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PSSRU

Personal Social Services Research Unit

QORU

quality and outcomes
of person-centred care
research unit

Developing a social care outcome measure for unpaid carers

Diane Fox, Stacey Rand, Juliette Malley
& Ann Netten

University of
Kent

LSE THE LONDON SCHOOL
OF ECONOMICS AND
POLITICAL SCIENCE ■

 UNIVERSITY OF
OXFORD

Overview

- Evolution of two *different but related* carers outcome measures from their origin in surveys.
- Outline the differences between the two outcome measures and their different applications.
- Developing the ASCOT-Carer INT4.

Evolution of measures

2008 Kent Carers Survey

(Jacquetta Holder, Nick Smith and Ann Netten)

Development had four stages

1. Appraisal of existing research on carers' needs, service quality and outcomes
2. **Outcome domain development via 4 focus groups with adult carers (n=20) and two focus groups with care managers (n=10)**
3. Design of survey questions
4. Cognitive testing of survey questions with more carers

Evolution of measures

Differences between service user and carer social care related quality of life (SCRQoL) domains

Service user (SCRQoL) domains	Carer (SCRQoL) domains
Control over daily life	Control over daily life
Occupation	Occupation
Social participation and involvement	Social participation and involvement
Personal safety	Personal safety
Personal cleanliness and comfort	Self-care
Food and drink	
Accommodation cleanliness and comfort	-
Dignity	-
	Time and space
	Encouragement and support

Evolution of measures

Response categories - 3 levels

Ideal state

I am able to spend my time as I want, doing things I value or enjoy.

Some needs

I do some of the things I value or enjoy with my time but not enough.

High-level needs

I do not do any of the things I value or enjoy with my time.

Evolution of measures

In 2008 the UK government published the National Carers Strategy - *“Carers at the heart of 21st-century families and communities”*

Adaptation of the Kent Carers Survey into the 2009/10 Personal Social Services Survey of Adult Carers in England (PSS SACE) questionnaire for national use. (Jacquetta Holder, Diane Fox and Ann Netten)

Psychometric testing of the data from the PSS SACE established the Carer SCRQoL as a viable outcome measure. (Juliette Malley, Diane Fox, Ann Netten)

Differences between Carer SCRQoL and ASCOT-Carer INT4

Carer SCRQoL	ASCOT-Carer INT4
Measures current SCRQoL only	Measures current state and expected SCRQoL in the absence of services
Collected via self-completion questionnaire	Collected via interview
6 outcome domains	7 outcome domains
3 response levels	4 response levels
Used in the PSS SACE which populates the Adult Social Care Outcomes Framework (ASCOF)	

Developing the ASCOT-Carer INT4

- Aims

- To develop a measure of the impact of long term care on carers' quality of life

The 'INT4' method: a pragmatic approach to estimating the impact of social care on quality of life (Netten et al, 2012).

- Methods

- Review of existing literature and research on carers' outcomes
- Development of survey questions
- Cognitive testing with 31 adult carers in three local authorities in England

Developing the ASCOT-Carer INT4

- Current quality of life

“Which of the following statements best describes how you spend your time?”

- Filter

“Do the support and services that [*You and/or Name of care recipient*] get from [*Examples*] affect how you spend your time doing things you value and enjoy?”

- Expected quality of life

“Imagine [*You and/or Name of care recipient*] did not get the support and services from [*Examples*] 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-Carer INT4

Response categories - 4 levels

Ideal state

I am able to spend my time as I want, doing things I value or enjoy.

No needs

I am able to do enough of the things I value or enjoy with my time.

Some needs

I do some of the things I value or enjoy with my time but not enough.

High-level needs

I do not do any of the things I value or enjoy with my time.

Developing the ASCOT-Carer INT4

‘Expected quality of life’ –

- Defining long term care in England
 - Provided by different organizations/agencies
 - Overlap with other public services, e.g. health, housing
 - Long term care support ‘for’ carers
 - Community-based support ‘for’ the care-recipient

Developing the ASCOT-Carer INT4

‘Expected quality of life’

- Cognitively demanding?

The respondents were able to understand, evaluate the different response options, and respond to the questions.

For example: ‘Expected quality of life’ is rated as worse than current quality of life for *Time and space to be myself* because with home care support the carer can leave the house without feeling worried.

“I don’t have that constant in the back of my mind, is he alright?”

Developing the ASCOT-Carer INT4

‘Expected quality of life’

- Sensitivity?
 - Long term care services withdrawn, reduced or replaced by local authority
 - Recent experience of substantial caring without formal long term care support

“I'm imagining the situation I was in earlier on this year... I was just absolutely exhausted.”

“If I think back it was horrendous.”

Next steps

- Further psychometric testing of the measure
- Preference weights
- Mapping between ASCOT and ASCOT-Carer
 - What is the ‘wider impact’ of long term care on both care-recipients and carers?

Contacts and Acknowledgements

Contact details

s.e.rand@kent.ac.uk

d.fox@kent.ac.uk

For more information see:

www.qoru.ac.uk/wp-content/uploads/2013/07/A05-IIASC-Interim-Technical-Report-FINAL-DP-2833.pdf

www.pssru.ac.uk/ascot

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