



The needs and outcomes for older carers in end of life care

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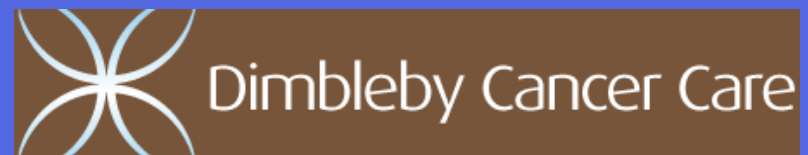
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Importance of carers

Enabling end of life care and death at home depends on the contribution of family carers ^{1 2}

- An estimated 500,000 carers are providing end of life care in the UK ³

Costs of care giving

- Psychological health
- Physical health/ mortality
- Social & relationship challenges
- Financial & occupational difficulties
- Activity restrictions
- Quality of Life



Carer Support Needs

- Lack of support is related to worse outcomes^{1, 2}
- Important to assess and address carer support needs
- Carer Support Needs Assessment Tool (CSNAT)³:
 - developed from focus groups and interviews with N=75 bereaved carers
 - 14 support domains covering support to help carer support patient and support for carers themselves

Aims

- To investigate where most support was needed
- To investigate the relationship between insufficient support and negative outcomes for carers:
 - To assess which outcomes appear most affected by lack of support
 - To assess the relative contribution of different support domains on outcome

Study Design

- Six Hospice at Home (H@H) services identified all patients currently on their caseload
- Main carer for each patient identified
- A survey pack was mailed to carer or handed over by H@H nurse

CSNAT support domains

- knowing who to contact when concerned
- understanding the patient's illness
- what to expect in the future
- managing symptoms and medicines
- talking to the patient about their illness
- equipment to help care for the patient
- help with personal care
- own physical health concerns
- dealing with their own feelings and worries
- beliefs or spiritual concerns
- practical help in the home
- financial and work issues
- day time respite
- overnight break from caring

Outcomes

- Strain
- Distress (FACQ-PC)¹
- Global Health /Quality of life (EORTC QLQ-C30²)
- Preparedness (CPCQ)³

Analysis

- Multivariate linear regression
- Relative importance of the CSNAT support domains:

Pratt index (d); quantifies each domain's contribution to the explained variance as a percentage

- Best-selection used to obtain a parsimonious model by identifying domains most important for each outcome. Bayesian Information Criterion used to select the best subset of variables

Results: sample

N = 225 carers, 25% response rate

Gender: 66% women

Work status: 61% retired

Age: Mean 63 years (SD13)

Relationship: 80% spouse, 17% son/daughter

Diagnosis: 87% cancer

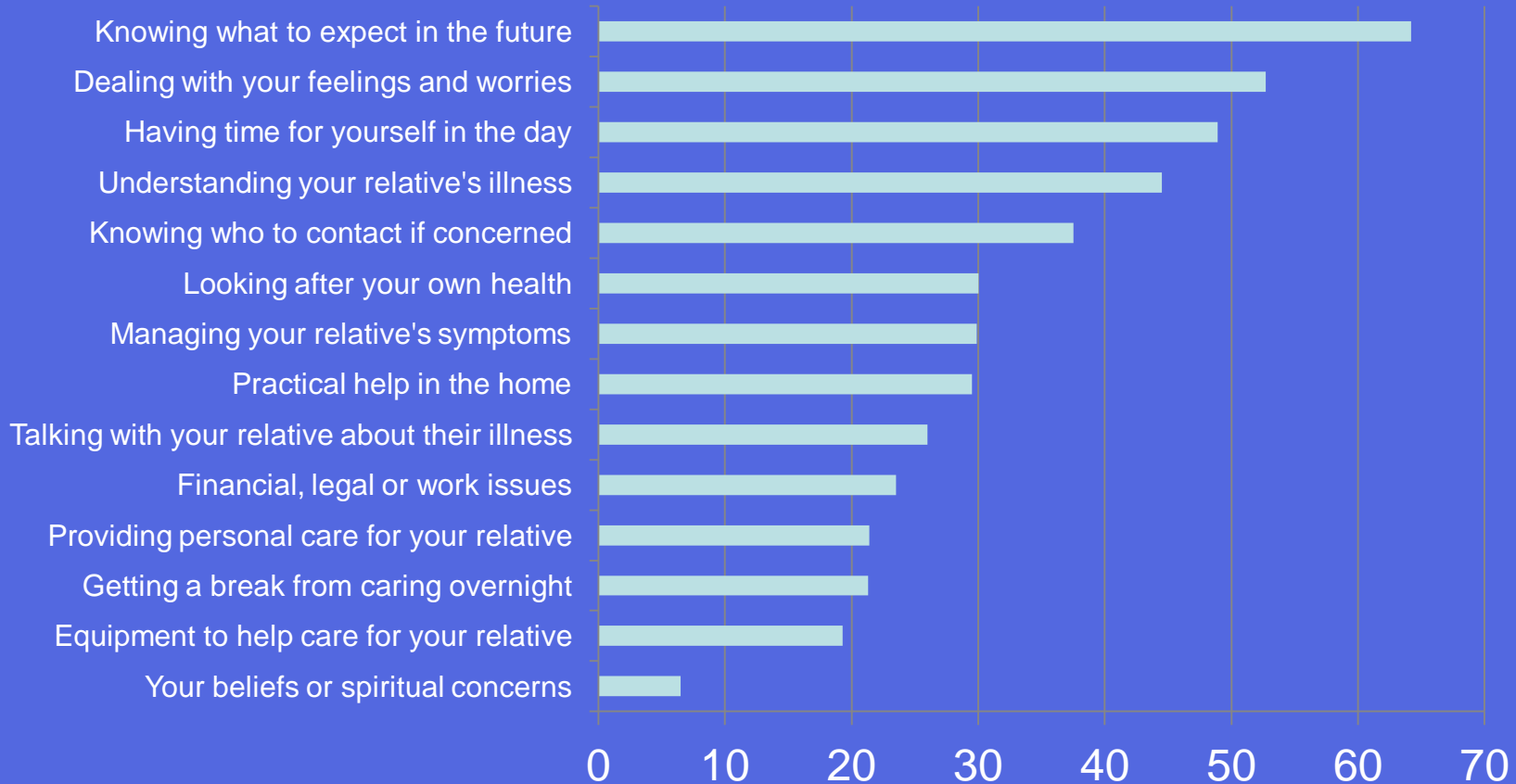
Support: 92% provided practical/physical support

Same generation: N=184 (66.5 yrs, SD 11.0);

Younger generation: N= 39 (49.3 yrs, SD

11.6)

Support needs: total sample

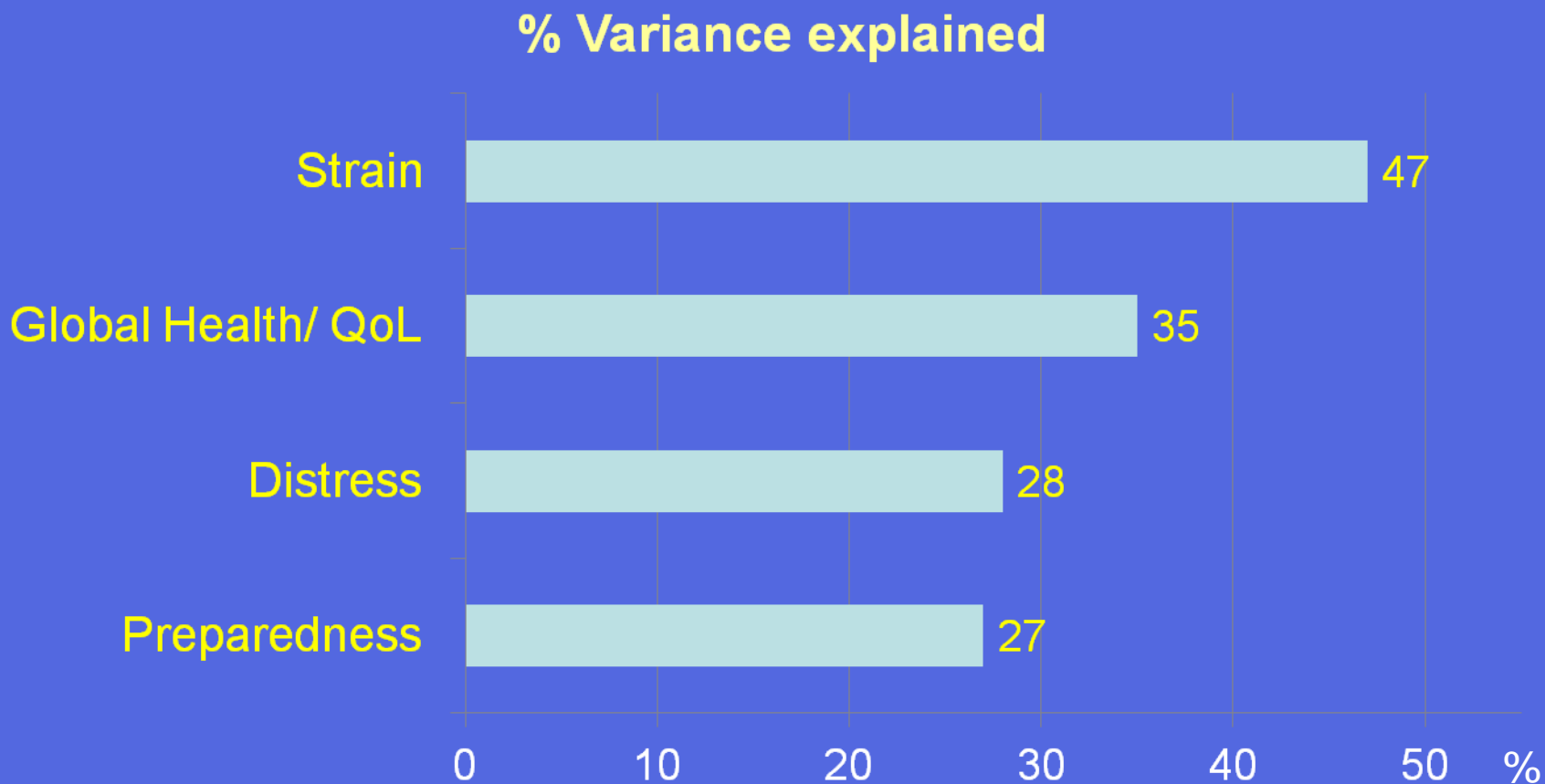


%

Needs of carers of same and younger generation to patient

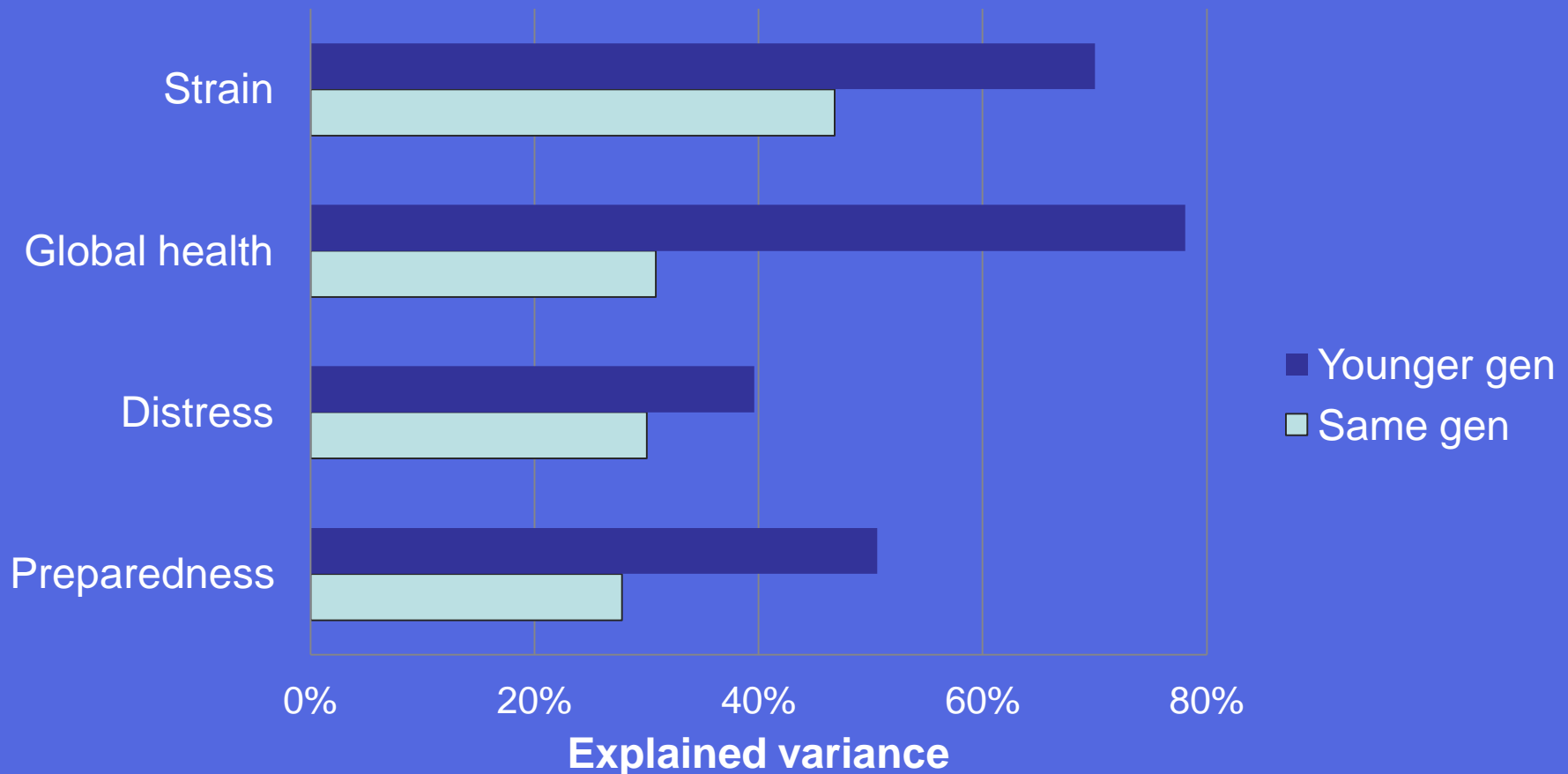


Variance in carer outcomes explained by CSNAT domains

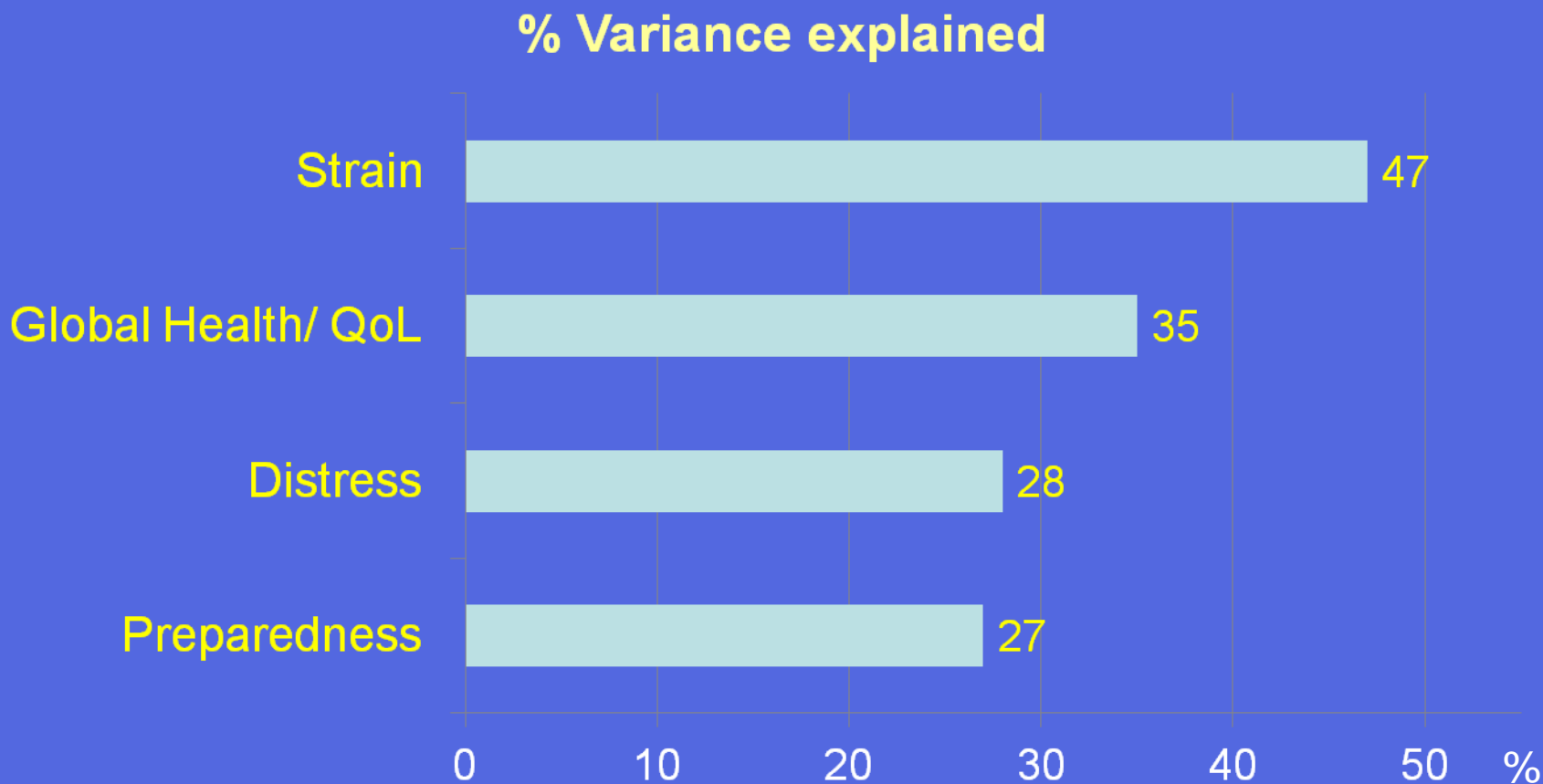


Variance in carer outcomes explained for younger and older generation carers

% Variance explained

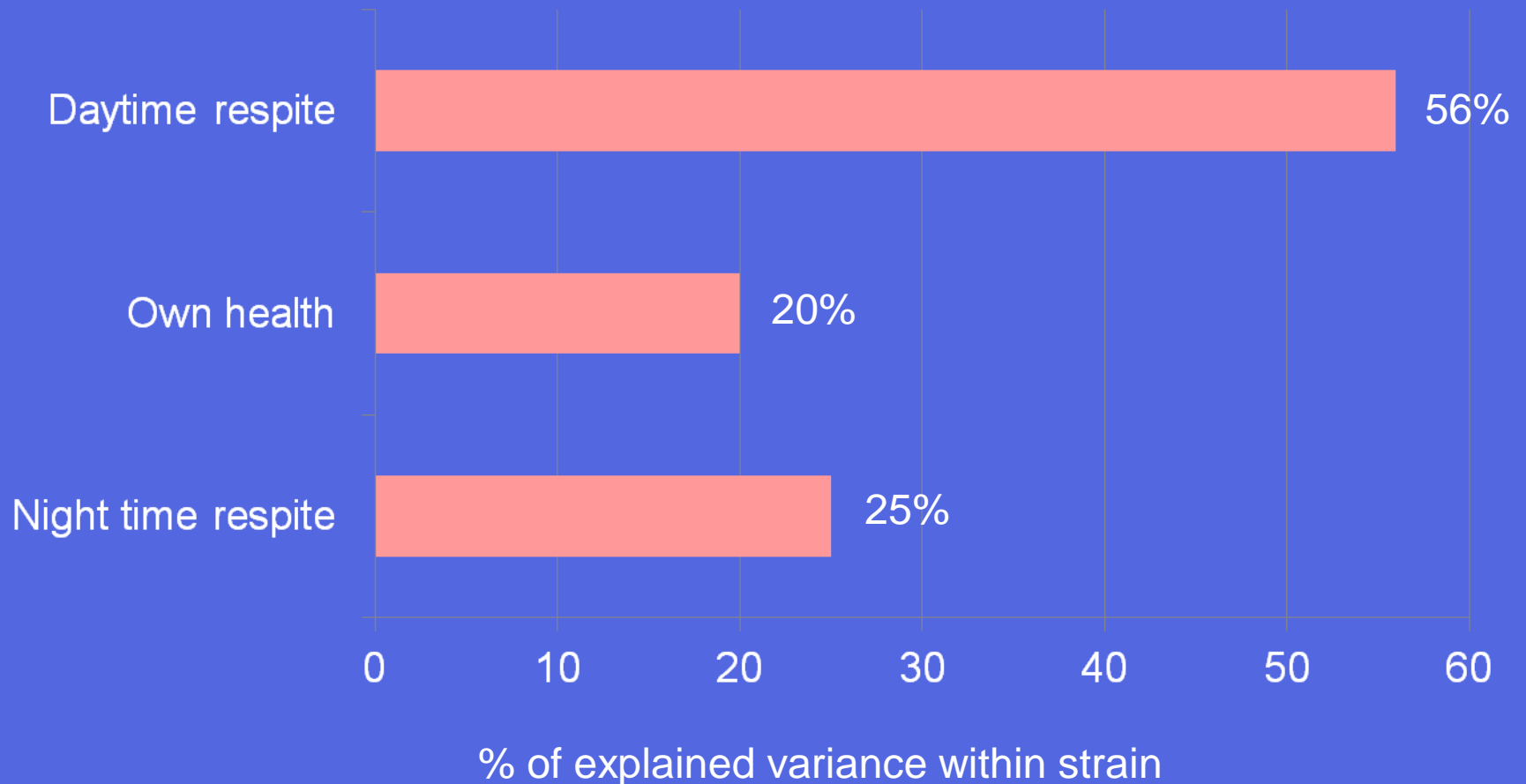


Variance in carer outcomes explained by CSNAT domains



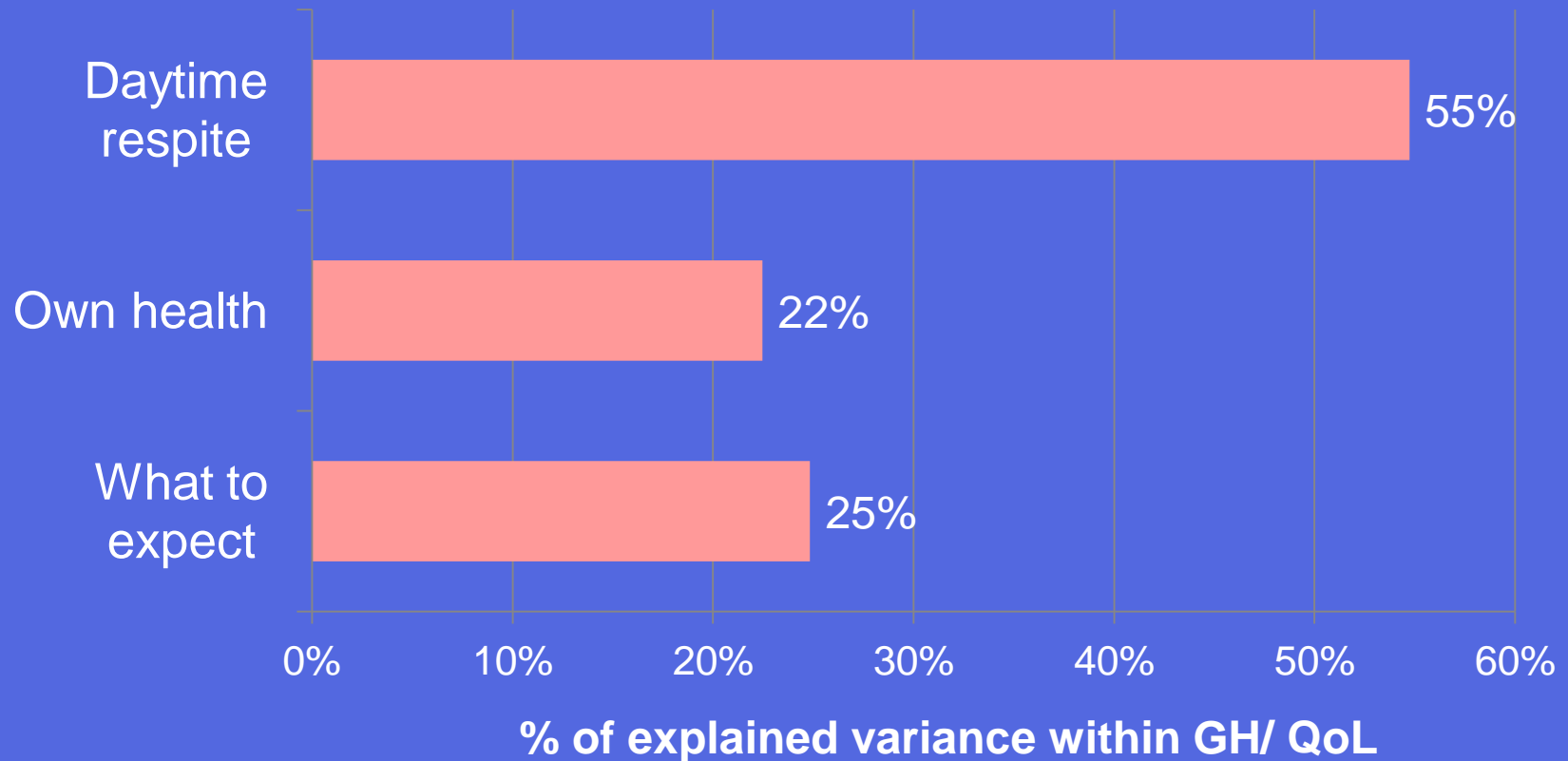
Carer strain: parsimonious model

Relative importance of CSNAT domains



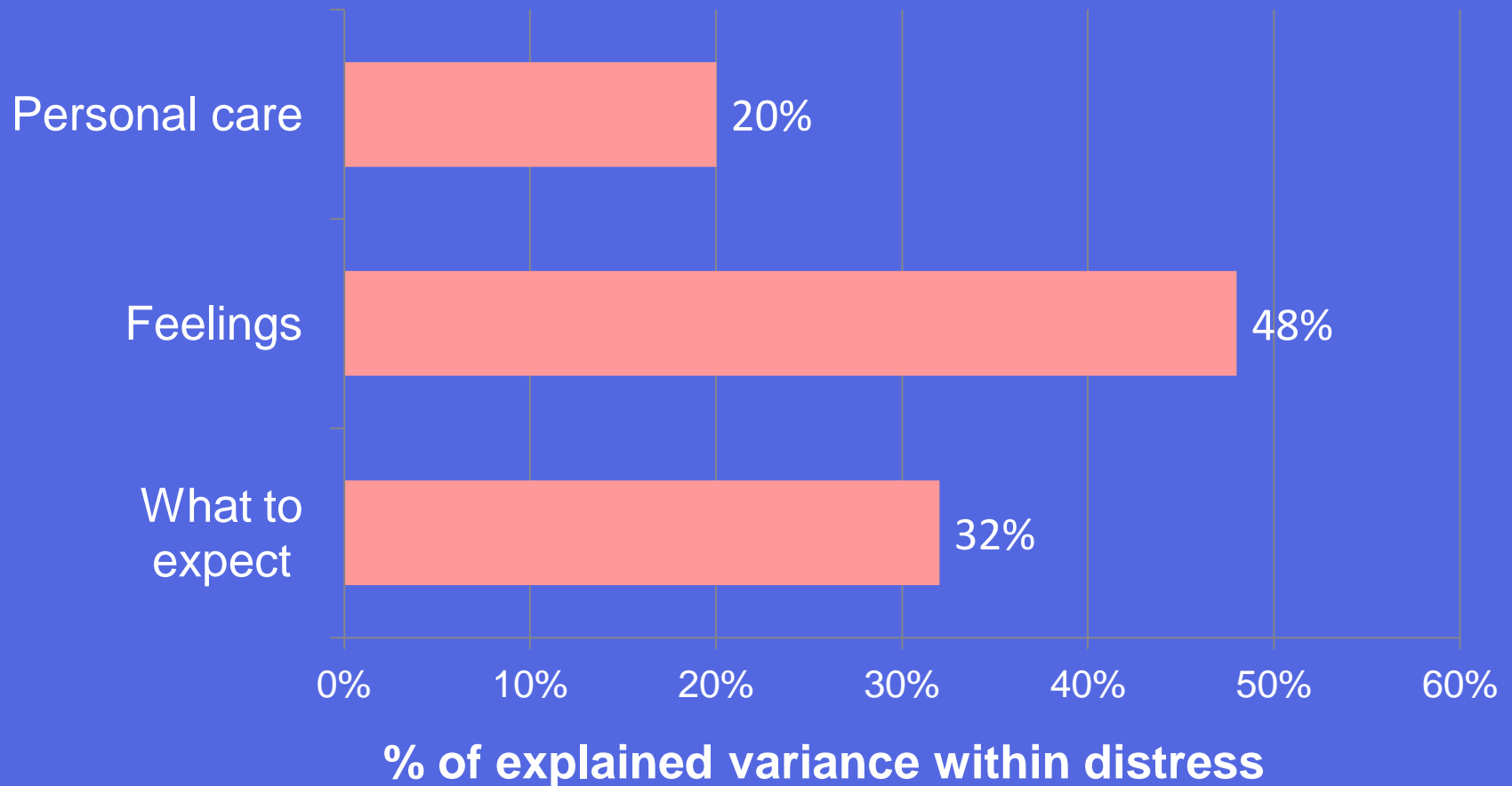
Global Health/ QoL: parsimonious model

Relative importance of CSNAT domains



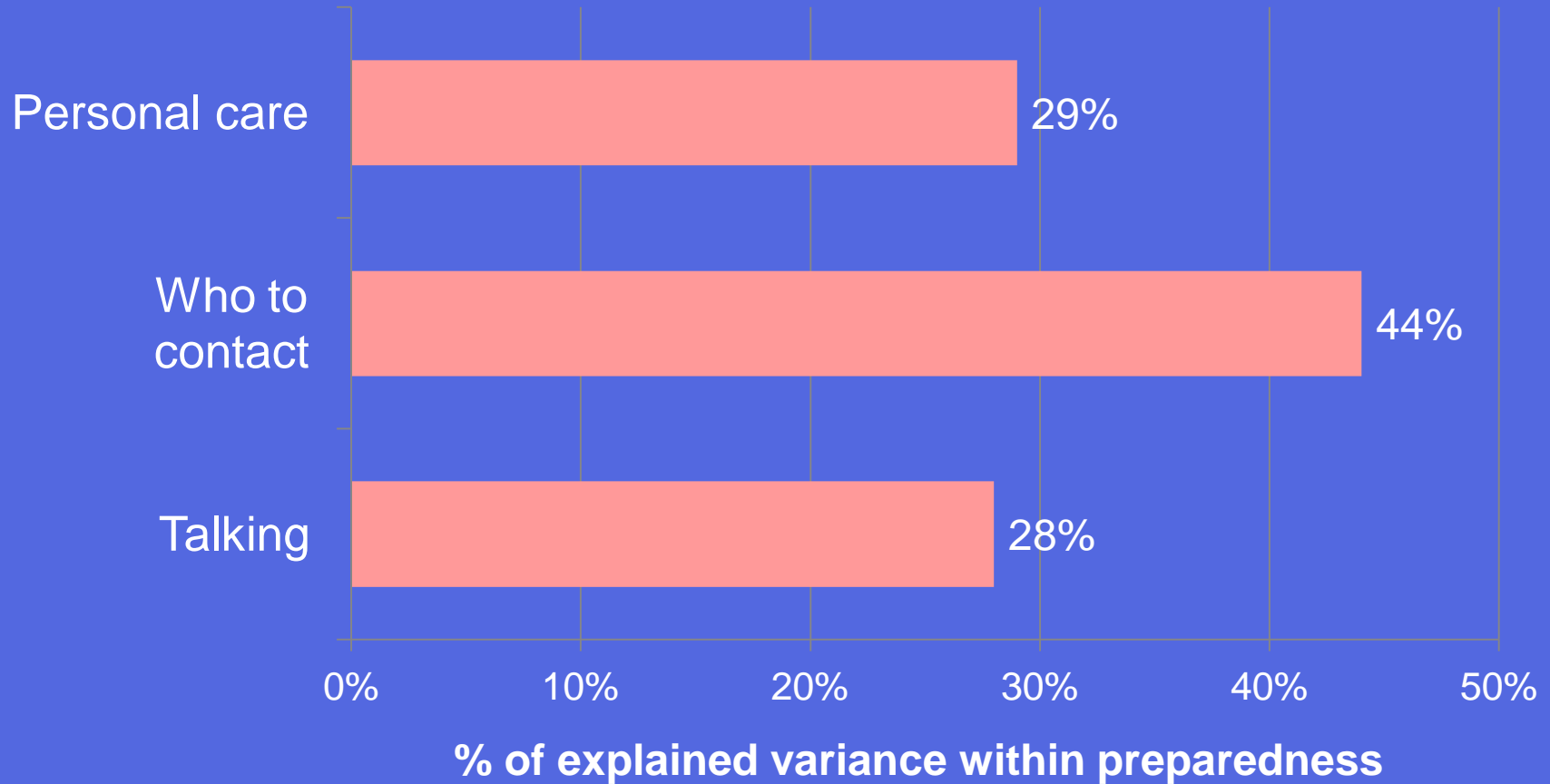
Distress: parsimonious model

Relative importance of CSNAT domains

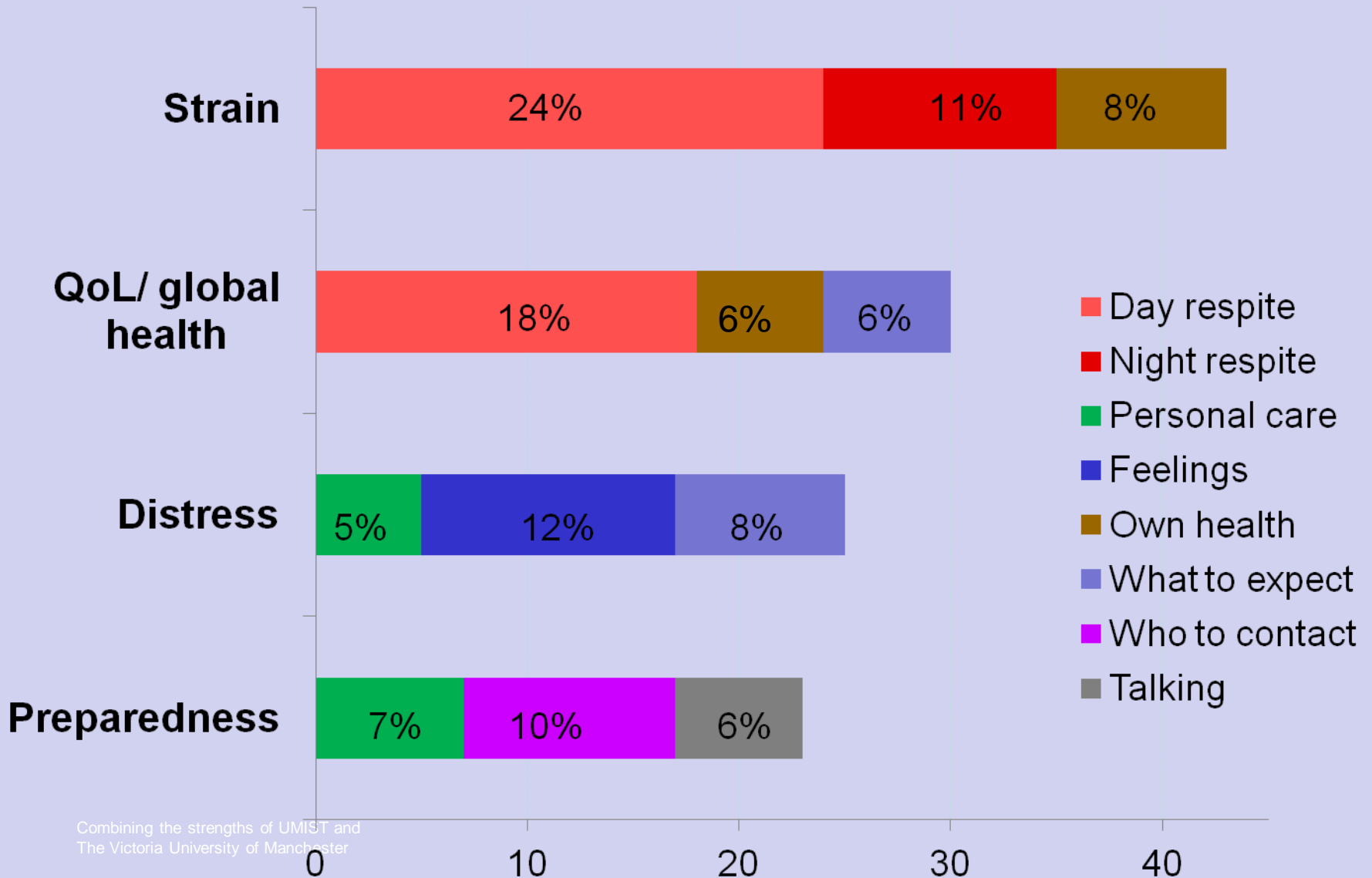


Preparedness: parsimonious model

Relative importance of CSNAT domains



Percentage of variance in impact explained by support domains (parsimonious model)



Conclusion

- Level of support is related to carer outcomes
- Need to understand the likely contribution of different domains of support in preventing negative outcomes
- Respite and reducing uncertainty about what to expect in the future are both important but affect outcomes differently

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