



Measuring carers' care-related quality of life outcomes

Stacey Rand, Juliette Malley, Julien Forder & Ann Netten

University of
Kent

LSE THE LONDON SCHOOL
OF ECONOMICS AND
POLITICAL SCIENCE ■

 UNIVERSITY OF
OXFORD

Policy Background

- Carers' Strategy in England (1999, 2010, 2014)

“It is of crucial importance that we consistently keep in mind the potential impact of caring on the lives of carers, in particular the impact on their ***health and well-being; education and employment opportunities; social life and social inclusion; and both individual and family finances***”.

- The Care Act (2014)
 - Individual wellbeing and quality of life
 - Carers' entitlement to social care services to meet their own needs
 - Services 'for' the carer (e.g. carer support group)
 - Services 'for' the cared-for person (e.g. home care)

Key questions:

Are social care services effective? Do they affect carers' QoL?

How do we measure carers' 'social care-related quality of life'?

Development of a measure of Carer Social Care-related Quality of Life (SCRQoL)

Kent Carers Survey (2008)

- Focus groups with carers to identify relevant domains of QoL
- Cognitive interviews to test survey questions with carers

Smith, Holder & Netten (2008); Holder, Smith & Netten (2009)

Personal Social Services Survey of Adult Carers in England (PSS SACE)

- Further cognitive interviewing and a pilot survey
- ‘Carer SCRQoL’ in the Adult Social Care Outcomes Framework

Fox, Holder & Netten (2010); Malley, Fox & Netten (2010)

Development of a measure of Carer Social Care-related Quality of Life (SCRQoL)

Adult Social Care Outcomes Toolkit for Carers Interview (ASCOT-Carer INT4)

- SCRQoL measure for use in research
 - Seven QoL domains, four levels of response
 - May be used alone or alongside ASCOT for the cared-for person
 - Interview version to measure both **current** and **expected** SCRQoL
- Cognitive interviews (n=31) and a survey of carers in England (n=387)

Rand, Malley & Netten (2012); Rand et al. (In press)

ASCOT-Carer INT4 Questionnaire:

Occupation ('doing things I value and enjoy')

Q1. (Current): Which of the following statements best describes how you spend your time?

When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others.

- I am able to spend my time as I want, doing things I value or enjoy
- I am able to do enough of the things I value or enjoy with my time.
- I do some of the things I value or enjoy with my time but not enough.
- I do not do any of the things I value or enjoy with my time.

Q2. (Filter): Do the support and services that *you* get from the *carer support group* affect how you spend your time doing things you value and enjoy?

Q3. (Expected): Imagine *you* did not get the support and services from the *carer support group* that you do now and no other help stepped in. In that situation, which of the following statements would best describe how you would spend your time?

Developing the ASCOT-Carerer Interview (INT4): Key Findings from Cognitive Interviewing

- **Current questions**

- Minor wording changes only

- **Filter/Expected questions**

- Carers are able to understand and answer these questions provided that 'support and services' are clearly defined.

"I can go off on a Thursday knowing he's cared for... And I go out and have lunch and do just what I want to do."

- Some carers used past experience to answer the expected questions, so interviewers need to be sensitive to the potential emotional impact of asking these questions.

"I'm imagining the situation I was in earlier on this year... I was just absolutely exhausted it was horrendous."

Developing the ASCOT-Carer Interview (INT4): Key Findings from the Survey

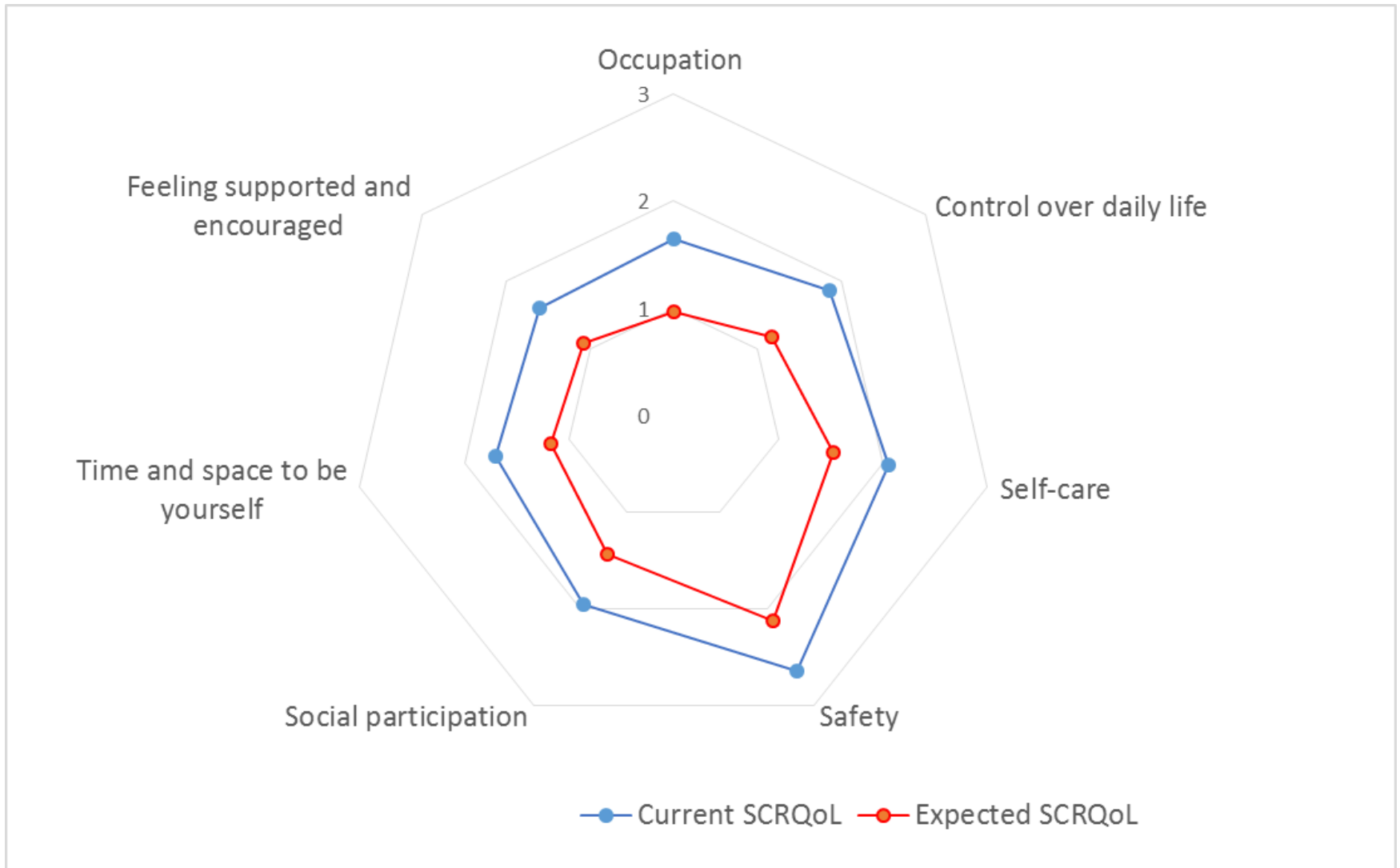
- Survey of carers in England (n=387)
 - Interviews conducted in 2013/14
 - By telephone or face-to-face
- Data collection included:
 - ASCOT-Carer interview (INT4)
 - Scales for convergent validity analysis (EQ-5D, Carer experience scale (CES), Carer Strain Index (CSI), overall QoL)
 - Variables hypothesised to be associated with carers' current SCRQoL (e.g. gender, age, employment status, health etc.).

Developing the ASCOT-Carer Interview (INT4): Key Findings from the Survey for Current SCRQoL

- Feasibility
 - Only three respondents (<1%) had 1 or more missing values
- Construct validity
 - Expected relationships observed between ASCOT-Carer current SCRQOL score and associated constructs (e.g. carer strain, health-related QoL)
 - Majority of hypothesised relationships between ASCOT-Carer current SCRQOL score and individual characteristics were also observed

Rand et al. (In Press)

Developing the ASCOT-Carer Interview (INT4): Key Findings from the Survey for Expected SCRQoL



Conclusions

ASCOT-Carer Current SCRQoL

- Evidence of good feasibility and construct validity
- Data collection by interview or self-completion survey
- An outcome measure in research designs (e.g. RCTs) to assess the effectiveness of social care interventions

ASCOT-Carer Expected SCRQoL

- Data collection by interview only
- The ASCOT-Carer interview (INT4) may be used:
 - To evaluate social care services where other methods are not feasible
 - As a framework to explore the effect of services on QoL in qualitative research
- Further work to explore psychometric properties

Contact details

s.e.rand@kent.ac.uk

For more information

www.pssru.ac.uk/ascot

Disclaimer

This presentation is based on independent research commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

References

Department of Health (2014) 'Carers strategy: second national action plan 2014-2016', HM Government, London.

Department of Health (2010) 'Recognised, valued and supported: Next steps for the Carers Strategy', HM Government, London.

Fox, D., Holder, J. and Netten, A. (2010) 'Personal Social Services of Adult Carers in England 2009-10: Survey development project – Technical Report', PSSRU Discussion Paper No. 2643 (2), Personal Social Services Research Unit, University of Kent.

Holder, J., Smith, N., and Netten, A. (2009) 'Outcomes and quality for social care services for carers: Kent County Council carers survey development project 2007–2008'. Internal Discussion Paper, Canterbury: Personal Social Services Research Unit, University of Kent.

Malley, J., Fox, D. and Netten, A. (2010) 'Developing a carers' experience performance indicator', Discussion Paper 2734, Personal Social Services Research Unit, University of Kent.

Netten, A. P., Burge, P., Malley, J., Potoglou, D., Towers, A., Brazier, B., et al. (2012) 'Outcomes of social care for adults: Developing a preference-weighted measure'. *Health Technology Assessment*, 16(16), 1–166.

Rand, S., Malley, J., Netten, A., Forder, J. (In Press) 'Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)'. *Quality of Life Research*.

Rand, S., Malley, J. (2014) 'Carers' quality of life and experiences of adult social care support in England'. *Health and Social Care in the Community*, 22(4), 375-385.

Rand, S., Malley, J., and Netten, A. (2012). 'Identifying the impact of adult social care (IIASC): Interim technical report'. Discussion Paper 2833, Canterbury: Personal Social Services Research Unit, University of Kent.

Smith, N., Holder, J., and Netten, A. (2008) *Measuring Outcomes for Carers*, paper presented at the British Society of Gerontology Annual Conference 2008 'Sustainable futures in an ageing world', University of the West of England and the University of Bristol, 4 – 6 September 2008.