snow⁴, Millie McLuskie⁴

¹University of Westminster, UK; ²Roche Global, Switzerland; ³Alzheimer's Disease International, UK; ⁴Studio Health, UK.

Portraits
of
CARE

BACKGROUND

Care partners are crucial in providing informal care to people with Alzheimer's disease¹. The literature demonstrates that challenges associated with caring for a person with Alzheimer's or other dementias, such as stress, burden and loneliness, can have a detrimental impact on mental and physical health and wellbeing across the care partnership dyad¹⁻⁴. The literature indicates cultural and structural variation in caregiving⁵, yet there are few multi-country studies exploring the experiences of care partners across different cultural norms and support systems.

OBJECTIVE

In partnership with Alzheimer's Disease International (ADI) and Roche, this study explored (1) wellbeing and burden, (2) satisfaction with support, and (3) support needs, among care partners from three different continents (Europe, North America, and South America).

METHODS

An online survey, administered to participants from the US, UK and Brazil, investigated care partners' anxiety and depression, using the Patient Health Questionnaire⁶, loneliness, using the UCLA Loneliness Scale⁷, burden, using the Caregiver Burden Inventory time-dependence subscale⁸, and satisfaction with and need for pre-defined categories of support. Data were collected between April 2022 and March 2023. Recruitment was through existing carer networks and social channels, led by ADI member organisations in each country, and research portals in the UK and US. Descriptive statistics were calculated using SPSS, and multivariate analyses examined factors predicting care partner wellbeing, burden (beta coefficients are reported), satisfaction with and need for each support domain (frequencies are reported).

RESULTS

SAMPLE CHARACTERISTICS

A total of 452 care partners participated (82.3% female; mean age 56.18 years, SD 12.75) from the US (47.8%), UK (28.1%) and Brazil (24.1%). 68.0% cared for a parent, 51.1% co-habited with the person they cared for, and 69.3% were the main care partner. 94.4% had received a dementia diagnosis, including Alzheimer's (65.3%), mixed dementia (11.1%), vascular dementia (9.2%), and other (14.4%). The largest proportion (44.5%) cared for someone with severe dementia ('cannot function independently at home or be taken outside the home'), and 71.4% cared for someone with at least one co-morbidity. 52.9% reported being in full-time, part-time or self-employment. 71.7% reported an impact on employment due to care partnering (Figure 1).

References

- Quinn C, Nelis SM, Martyr A, Morris RG, Victor C, Clare L. Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study. *Aging & Mental Health*. 2020 Sep 1;24(9):1505-13. doi:10.1080/13607863.2019.1602590 PubMed PMID: 31104475.
- Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: a systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care*. 2024 May 1;14(e1):e38-49. doi:10.1136/bmjspcare-2020-002242 PubMed PMID: 33055092.

Figure 1 - Impact on employment

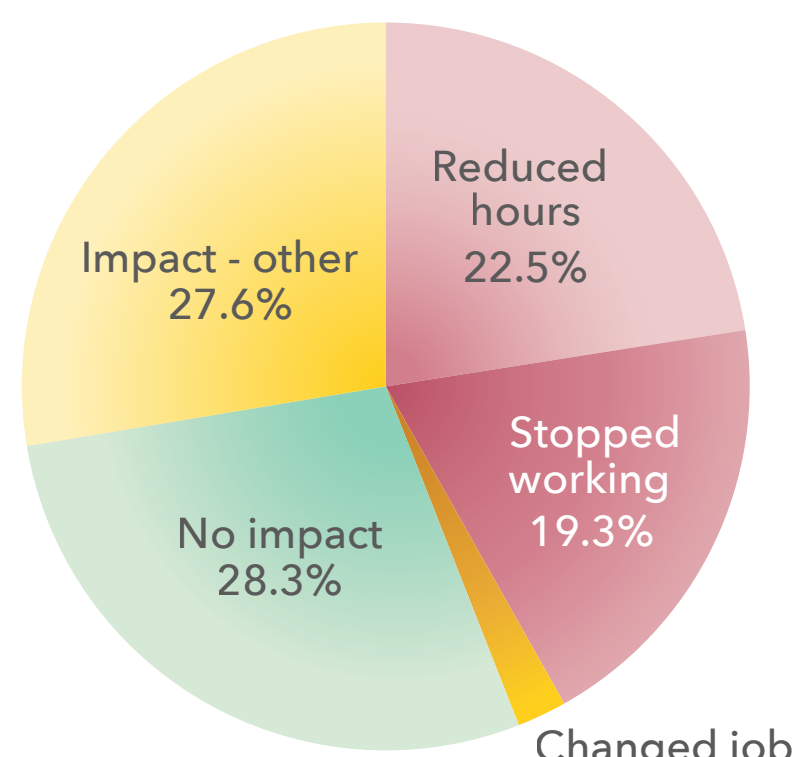
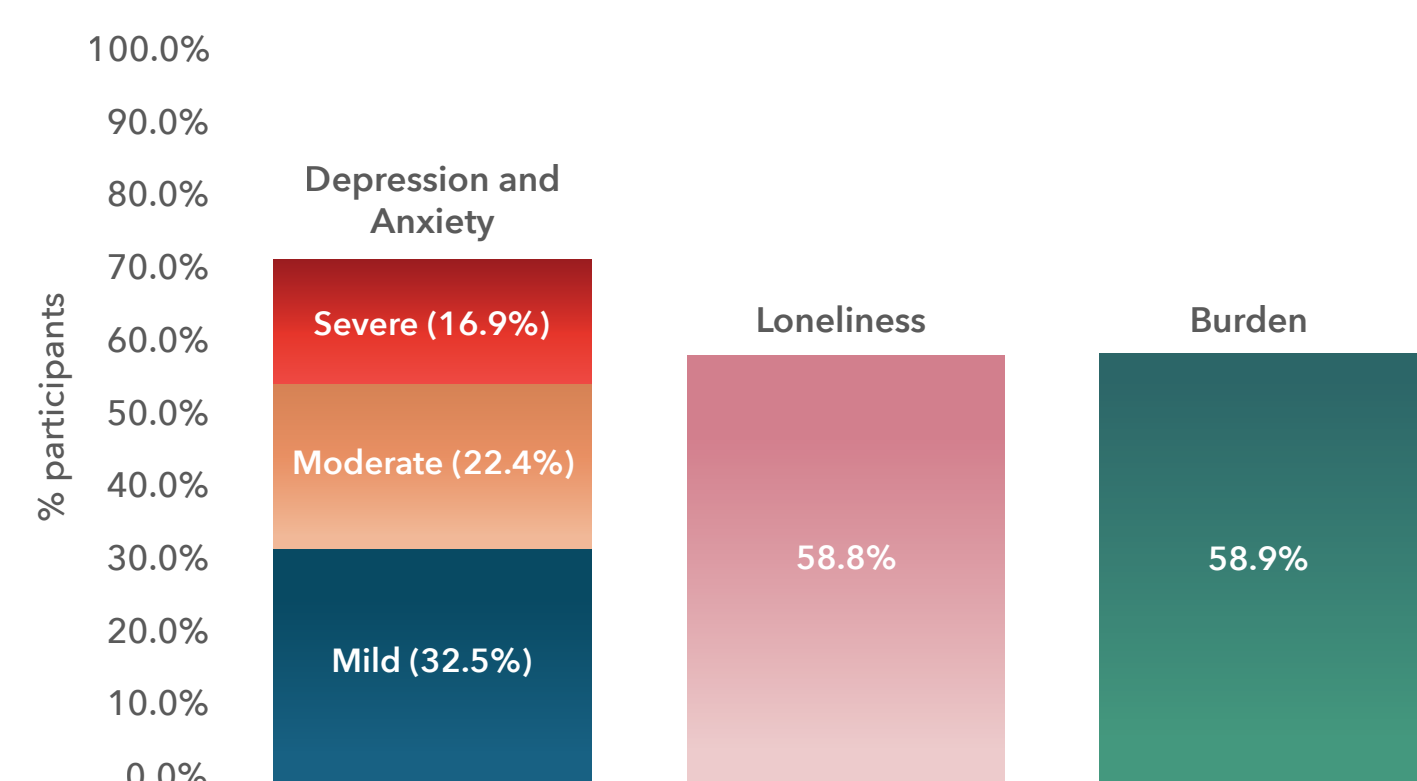
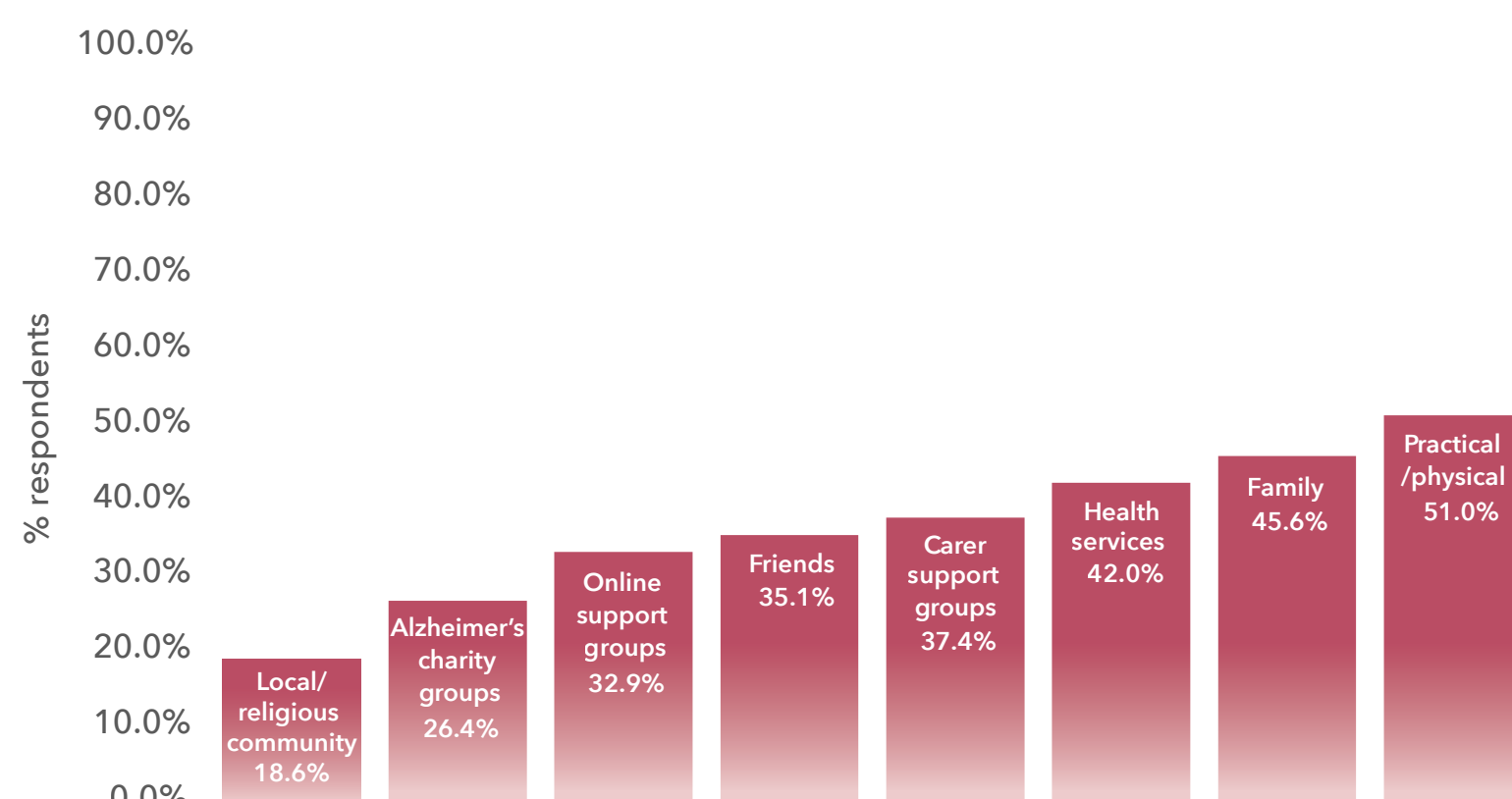


Figure 2 - Care partner wellbeing & burden



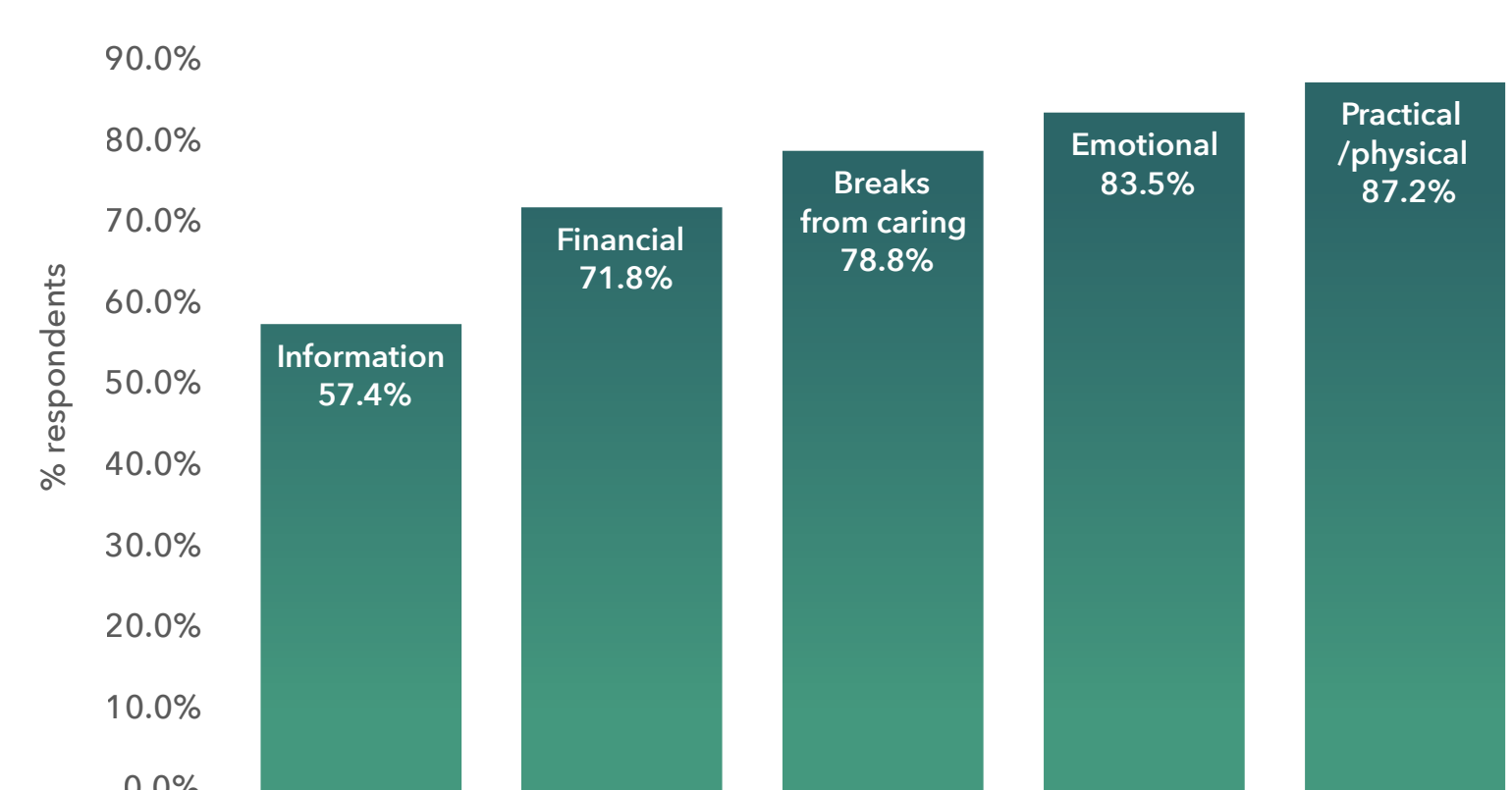
Depression and anxiety measured using PHQ-4 (scores are rated as: normal (0-2), mild (3-5), moderate (6-8), severe depression/anxiety (9-12)). Loneliness measured using UCLA (lonely defined as scores >6); Burden measured using CBI time-dependence subscale (burden defined as scores >11)

Figure 4 - Satisfaction with support



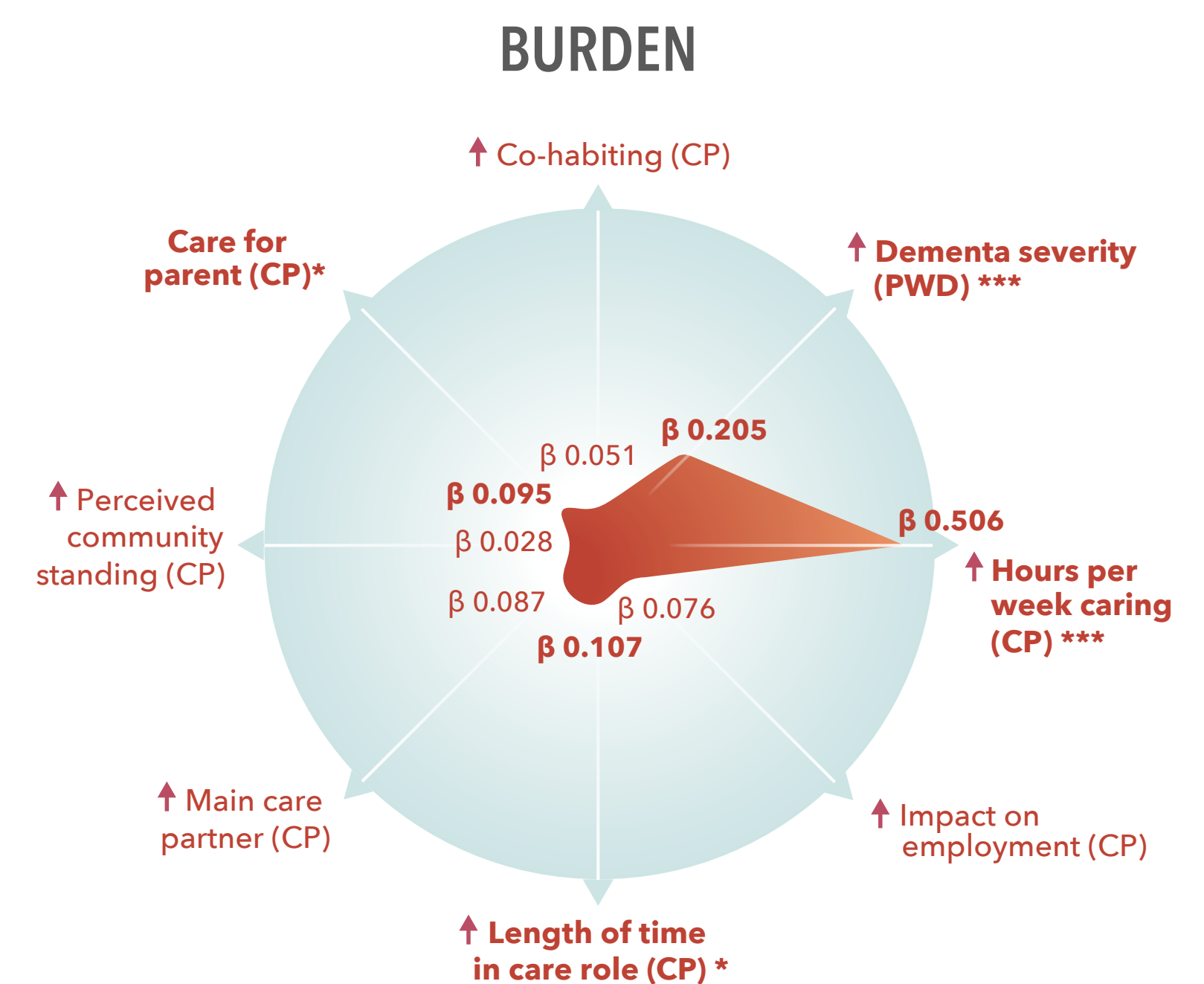
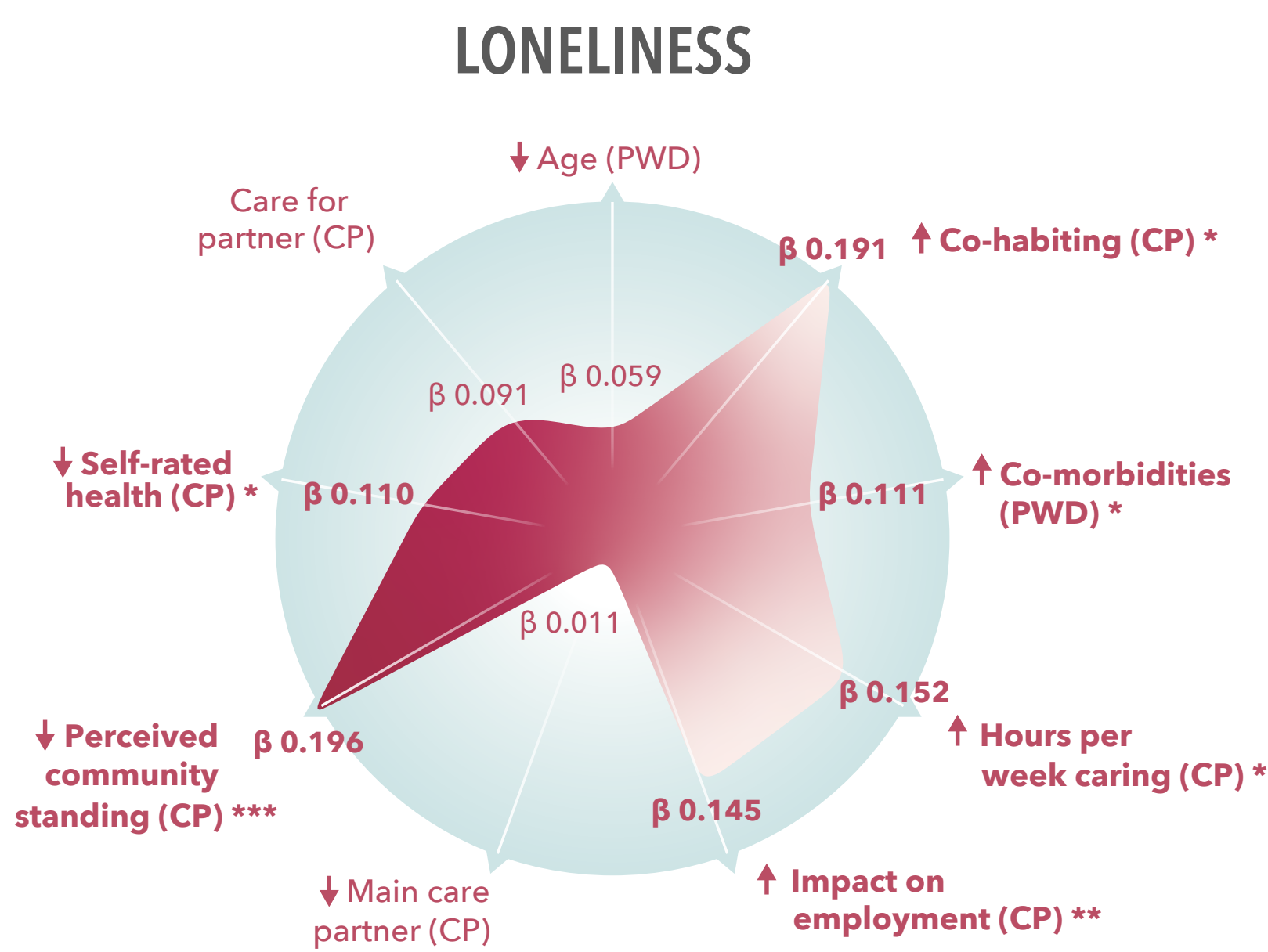
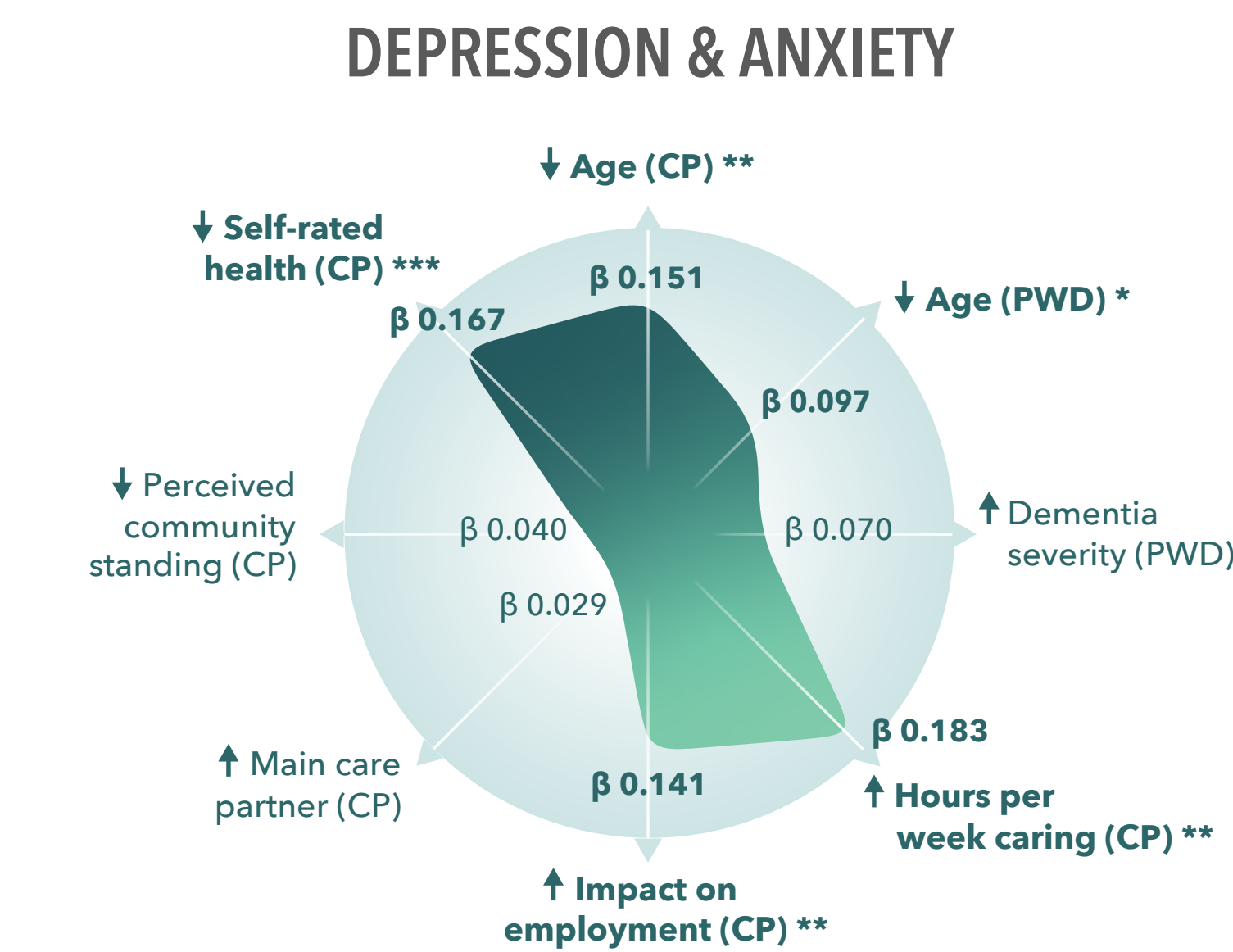
% of respondents satisfied or very satisfied with support, as measured on a 5-point Likert scale

Figure 5 - Support needs



% of respondents agree and strongly agree support type would make role easier, as measured on a 5-point Likert scale

Figure 3 - Predictors of care partner wellbeing and burden



* = p < .05; ** = p < .01; *** = p < .001
CP = care partner; PWD = person with dementia.
↑ indicates positive relationship; ↓ indicates negative relationship.



CARE PARTNER WELLBEING & BURDEN

Participant experiences of depression and anxiety, loneliness, and burden are presented in Figure 2.

Linear regression analysis: Greater hours per week caring significantly predicted all three measures of wellbeing and burden. Of interest, impact on employment significantly predicted loneliness, depression and anxiety, but not burden, while lower perceived community standing was the strongest and most significant predictor of loneliness (Figure 3).

SATISFACTION WITH SUPPORT

Participant satisfaction varied across support type (Figure 4).

Linear regression analysis: Loneliness was the strongest predictor of lower satisfaction with support (β s -0.132 to -0.315, p < 0.001 to 0.042). Other significant predictors were depression and anxiety, being the main care partner, and gender of both care partner and person being cared for (p 0.010 to 0.037).

SUPPORT NEEDS

Using pre-defined categories of support, participants reported what would make their caring role easier (Figure 5).

Linear regression analysis: The most common predictor of support needs was depression and anxiety, (β s 0.114 to 0.244, p < 0.001 to 0.045), followed by younger age and impact on employment (p < 0.001 to 0.029). Other significant predictors included loneliness, burden, being the main care partner, and length of time in care role (p < 0.001 to 0.033).

COUNTRY VARIATION

Participants from Brazil reported higher rates of depression, anxiety, loneliness and burden, as well as the greatest support needs across all domains. Tests of significance examining between-country differences are not reported due to differences in sampling methods.

LIMITATIONS

Given the time of data collection (2022-23), restrictions introduced due to COVID-19 are likely to have impacted both wellbeing and access to support services.

CONCLUSION

This multi-country study offers insight into the impact of informal caregiving on wellbeing, burden and daily life – factors evidenced in the literature to be associated with poorer mental and physical health outcomes across the care dyad¹⁻⁴. Investigating experiences and predictors of support satisfaction and needs across three continents, the data underscore the ways in which care partner experiences vary both between and within different countries. Our findings highlight the importance of tailoring care partner support services to diverse cultural and structural contexts.

This research was carried out by researchers at the University of Westminster (London, UK), in partnership with Alzheimer's Disease International (ADI) and Roche. Roche provided funding and, alongside ADI, contributed to the development and design of the study. Writing and analysis were supported by Studio Health.