Enhancing the role of carers in the chemotherapy outpatient setting: a participatory approach

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Background

- Ambulatory chemotherapy
  Organising clinic visits & tests
  Drug management
  Monitoring & managing side effects; accessing help
  Passing information about care between providers & HCPs

- Carer experience
  Unprepared, ill-equipped, stressed, concerns for patient wellbeing & safety

McIlfatrick et al., 2006; Ream et al., 2013; Macmillan Cancer Support, 2013
Aims

Develop and test a carer support package in the chemotherapy outpatient setting using EBCD.

- Understand support provided by healthcare professionals to carers
- Develop a short film depicting carers’ experiences
- Bring healthcare professionals and carers together in co-designing components of an intervention for carers
- Develop and implement a carer intervention.
- Explore feasibility and acceptability
Phase 1 Methods

**Getting at the ‘experience’ part of EBCD**

- General observation of chemotherapy day unit
  - 20 hours over 4 weeks
- Observation of scheduled consultation
  - Consultation to consent (n=6)
  - Pre-chemo consultation (n=6)
- In-depth interviews
  - Staff (n=20)
  - Carers (filmed, n=20)
Phase 2 Methods

**Co-design**

- **Staff event**
  - findings from interviews fed back to staff followed by discussion of dilemmas and challenges

- **Carer event**
  - carers viewed film for first time. Discussed whether film captured carers’ experiences & role of film in intervention

- **Joint staff/ carer event**
  - enabled sharing of experiences & perceptions of carer support
  - discussed what support package should comprise, content/style of DVD & how other materials could be used
Outcomes from joint carer/staff feedback event

Support package to include a DVD, information leaflet and one-off consultation that will:

• Explain what it means to be a carer
• Recognise and acknowledge role of carer important
• Include practical information
• Top tips for coping, importance of taking time out for themselves
• Create awareness of existing services, locally, nationally
• Be clear about who carers need to contact
• Provide contact details, who to call/when, getting through to dept
• Provide permission to contact- ‘HCPs are not too busy!’
• Provide exemplar questions to ask HCPs
• Map of departments within hospital
Developing the package...

**Ongoing co-design meetings to further develop package**

- **Review**
  - Carers and staff reviewed and refined support package
  - Decided how, where, when and by whom it will be delivered.

- **Revision**
  - New scripted film (DVD) grounded in carer experiences

- **Augmentation**
  - Written resource provided alongside DVD with information about local services, contacts etc

- **Delivery**
  - By chemotherapy nurse in one-off consultation to max 5 carers
Take Care
A guide for family and friends supporting someone through chemotherapy

Managing side effects

Joe, caring for his mother
Phase 3 Mixed-method feasibility trial

Aim

To test feasibility and acceptability of delivering *Take Care* in chemotherapy outpatient setting

- Exploratory RCT (n=47)
  - Self-completion questionnaires
    - Knowledge (100mm VASs)
    - Unmet info needs (SCNS-P&C44)
    - Experience & satisfaction with care (investigator-developed)
    - Confidence in coping (Schwarzer & Fuchs, 1996)
    - Emotional wellbeing (12 item GHQ-12)
- Focus groups: Carers (n=4) & HCPs (n=6)
Feasibility & acceptability

• Recruited at anticipated rate (10/month)
• But 80 approached to recruit 47
• Challenges: working carers; carer health
• 22 of 24 carers attended planned sessions
• Feedback:
  – Valuable; enhanced understanding of symptoms; empowering; reassured; boosted confidence; legitimised role; lessened anxiety
## Outcome measures

<table>
<thead>
<tr>
<th>Carer knowledge</th>
<th><strong>All items</strong>: intervention arm sig enhanced knowledge vs control ((p&lt;0.001-0.012))</th>
<th>How adequate was info received from Drs &amp; chemo nurses re benefits of chemo?</th>
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</thead>
<tbody>
<tr>
<td><strong>Information needs</strong></td>
<td><strong>8 of 12 items</strong>: intervention arm sig greater improvement in info needs being met ((p&lt;0.001-0.03))</td>
<td>Did you need info on dealing with symptoms &amp; SEs of chemo at home?</td>
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<tr>
<td><strong>Experience of care</strong></td>
<td><strong>6 of 11 items</strong>: intervention sig better experience of care ((p&lt;0.002 - 0.048))</td>
<td>How satisfied were you with how friend/relative symptoms managed?</td>
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<tr>
<td><strong>Coping</strong></td>
<td><strong>1 of 6 items</strong>: intervention arm sig more confident in coping ((p=0.016))</td>
<td>How confident do you feel supporting your friend/relative through chemo if their health declines?</td>
</tr>
<tr>
<td><strong>Emotional wellbeing</strong></td>
<td><strong>No sig differences</strong></td>
<td>Have you recently lost much sleep over worry?</td>
</tr>
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Conclusions

• This study has adapted the EBCD approach to develop a support package to improve support for informal carers during chemotherapy

• Illustrates that EBCD is a powerful and flexible approach to service development but also to the development of discrete interventions

• EBCD was used successfully not only in the co-design of the intervention but also in the process of implementing the intervention

• The first study of its kind to use EBCD in this way and we now plan to undertake a larger randomised trial of the co-designed intervention.

Next steps

• Multi-site fully powered RCT to confirm effectiveness & cost effectiveness
If a carer is carrying anxiety or anger or a difficult emotion then the impact will be felt by everybody in the family. That means more appointments for the GP, you know how do we calculate it all? Anything we can do to improve things, I think does have a massive impact, in ways we don’t always imagine.

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