

VARIABLES ASSOCIATED WITH CARER QUALITY OF LIFE IN ENGLAND USING A LARGE, NATIONAL DATA SET

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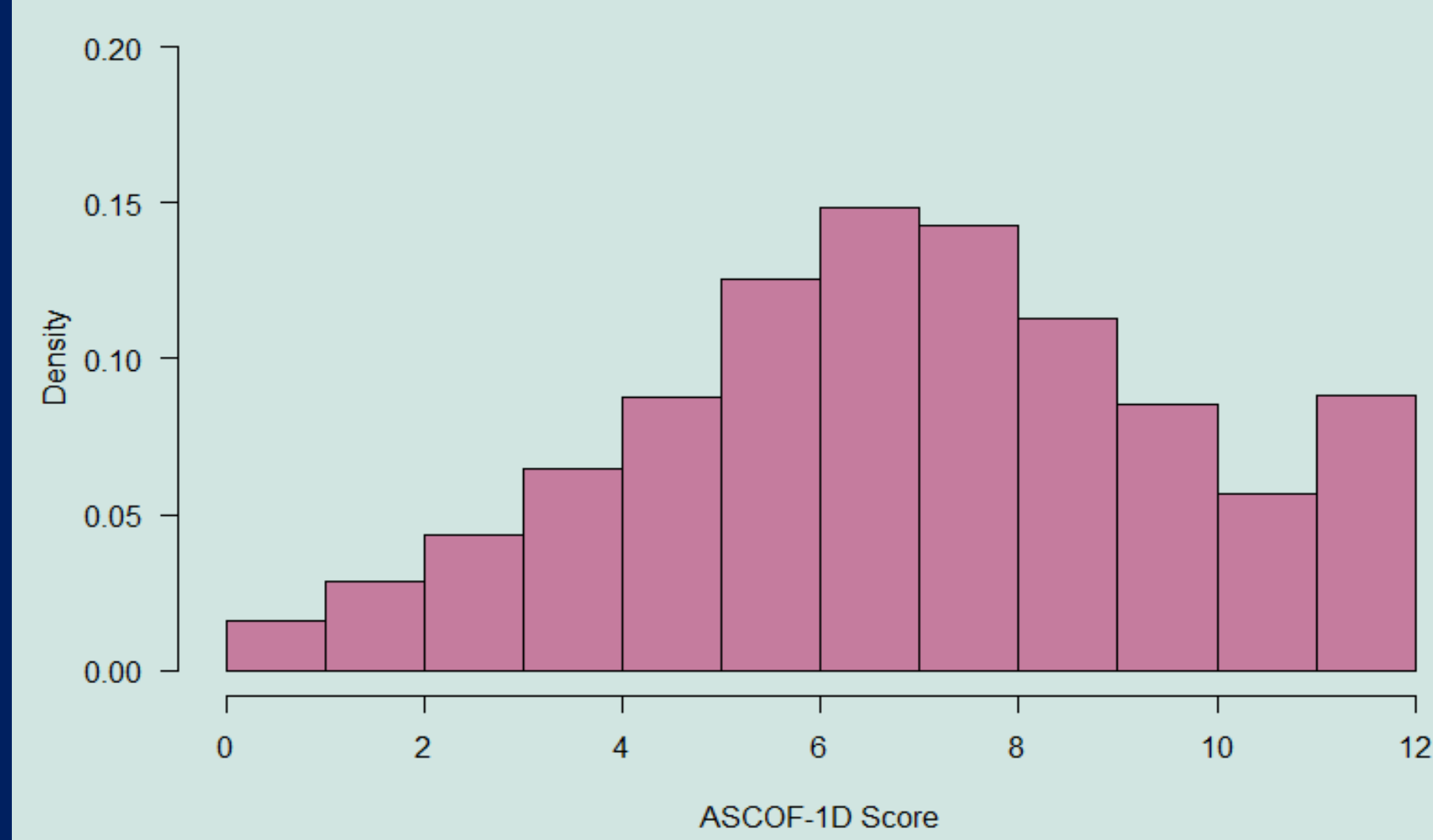


Introduction

- There is growing literature discussing the importance of accounting for carer quality of life (QoL) within economic evaluations. However, clinical trials are often focused on changes to patients' quality of life and capture little to no data on the impact to caregivers.
- Furthermore, there are limited studies considering the key drivers of carer QoL.
- The national survey of adult carers in England (SACE) takes place every two years. The survey seeks the opinions of carers aged 18 or over, caring for a person aged 18 or over, about their QoL, their general health and wellbeing.¹
- Responses collected as part of Questions 7-12 in the carers survey (Figure 1) are used for the Adult Social Care Outcomes Framework (ASCOF-1D) and a carer QoL tool ranging from 0 (lowest score) to 12 (highest score).²
- The survey also captures other data relating to demographics and carer lifestyles.

Objective: This study aims to determine the key variables related to carer QoL in England.

Figure 2 – Histogram of ASCOF-1D scores from 30,987 participants



Abbreviations: ASCOF-1D, Adult Social Care Outcomes Framework One Dimension

Results

- The mean ASCOF-1D score was 7.41 (SD 2.72) in the sample population (Table 2).
- The final regression model included the dependant variables:
 - Carer demographics: gender, ethnic group and age.
 - Caring characteristics: age of the person cared for, whether the carers lived with cared for person or not, the impact on caring for people other than the cared for person and how long they have been a carer for
 - Location: whether the carer lived in the North or South of England.
 - Socioeconomics: financial difficulties and employment status.
 - Health: physical and mental impairment.
- The exploratory regression analysis found that:
 - Only location (p=0.16) and ethnicity group classed as “refused/not stated” (p=0.50) were found to be non-significant.
 - All other variables were significantly associated with carer QoL as measured through ASCOF-1D, with increased financial difficulties (coef. -1.35; p<0.001), carer mental health conditions (coef. -0.96; p<0.001) and the hours of care provided per week (coef. -0.82; p<0.001) having a key relationship to QoL.
- The adjusted R-squared (0.27) highlights that only a minority of the variation observed in the ASCOF-1D scores can be explained by the included variables.

Table 1 – Results of stepwise selection linear regression models

Coefficients	Estimate	Pr(> t)
Intercept	12.973	<0.001
Region: North vs. South	-0.037	0.162
Gender: Male vs. Female	-0.225	<0.001
Ethnicity: White vs. Non-White	-0.100	<0.05
Ethnicity: White vs. Refused/Not stated	0.040	0.496
Age: 18-64 vs. 65+	0.079	<0.05
Age of the person cared for: 18-64 vs. 65+	-0.394	<0.001
Live with cared person vs. live elsewhere	0.151	<0.001
Impact on caring for others	-0.356	<0.001
Increasing financial difficulties	-1.351	<0.001
Unemployed vs. employed	-0.073	<0.05
Duration of caring responsibilities (overall)	-0.018	<0.05
Time required in caring responsibilities (per week)	-0.824	<0.001
Physical impairment: none vs. some	-0.551	<0.001
Mental impairment: none vs. some	-0.958	<0.001

Table 2 – Mean ASCOF-1D scores in key subgroups

Population	N	Mean ASCOF-1D score
All participants	30,987	7.411
Financial difficulties		
None at all	15,874	8.322
Some	11,563	6.665
A lot	3,550	5.091
Mental health problem or illness		
None	27,471	7.507
Yes	3,516	5.981
Time spent each week caring		
<20 hours per week	4,392	8.962
20-49 hours per week	7,807	7.621
50+ hours per week	18,788	6.833

Abbreviations: ASCOF-1D, Adult Social Care Outcomes Framework One Dimension

Discussion

- This analysis highlights which of the key variables collected in the SACE survey are related to carer QoL.
- The regression analysis indicates that carers' QoL may be negatively related by increasing financial difficulties, mental health conditions, increased time required for caring responsibilities weekly, physical impairments, caring for an elderly person compared to someone younger, increasing impact on other caregiving requirements, being female, being non-white, being employed and as the duration of caregiving increases (listed based on magnitude).
- The regression analysis indicates that carer QoL may be positively related to their own age and if they live independently to the cared for person (listed based on magnitude).
- This analysis highlights the importance of considering equity when making decisions about treatments which may prompt effects beyond the patient.
- The exploratory analysis makes use of a large publicly available data set and highlights variables found to be related to care QoL. However, it does have limitations, for example:
 - Likely impact of unmeasured variables.
 - Results are limited to England
 - Limitations of the ASCOF-1D measure (e.g., inability to convert these scores into utility values for economic evaluation).

Conclusion

The literature detailing influencers on patient QoL is vast, but there is less research exploring influencers on carer QoL. This exploratory analysis, using a large, national data set. Further research is needed to consider which potentially key variables remain unmeasured.

References

1. NHS Digital. Personal Social Services Survey of Adult Carers in England, 2021-22. [online] Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2021-22>.
2. NHS Digital. (2018). Measures from the Adult Social Care Outcomes Framework - NHS Digital. [online] Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof>.

Abbreviations

ASCOF-1D, Adult Social Care Outcomes Framework One Dimension; n, number; QoL, quality of life; SACE, survey of adult carers in England

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Figure 1 – Questions included in the SACE survey informing the ASCOF-1D

Q7. Which of the following statements best describes how you spend your time?
 a) I'm able to spend my time as I want, doing things I value or enjoy
 b) I do some of the things I value or enjoy with my time but not enough
 c) I don't do anything I value or enjoy with my time

Q8. Which of the following statements best describes how much control you have over your daily life?
 a) I have as much control over my daily life as I want
 b) I have some control over my daily life but not enough
 c) I have no control over my daily life

Q9. Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?
 a) I look after myself
 b) Sometimes I can't look after myself well enough
 c) I feel I am neglecting myself

Q10. Thinking about your personal safety, which of the statements best describes your present situation?
 a) I have no worries about my personal safety
 b) I have some worries about my personal safety
 c) I am extremely worried about my personal safety

Q11. Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?
 a) I have as much social contact as I want with people I like
 b) I have some social contact with people but not enough
 c) I have little social contact with people and feel socially isolated

Q12. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?
 a) I feel I have encouragement and support
 b) I feel I have some encouragement and support but not enough
 c) I feel I have no encouragement and support

Abbreviations: ASCOF-1D, Adult Social Care Outcomes Framework One Dimension; SACE, survey of adult carers in England

Methods

- The exploratory analysis used SACE 2018-2019 participants with complete data across all variables (n=30,987).
- The ASCOF-1D score was calculated based on responses to Questions 7-12 (Figure 1).
- A multivariate linear regression was conducted in R to assess whether any participant characteristics (dependant variables) were associated with carer QoL (ASCOF-1D).
- A significance level of 0.05 was used to interpret the results.
- Variables for inclusion in the regression were identified using stepwise linear regression (forward and backwards), prior to specification of the final model.