Work is an important – and neglected – issue in palliative care

Dr Gail Eva

13th Australian Palliative Care Conference
Melbourne
2nd September 2015
Work support for people with cancer in the UK

Who will help us to return to work?

- Cancer services: Focussed on treatment
- Occupational health: Limited to large employers
- NHS rehab services: Focussed on hospital discharge
- DWP programmes: Concerned with benefit recipients

Brunel University London

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The benefits of work for people who are ill and disabled

- Helps to promote recovery and rehabilitation.
- Leads to better health outcomes.
- Minimises the harmful physical, mental and social effects of long-term sickness absence.
- Reduces the risk of long-term incapacity.
- Promotes full participation in society, independence and human rights.
- Reduces poverty.
- Improves quality of life and well-being.

Two research studies

NCSI Vocational Rehabilitation Pilot Project\(^5\)

- Realist evaluation of seven cancer VR services
- April 2010 – July 2012
- Funding: NCSI £158,000
- Ethics approval: REC Ref: 11/H0716/5

The REJOIN Study (REhabilitation for Job and Occupational INdependence)

- Co-investigators: Diane Playford, Julie Barber, Ramon Luengo-Fernandez, Bee Wee
- January 2012 – December 2015
- Funding: NIHR £354,765.00
- Ethics approval: REC Ref: 12/LO/1925

Aim

To identify a model of cancer VR capable of being widely implemented with good outcomes.

Method of investigation

Realistic Evaluation (Pawson and Tilley 1997) was used to develop explanatory accounts of ‘what works’ in cancer vocational rehabilitation.

Data collection and analysis

- **Service structure and delivery**: 4 interviews and 7 focus groups with 22 service providers; standardised service data templates (330 returned); content analysis of final reports.

- **Definition, content and competencies for cancer VR**: Consensus development using a modified Nominal Group Technique.

- **Perspectives of service users**: In-depth interviews with 25 service users.

- **Health economic data**: Expenditure – patient-related staff costs and support costs; service users invited to complete EuroQOL EQ-5D-3L; modified Client Services Receipt Inventory. 143 returns at baseline, 86 at six months (60.1% response rate)
The REJOIN study – developing and testing a cancer-specific VR intervention

Aim
To determine the feasibility of a randomised controlled trial to evaluate the clinical and cost effectiveness of a cancer-specific VR intervention (the REJOIN intervention – REhabilitation for Job and Occupational INdependence), delivered in the context of routine clinical practice.

Method of investigation
Feasibility randomised controlled trial.

Data collection and analysis
• 60 participants recruited from 8 cancer treatment centres over 24 months
• Evaluation of acceptability of therapist training and intervention delivery.
• Participant measures: work status and duration of sick leave, cost effectiveness, mood, fatigue, cognition and fatigue at baseline, 3, 6 and 12 months.
• Nested qualitative study examining helpful and unhelp support received by participants in both intervention and control groups.
NCSI VR Pilot – overview of findings

- 597 people were referred across all pilot sites. Analysis of 330 service data templates: ‘positive’ work outcomes recorded for 46.4%, i.e. sick leave → full/modified work; remained in work; unemployed → working.
- Cost of VR intervention: weighted average per person cost of £842.23 (range £384.86 - £1590.02).
- Contact time per person: 4.8 hours – 8.4 hours.
- Strategic framework for providing adequate work support for people living with and beyond cancer.
- Ways in which health professionals’ interactions with service-users both help and hinder the achievement of optimal work outcomes.
- Needs of people living with advanced disease.
Strategic framework for cancer work support

Figure 1: Strategic model of cancer work support

**Strategic framework for Cancer Work Support**

**Core Service Components**

**Employers**
- Working with employers at an organisational level
  - Ensure that employers understand the needs of employees with cancer, and that they incorporate just, fair and informed practices into company policies and procedures.
- Working with employers and employees at an individual level
  - Provide advocacy and support for individuals with cancer in liaising with employers.
  - Ensure effective channels of communication between health professionals, employers and occupational health departments.

**People with cancer and their families/carers**
- Provide support at three levels:
  - **Level 1**
    - Open access to information, support and signposting for all patients
  - **Level 2**
    - Active support for self-management for those with straightforward problems and concerns
  - **Level 3**
    - Specialist vocational rehabilitation for people with complex problems

**Specialist vocational rehabilitation services**
- Ensure that specialist vocational rehabilitation services are available for people with complex problems, incorporating the following types of interventions:
  - Assessment of individual capacity and workplace requirements.
  - Rehabilitation to build work skills.
  - Negotiation of phased return to work.
  - Psychological interventions.
  - Information on legal rights and responsibilities.
  - Supported withdrawal from work, where appropriate.

**Cancer services**
- Health professionals
  - Ensure that health professionals have adequate knowledge to provide early and on-going support.
- Health service delivery
  - Embed screening for work problems and provision of work support into assessment tools, treatment
- Cancer information services
  - Ensure that work support information, tailored to meet local needs, is available from cancer information and support centres.

**Organisations providing work support**
- Disability Law Service (DLS)
- Access to Work
- Other local services

**Collaboration between employers, health professionals, service providers, patients and their families is needed for successful work outcomes.**
Strategic framework for cancer work support

Employers

Cancer services

Specialist vocational rehabilitation services

People living with cancer

Organisations providing work support

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Levels of support required

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Level 1:
Everyone who works or have the potential to work

Level 2:
People with ‘straightforward’ problems

Level 3:
People with complex problems

Levels of support required

Level 1:
Everyone who works or have the potential to work

Level 2:
People with ‘straightforward’ problems

Level 3:
People with complex problems

Putting work on the agenda: ‘positive messages’, signposting

Tailored information, advice and support

Specialist vocational rehabilitation

Work issues identified by service-users

• For some people with life-limiting illness, work is important. It supports a sense of competence and normality and legacy and is a welcome distraction.

• Uncertainty and the difficulty of planning for the future has consequences for remaining at work.

• There is a tension between the person’s health needs and the employer’s business needs.

• What does it mean to be ‘fit for work’?

• Negotiation skills and the willingness to compromise are important.

• (People make assumptions about) being a burden.

• Achieving a positive withdrawal from work, where this is the best option.
Work is important: competence, normality, distraction, legacy

You need to have a sense of value, to be needed, and that’s why I like my job. I get a lot of good feedback from my clients. I can see the difference I make in some of their lives and that helps me to feel that I’m leaving something worthwhile behind.’

Wendy, social worker
We found out [after the surgery] that it was a Grade 3 anaplastic astrocytoma. Before the operation the surgeons were very positive – it was, ‘Get over this, get back to work.’ Although they must have known even at that stage that it was going to take months even if everything went bang according to plan. It’s sort of… it’s as if they withhold bad news, isn’t it?

Richard, accountant
‘The doctor told me I had Stage III cancer and we discussed what kind of treatment I should have. I immediately told my manager what my diagnosis was, and she said, ‘Does that mean you’re going to die? How long have you got?’ Which I thought was, you know, superb. I said, ‘I don’t know. I’m telling you as much as I know.’

Wendy, social worker
Nobody told me when I could go back to work. I think I was looking for someone to say, it’s time for you to get your act together and get back to work, but the doctors were leaving it up to me and work were basically saying, we don’t want you back until you’re well.’ The organisation changed a lot while I was away and my boss, a new boss, a man I did not know, basically said, ‘Come back to work when you’re ready.’ They were accommodating and had the best of intentions but they were actually not very helpful.

James, company director
Being able to negotiate

‘I was struggling with pain and I was taking more oramorph at work. I made an error and the company disciplined me for it. Because I was having the vocational rehabilitation support, it gave me a lot of information that I wasn’t aware of. Like it didn’t occur to me that I would be, well, classed as disabled. Once I knew I had rights, I put the information about the Equality Act on the table with my manager and HR and at that point they did a complete turnaround and said, ‘Look, we’re really sorry that we put you through this.’

Martin, operations manager
I felt bad about all the time I had taken off. My manager was very supportive and sympathetic. We talked about a phased return and how they could arrange light duties, but getting that organised was going to take so much effort and involve so many meetings, and my colleagues would have to fill in for me. When she said, ‘Are you sure this is what you want?’ I thought ‘I could just resign. That might be the easiest thing for everyone.’

Mark, cook
A positive withdrawal from work

‘I used to love my job. But while I was having chemotherapy they changed it all and they put me in the call centre. Well my memory is so bad now because of the brain tumours [secondary to lung cancer] and there was a terrible amount of stuff that you had to learn. I couldn’t cope with it so I left. I might go and do some voluntary work in the charity shops but I don’t know.

Nora, sheltered housing warden
Some brief discussion points

• What constitutes a good work outcome?

• Distinguishing between ‘work’ and ‘good work’.

• Attitudes to work and how this shapes our responses.

• A need to know the answers.
What constitutes a good work outcome?

“Work is not always required of a person. There is such a thing as a sacred idleness, the cultivation of which is now fearfully neglected.”

George MacDonald.
1824 – 1905
What constitutes a good work outcome?

- Different stakeholders have different views on this.
- Unwanted / undesirable / unnecessary withdrawal from work.
Work is good for us
But some jobs are horrible...
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‘Good work’ is characterised by:

Reasonable job security.

Work that is not monotonous.

A degree of autonomy, control and task discretion.

The opportunity to be creative.

A reasonable balance between effort and reward.

Having the proper skills to do the job well.

Support to cope in periods of intense pressure.

A sufficiently safe and healthy working environment.

Strong workplace relationships.

Attention to a decent work-life balance.

Attitudes to work

People with life-limiting illness might want ‘to put work on hold for the time being.’

If health professionals perceive work as a worry or a burden, we feel we are being supportive by encouraging people to do this.
“If I don’t know the answer I can’t help you”
Practice implications

- Acknowledge and identify areas of uncertainty.
- Tease out the assumptions being made.
- Determine person’s capabilities and match these against the demands of the job.
- Identify the pros and cons of possible decisions.
- Consider changes that can be made to facilitate continuing to work.
- Talk to employers.
- Identify expert advice needed and facilitate its provision.
- Support leaving work positively, where appropriate, with attention to dignity and self-esteem.
- Provide active support for new activities and roles.
Contact details

gail.eva@brunel.ac.uk

www.facebook.com/gail.eva

www.twitter.com/gaileva

Palliative Rehabilitation Group on Facebook:
https://www.facebook.com/groups/110818868948811/