EVALUATION AND VALIDATION OF THE PROACT MEASURES FOR CANCER PATIENTS AND INFORMAL CAREGIVERS
Valerie Shilling, Rachael Starkings, Valerie Jenkins, Lesley Fallowfield
Sussex Health Outcomes Research and Education in Cancer (SHORE-C), Brighton and Sussex Medical School, UK

Background
Formal assessment capturing broader aspects of life that are affected by cancer and cancer treatments, e.g. the impact on roles and responsibilities, is not normal practice. However, childhood, jobs and careers, finances, family relationships and future plans are all likely to be impacted by diagnosis and treatment.
Systematic reviews revealed a need for rigorously developed, well-validated measures to assess these neglected topics. In the PROACT study we developed two scales to enable a broader evaluation of these ‘real world’ impacts of cancer and cancer treatment.

Aims
The primary aim of PROACT is the development and evaluation of two new scales measuring broad life impacts of cancer and cancer treatment for patients (to be administered alongside FACT-G) and informal caregivers (a standalone measure).

Results

Patient Measures
- 2 systematic reviews of existing PROMs
- 2 qualitative interview studies to inform questionnaire development
- Initial evaluation and validation of new scales
- Further evaluation and validation of new scales

Caregiver Measures
- CRRS (60 items)

Here we present data from Stage 3 – initial evaluation and validation of the Patient Roles and Responsibilities Scale (PRRS) and the Caregiver Roles and Responsibilities Scale (CRRS).

Methods
- Participants were recruited from 11 UK sites, stratified by age and tumour site
- PRRS or CRRS completed on paper or online (participant choice) at 3 time points: baseline, 7 days and 2 months (only baseline and test-retest data are presented here)
- PRRS/CRRS completed with other measures of Quality of Life and wellbeing at baseline and 2 months; completed alone at 7 days for test-retest

Patient Measures
- CRRS
- FACT-G
- WHOQOL-BREF

Caregiver Measures
- CRRS (60 items)

Social Difficulties Inventory (SDI) (Wright et al)

PRRS (29 items) CRRS (60 items)

Family and home life (N=13) Family and support (N=12)
Financial wellbeing (N=8) Relationships and communication (N=7)
Jobs and careers (N=8)* Lifestyle and Outlook (N=12)

Health and wellbeing (N=14) Financial wellbeing (N=6)
Jobs and careers (N=9)*

* Items relating to jobs and careers are only completed by participants currently working. These items are not included in the analysis presented here as too few participants completed to reliably evaluate the items

Example items

People with cancer:
- Not at all
- A little
- Some
- What
- Quite a bit
- Very much

<table>
<thead>
<tr>
<th>Item</th>
<th>Scale</th>
<th>N</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>I worry about the impact of my illness on my partner (or the person who is my main support)</td>
<td>PRRS</td>
<td>83 (75.5%)</td>
<td>60 (18 – 88)</td>
<td></td>
<td></td>
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<tr>
<td>People who offer support:</td>
<td></td>
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<td></td>
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<tr>
<td>I make time to do things for myself</td>
<td>PRRS</td>
<td>83 (75.5%)</td>
<td>60 (18 – 88)</td>
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<tr>
<td>I am concerned about keeping my job and income</td>
<td>PRRS</td>
<td>83 (75.5%)</td>
<td>60 (18 – 88)</td>
<td></td>
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Summary and Conclusions
- We developed two scales to measure broad life impacts of cancer for patients and informal caregivers
- Both scales demonstrated good internal consistency, test-retest reliability and the expected patterns of association with other measures
- Measures demonstrated high levels of acceptability; the rate of missing data was extremely low
- Measures will be further validated in a large study with a broader range of tumour sites and stages
- PROACT-IV will commence recruitment in December 2017 and will include early stage (I-II) as well as advanced cancer
- Patients with head and neck, colorectal and renal cell cancers and the tumour groups represented in earlier studies
- Further validation is essential to test that the measures are sufficiently generic and appropriate for use in clinical trials and real world studies

References

Contact us: v.m.shilling@sussex.ac.uk
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