

Effective monitoring & evaluation tools to assess the impact of emotional support services provided for carers

WEST CUMBRIA CARERS
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Background

- West Cumbria Carers (WCC) is a Registered Charity and Company Limited by Guarantee it was established in 1992
- WCC provides support to carers in the boroughs of Allerdale and Copeland in Cumbria
- WCC covers an area of 762 m² and a population of over 164,000
- 2011 Census indicated that between 11-12% of the population considered themselves to be in a caring role. WCC are currently in contact with approx. 1,800 carers
- The area WCC covers is largely rural but has 6 wards/areas that appear in the top 10% most disadvantaged areas on England using the Index of Multiple Deprivation (IMD)
- Initial funding for WCC Health Project (Nov 2011 - June 2014) came from Cumbria Clinical Commissioning Group (CCG)
- As a result of the Better Care Fund the funding from CCG and Cumbria Adult Social Care has been brought together in a single contract and a series of small scale grant funds

Why services to support carers mental wellbeing?

A series of recent reports produced by national organisations; Carers UK and Carers Trust (formerly Princess Royal Trust for Carers) and Scottish organisation Carers Scotland have highlighted the huge numbers of unpaid carers who have significant mental health problems as a direct result of their caring role

- Sick, tired and caring (Carers Scotland 2011) 86% of carers questioned reported that they suffered from stress, anxiety and depression
- The State of Caring (Carers UK 2013) 92% of carers said that their mental health has been affected by caring
- In Sickness and in Health (Carers Trust 2013) 87% of carers stated that caring had a negative impact on their mental health
- The Cost of Caring (Carers UK 2011) 85% of carers who had been in debt (as a result of their caring role) also had suffered poor mental health

What WCC provides

- Regular relaxation session (1 hour per month)
- Mindfulness Programme (8 week followed by 1 x monthly)
- Singing workshops (6 x monthly sessions)
- One to one counselling service (volunteer counsellors)
- Complimentary therapies (via ASC Carer Budgets)

Why is monitoring important?

- To ensure that the therapeutic interventions we provide to carers produce positive results for their mental well being
- To support carers to identify when therapeutic interventions have had a positive outcome
- To provide evidence to seek additional funding
- To provide quality feedback to existing funders
- To enable benchmarking against similar services

Improving access to Psychological Therapies (IAPT) - background

Launched in 2008 the Improving Access to Psychological Therapies (IAPT) programme is a large scale government initiative that aims to significantly increase the availability of NICE recommended psychological treatments for depression and anxiety disorders within NHS commissioned services in England.

The services have different names in each area:

- Cumbria & Northumberland – First Steps
- Manchester – Psychological Wellbeing Service
- East Lancashire – Healthy Minds

Our search for quality monitoring tools

- WCC designed evaluation and monitoring
- **The Warwick-Edinburgh Mental Well-being Scale**
- **Affect Balance Scale (ABS) (Bradburn, 1969)**
- **Affectometer 2 (Affect 2) (Kammann and Flett, 1983)**
- Depression-Happiness Scale (DHS) (McGreal and Joseph, 1993)
- Oxford Happiness Questionnaire (OHQ) (Hills and Argyle, 2002)
- Oxford Happiness Questionnaire - Short-Form (OHQ-SF) (Hills and Argyle, 2002)
- Psychological General Wellbeing Index (PGWBI) (Dupuy, 1984)
- **Short Depression-Happiness Scale (SDHS) (Joseph et al, 2004)**
- Wellbeing Questionnaire 12 (WBQ12) (Bradley, 1994; 2000)

National Institute of Clinical Excellence

All talking therapies delivered through IAPT services are approved through the National Institute for Health and Clinical Excellence (NICE)

NICE provide a full set of guidelines for the delivery of all services and recommend tools, methods and scales to use to assess

A good 'read' are a series of guides produced by Health Scotland www.healthscotland.com/mental-health-publications.aspx and in particular

'Mental Health Improvement: Evidence and Practice. Guide 5: Selecting scales to assess mental wellbeing in adults'

Patient Health Questionnaire for Depression (PHQ9)

Over the last 2 weeks how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Worrying too much about different things	0	1	2	3
Trouble relaxing	0	1	2	3
Being so restless that it is hard to sit still	0	1	2	3
Becoming easily annoyed or irritable	0	1	2	3
Feeling afraid as if something awful might happen	0	1	2	3

Column totals: ___ + ___ + ___ + ___ = Total Score _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all Somewhat difficult Very difficult Extremely difficult

From the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission

Work & Social Adjustment Scale (W&SAS)

Work and Social Adjustment Scale

Adapted from Marks et al, 1986)

Name:

Date:

Please rate each of the following questions on a 0 to 8 scale:

0 indicates no impairment at all and 8 indicates severe impairment

1) Because of the way I feel, my ability to work is impaired

0	1	2	3	4	5	6	7	8	
Not at all								Severely	
impaired								impaired	

2) Because of the way I feel, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired

0	1	2	3	4	5	6	7	8	
Not at all								Severely	
impaired								impaired	

3) Because of the way I feel, my social leisure activities involving other people (such as parties, outings, visits, dating, home entertainment, cinema) are impaired

0	1	2	3	4	5	6	7	8	
Not at all								Severely	
impaired								impaired	

4) Because of the way I feel, my private leisure activities done alone (such as reading, watching TV, gardening, craft work, walking, sewing) are impaired

0	1	2	3	4	5	6	7	8	
Not at all								Severely	
impaired								impaired	

5) Because of the way I feel, my ability to form and maintain close relationships with others, including those I live with is impaired

0	1	2	3	4	5	6	7	8	
Not at all								Severely	
impaired								impaired	

Patient Health Questionnaire for Anxiety (GAD7)

Over the last 2 weeks how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things				
Feeling down, depressed, or hopeless				
Trouble falling or staying asleep, or sleeping too much.				
Feeling tired or having little energy				
Poor appetite or overeating				
Feeling bad about yourself — or that you are a failure or have let yourself or your family down				
Trouble concentrating on things, such as reading the newspaper or watching television				
Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving .around a lot more than usual				
Thoughts that you would be better off dead or of hurting yourself in some way				

Pre & Post Questionnaire pilot

Our therapeutic interventions were evaluated in a fairly informal manner using specifically designed evaluation forms and questionnaires.

Analysis of these evaluations and questionnaires suggested that the interventions were producing some very positive responses and that carers mental health was showing significant signs of improvement as a result.

It was felt that it was important to look for a more formal context in which to develop benchmarking and evaluation processes to track and record the positive impact of the interventions.

We decided to pilot a more formal process with a small group of carers that had accessed one or more of the following:

- One to one counselling with a trained counsellor
- One hour relaxation and meditation technique sessions
- Eight week programme of two hour Mindfulness and Therapeutic Exercise session
- One to one therapy sessions including; massage, reflexology, Indian head massage etc

Initially an availability letter was sent to thirteen carers who had accessed one or more of the interventions.

Carers were asked to indicate their willingness to be involved in the study and their availability for telephone interviews. Those who indicated a willingness to be involved were contacted at a time convenient to them between December 2013 and February 2014. Of the thirteen carers approached, nine responded, all of whom completed the questionnaires in full.

The questionnaires were delivered via the telephone and participants were given the opportunity to expand on or refuse to answer any of the questions which were of a particularly sensitive nature.

Recording responses

Carer Details								Pre Treatment Assessment						Post Treatment Assessment						Progression <small>Note - A Minus Score indicates a positive change - i.e. Level of depression etc has decreased by xx value</small>											
Carers Surname	Carers First Name	Carer ID	Carer DOB	Sex	District	Relationship to Cared For	Condition of Cared For	Treatment Received	Anxiety (GAD Score)	Anxiety (GAD Rating)	Depression (PHQ9) Score	Depression (PHQ9) Rating	Work and Social Adjustment Score	Work and Social Adjustment Rating	Impact on Caring Score (0=Low Impact, 8=Severe Impact)	Anxiety (GAD Score)	Anxiety (GAD Rating)	Depression (PHQ9) Score	Depression (PHQ9) Rating	Work and Social Adjustment Score	Work and Social Adjustment Rating	Impact on Caring Score (0=Low Impact, 8=Severe Impact)	Anxiety Score Change	Anxiety Percentage Change	Depression Score Change	Depression Percentage Change	Work and Social Adjustment Score Change	Work and Social Adjustment Percentage Change	Impact on Caring Score Change	Impact on Caring Percentage Change	
Example	Example	1111	11/11/2011	Male	Allerdale	Spouse	Mental Health	Example	19	Severe	24	Severe	33	Moderate to Severe Psychopathology	7	3	Moderate	7	Mild	9	Normal	3	-3	-10	-47.62%	-17	-62.96%	-24	-60.00%	-4	-50.00%
		357	02/01/1944	Female	Copeland	Spouse	Mental Health	Mindfulness	19	Severe	29	Severe	36	Moderate to Severe Psychopathology	7	3	Mild	3	None	5	Normal	0	-3	-16	-76.19%	-23	-81.48%	-31	-77.50%		

Findings

Findings

The Patient Health Questionnaire for Depression (PHQ9), Patient Health Questionnaire for Anxiety (GAD7) and the Work and Social Adjustment Scale (W&SAS) were trialled on a small sample of nine carers. The findings were:

- Pre therapeutic intervention resulted in an average depression score of 15.3 (moderately severe). The average score for depression fell considerably after carers accessed therapies dropping to just 6.2 (mild).
- The overall average score for anxiety amongst the carers pre intervention was 16.1 which would indicate severe anxiety. After accessing the services provided by West Cumbria Carers the average score fell to a considerably lower average of 7.3 which reduces harmful severe bouts of anxiety to a more manageable moderate level of anxiety.
- Work and Social Adjustment questionnaire scores also changed in relation to pre and post therapeutic access with average scores dropping from 25.8 (moderately severe social impairment) to 15.5 (less severe social impairment)

This Pilot Study provides robust evidence that the use of PHQ9, GAD7 and Work and Social Adjustment Scale provides a clear, useful and accessible process for our organisation to assess the success of the following interventions with carers

- One to one counselling with a trained counsellor
- One hour relaxation and meditation technique sessions
- Eight week programme of two hour Mindfulness and Therapeutic Exercise session
- One to one therapy sessions including; massage, reflexology, Indian head massage etc

Current implementation

Having piloted the use of pre & post questionnaires we have now rolled out the process since July 2014 to cover all carers using the following:

- One to one counselling with a trained counsellor (*carers complete pre before 1st sessions and post at last session*)
- One hour relaxation and meditation technique sessions (*carers complete pre on first session attended & post 3 months after*)
- Eight week programme of two hour Mindfulness and Therapeutic Exercise session (*carers complete pre before 1st sessions and post at last session*)

Implementation results to date
