Support for family caregivers

State of the research

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90% of people with a brain tumour have become more reliant on others.
1 in 5 have moved in with a friend or family member

1 in 3 have made changes to where they live / need more support to live independently

2 in 3 have seen a negative impact on relationships with their partner

3 in 4 have their / their partner's working life affected

1 in 2 have seen a negative impact on their relationship with children / grandchildren
Caregiver burden

Diagnosis and treatment

Lack of education and training

Neurological and cognitive symptoms

Distress & quality of life issues
Caregiver needs

- Information
  - Symptoms
  - Treatment
  - Available resources
  - Health service needs
  - Care coordination

- Supportive care options:
  - Psychological support
  - Social care

- Communication
Unmet needs

- More than 50% of caregivers **do not receive support**
- NHS commitment to carers (2014)

*What is the effect of interventions to help carers cope with changes that occur in people with a brain or spinal cord tumour, compared with standard care?*
Cochrane systematic review

• Large-scale implementation of caregiver support is hindered by lack of high-quality evidence.

Interventions to help support caregivers of people with a brain or spinal cord tumour (Protocol)

Boele FW, Bulbeck H, Browne C, Rooney AG, Sherwood P

• Search: March 2017
• Results just in!
Methods

• Selection criteria
  – **Studies**: (quasi-) randomised controlled trials
  – **Participants**: >20% of the sample are adult caregivers of persons with a brain or spinal cord tumour (any type, any age)
  – **Interventions**: any type, with aim to improve caregiver wellbeing
  – **Outcomes**:
    • Caregiver emotional or physical wellbeing
    • Patient emotional or physical wellbeing
    • Health economic effects
Study selection

- 1666 records screened
- 1542 excluded
- 122 full-text
- 117 excluded
- 5 studies included
### Included studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Description</th>
<th>Neuro-oncology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boele 2013</td>
<td>56</td>
<td>Partner/spouse of high-grade glioma patient</td>
<td>100%</td>
</tr>
<tr>
<td>Dionne-Odom 2015</td>
<td>124</td>
<td>Patient-caregiver dyads (advanced cancer)</td>
<td>22%</td>
</tr>
<tr>
<td>Klosky 2007</td>
<td>80</td>
<td>Parents of child diagnosed with cancer</td>
<td>67%</td>
</tr>
<tr>
<td>Locke 2008</td>
<td>16</td>
<td>Patient-caregiver dyads (primary brain tumour)</td>
<td>100%</td>
</tr>
<tr>
<td>Wakefield 2016</td>
<td>47</td>
<td>Parents of child after cancer treatment</td>
<td>28%</td>
</tr>
</tbody>
</table>
Interventions

• Caregiver-focused interventions:
  – 6 face-to-face sessions with psychologist (Boele 2013)
    • Care as usual control group
  – 3 weekly online sessions with psychologist (Wakefield 2016)
    • 6 month waitlist control group

• Patient-caregiver dyadic interventions:
  – Early palliative care with coping skills training (Dionne-Odom 2015)
    • Delayed palliative care control group
  – Interactive-educational intervention for radiotherapy planning (Klosky 2007)
    • Non-interactive intervention control group
  – Cognitive rehabilitation and problem solving with psychologist (Locke 2008)
    • Care as usual control group
Results Caregiver wellbeing

**Improvements:**
- Psychological distress (2/4 studies)
- Mastery (1 study)

**Stable:**
- Quality of life (1/4 studies)

**No effects:**
- Caregiver burden (1 study)
- Quality of relationship (1 study)
Results Patient wellbeing

**Improvements:**
- One-year survival (1 study)

**Maybe:**
- Quality of life (1/4 studies)

**No effects:**
- Psychological distress (4 studies)
- Symptoms (4 studies)
- A&E visits (1 study)
- Hospitalisations (1 study)
Results Health economics

E.g., employment status, productivity loss at work, caregiver healthcare utilisation for acute or chronic conditions
Quality of evidence

Taking into account:
• Number of studies
• Study design
• Risk of bias
• Inconsistency
• Indirectness
• Imprecision
Summary of findings

No evidence for effectiveness
≠ evidence of no effect!

- Small samples
- Heterogeneous groups
- Different interventions
Gaps and future directions

• Lack of:
  – Caregivers of persons with brain metastases
  – Caregivers of persons with spinal cord tumours

• More consistent use of outcomes
  – Caregiver physical health, health economics?

• Australia, United States, the Netherlands
  – Non-Western perspective?
Non-controlled studies

- Nurse-led interventions
- Support groups
- Caregiver workshops
- Psycho-education
- Patient navigation or care coordination
- Telephone hotline or website

✓ Good uptake and increased family autonomy
Ongoing RCTs

1. ‘Care-IS’: Telephone based nurse-guided educational supportive programme (Halkett) - ongoing
2. ‘Making sense of brain tumour’: Therapist led dyadic programme (Ownsworth) – Awaiting caregiver outcomes
3. Online psychoeducational intervention (Langbecker) – in development
4. ‘SmartCare’: Online nurse-guided support (Sherwood) – awaiting results
eHealth solutions

Trend towards remote support
• As effective as face-to-face help
• Wider reach
• Lower threshold
• Lower cost (?)

• Combination of online and personal contact preferred
• Pilot needed?
Take home message

• More high quality evidence needed

• This can help to:
  – Offer support systematically
  – Reach those who don’t receive support
References

Protocol:

Included studies:
Other references

Ongoing studies:
- Langbecker D, Yates P. Development of an online psychoeducational intervention for family caregivers of high-grade primary brain tumour patients. Psycho-Oncology 2016; 25(Suppl.3):90.

Other references: