

Outcomes of a CAM bodywork Wellbeing Clinic on the quality of life in unpaid family members with caring responsibilities – a pilot study.

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Abstract

Wellbeing is a potential problem in unpaid caregivers. Limited studies have been performed on the use of CAM (complementary and alternative medicine) bodywork modalities and their ability to control the symptoms associated with stress or assisting in carers' general wellbeing.

CAM bodywork modalities are popularly used for relaxation and to address impairments in soft tissue dysfunction. The purpose of this study / report is to document the feasibility of using CAM bodywork modalities to help control the symptoms associated with stress and to describe the outcomes of a 1 year programme on the quality of life of individual family members with caring responsibilities. Participants were treated with a number of different CAM bodywork modalities by means of one to one treatments.

Carers' responsibilities were recorded together with the effect that caring has on their health and wellbeing. Outcomes were assessed using feedback forms and testimonials. Improvements were found in physical, mental and emotional discomfort as well as in carers' stress levels.

These results suggest a programme of one to one treatments combined with group activities may be an effective strategy in helping to improve carers' quality of life.

Introduction

The Carers Wellbeing Initiative (CWI) formed in July 2012 to help promote the health and wellbeing of family carers / caregivers who live in East Sussex and West Kent. Carers' face a continual stress of coping with the practicalities of care along with the emotional strains and anxieties associated with maintaining a positive relationship and good quality of life with a loved one. The CWI offers recognised CAM therapy techniques to help carers' improve their own wellbeing and their ability to cope.

Carers health.

“Makes me feel permanently under pressure.” Ms CC

Research suggests that carers are more likely than the rest of the population to suffer depression and develop other health problems. This was confirmed by a 2006 study at the University of Brighton (Fyvie-Gauld M et al, 2006).

A report from “The Princess Royal Trust for Carers, January 2004” found that common health conditions caused by caring responsibilities included;

(i) stress / nervous tension - 38%, with a slightly higher level amongst those caring for someone with learning disabilities.

“Tired all the time. Very stressed. Lack of sleep.” Mrs JD

(ii) depression - 28%, with a slightly higher level amongst those caring for someone with mental health difficulties.

(iii) anxiety - 27%, with a slightly higher level amongst those caring for those with learning difficulties.

“Effects my thinking of everything and how to rest my own mind.” Mr RM

(iv) back injury - 20%, mainly amongst carers undertaking heavy physical caring for those with physical disabilities. Often carers can carry out a great deal of lifting or assist with mobility. This may involve helping to change soiled clothes or bedding many times throughout the day and night.

“I have been diagnosed with mobility problems, post surgery. This has impacted on caring, working and exercising for my own health.” Ms CH

(v) high blood pressure - 10% of those caring for someone with dementia have this complaint more than other carers.

The principal focus of the CWI is to develop and provide therapy programmes for carers and those who offer support and / or companionship that include personal treatments as well as relaxation and exercise techniques.

Many different styles of bodywork can offer people an acceptable solution to symptoms of short duration and not of serious medical significance whilst also preventing the symptoms developing into more serious problems at a later date.

CAM for carers: free or low cost?

An online survey of 800 carers conducted by The Princess Royal Trust for Carers in July 2010 (www.carers.org/key-facts-about-carers) found that of those who care unpaid for a sick and disabled family member;

53% who work earn less than £10,000 a year,
60% have to spend all of their savings to support the person they care for,
89% say that they are financially worse off as a result of caring and consequently,
almost 39% fear they will lose their home.

To cover basic living needs 10% of carers questioned have borrowed exceptionally high-interest loans (41% plus APR),
62% have had to borrow money off family and friends.

The financial pressures are causing 45% of carers to want to run away from their caring role,

15% are turning to alcohol or drugs to cope.

35% of carers have missed out on state benefits because they didn't realise they could claim them.

Unsurprisingly 37% of carers surveyed are fearful of the future.

“Caring has affected me financially and was probably responsible for the break up of my relationship.” Ms AT

Whilst the popularity and use of complementary and alternative medicine (CAM) has remained high in the UK over the last twenty five years, access to therapies via publicly funded health and welfare systems has remained restricted over the same period (Rogers J, 2010).

In our experience many carers on limited income and who could most benefit from receiving CAM are prevented from doing so by the cost. In our study **28.5%** of carers said they had never experienced CAM because of the high cost of a treatment (see appendix 2). Unfortunately the simple truth is that CAM interventions continue to be relatively expensive at the point of delivery without any public subsidy.

Background to the Carers' Wellbeing Clinic in Hastings.

“The Carers Wellbeing Clinic” opened in January 2013 at the Isabel Blackman Centre, Hastings Old Town. The Isabel Blackman Centre (IBC) provides a service for older people managed by Age UK East Sussex in partnership with East Sussex County Council and Newhaven Community Development Association. The “Carers' Wellbeing Clinic” which operated on the ground floor of the building was part of what was known as the “Community Hub”.

Initially it was planned to run the clinic fortnightly as a pilot project providing free treatments for 3 months in order to ascertain the interest the project might generate. Two therapists provided 3 hours of treatments each, once a fortnight. A mixture of therapies was offered including massage, shiatsu, reflexology, aromatherapy and Indian head massage.

Because of the demand from carers for treatments, within a month the clinic was extended to run indefinitely on a weekly basis with both therapists providing 4- 5 hours of treatments. In short, the need was identified and the service increased from fortnightly to weekly with bookings for treatments being taken 3 – 4 weeks in advance.

“Very positive experience. Things have moved on in a good way.” Ms MA

“Found the whole experience wonderful. It’s nice that someone bothers with people like us.” Mrs RF

In August 2013 following the findings of a review and evaluation of services by East Sussex County Council, recommendations were made regarding the better use of the Isabel Blackman Centre (IBC) building, which resulted in all “Community Hub” activities being temporarily suspended.

CWI was asked to cease all activities and vacate the building. East Sussex County Council met with Age UK and NCDA and clarified a number of issues, but it was still not possible for us to resume running the Carers Wellbeing Clinic from the IBC.

We therefore had no option but to move the clinic to new premises at very short notice in the beginning of September 2013 to the Pinehurst Centre in St Leonards on Sea. Unfortunately this also incurred an increase in costs (room rental and laundry) and as a result we were forced to reduce the service we had been providing by 50%.

Sadly as a direct result of the move and because of the reduction in our service we also lost contact with a considerable number of carers.

Method

Each applicant was initially screened to ensure that they met our priorities and criteria ie; an unpaid carer living in Hastings or St Leonards or a surrounding village, that had developed symptoms associated with stress and other conditions commonly suffered by individuals with caring roles, and which our service could help to alleviate.

Each carer was separately evaluated and assessed. The purpose of this process was to establish together with the carer the therapy that would best help them. The therapist then created a case file to record an individual tailored programme of 6 sessions, comprising various therapies such as massage, reflexology and shiatsu. This file was regularly updated by the therapist on each subsequent attendance.

Each carer completed an initial questionnaire to establish the current effect of their caring role on their own health and wellbeing, and the extent to which they felt they successfully balanced their carer commitments on the one hand and their work and / or education commitments on the other. They also provided information as to the effect on matters such as their social life.

“Can’t go out without feeling selfish, leaving brother behind.” MrJB

“It’s separated me from friends and other members” Ms TW

A second questionnaire regarding their caring role was also completed. This gave us valuable information about who the participants care for, husband, wife, partner, child etc and the difficulty they experience when performing their role eg lifting, toileting, acting as power of attorney etc, and also how many hours a week they

devote to caring, as well as to get a glimpse of other day to day difficulties that carers may experience when looking after their loved ones (see appendix).

“ I will always have to be there (for my son) and I don’t feel comfortable when he’s not with me and I worry about him all the time : has affected my role as a mother to other and as wife and friend.” Mrs KB

The therapy service was delivered through one to one treatments in a clinical setting through two experienced holistic therapists. Each therapist delivered approximately three one hour long treatments once a week.

The therapists met and reviewed each other’s work and client progress on a monthly basis under the overall direction of the Clinical Director. The day to day running of the clinic was the responsibility of the Clinical Director under the overall direction and control of the board of Trustees / Management Committee. The Board met every 3 months in order to review progress of the project.

“Great. Really, really nice. I feel very tall now. Lovely man as well.” Ms KB

Results

The study covers The Carers’ Wellbeing Clinic in Hastings and St Leonards which provided 44 carers with approximately 6 treatments over a period of one year (January 2013 to 2014). We offered approximately 250 hours of one to one treatments / volunteering hours. The average current cost for an hour’s massage treatment in the Hastings area is approximately £40. This translates into approximately £10,000 worth of free treatments.

Some carers look after elderly relatives, some look after children. Some of the average values of “Questionnaire 1” of the subjects are shown in Table 1 below. (For more detailed information see Appendix 1.)

Table 1

Average age of carer	Average age of person being cared for	Percentage of cared for with dementia or alzheimers
58.5	71.7	37
Oldest age of carer	Oldest age of person being cared for	
85	93	
Youngest age of carer	Youngest age of person being cared for	
40	8	

Table 2 below shows the average overall results of the questionnaire that establishes the importance of the current effect of carers' roles on their own health and wellbeing, and the extent to which they feel they successfully balance their carer commitments with their work, social life and education commitments.

“My experience of caring (until recently) has been that it’s all consuming, exhausting and a potential for ill health.” Ms JF

Table 2

Do you think that caring affects your health?	Do you feel tired or stressed?	Have you been injured caring for someone?	Has your caring role affected your social life?	Has your caring role affected your work / career?	Has your caring role affected your ability to access education or training?
71.5%	93%	45.5% said yes.	71.5%	57%	35.5%
Important or very important issue	All or most of the time	24% of these were abused either physically or verbally	Important or very important issue	Important or very important issue	Important or very important issue

Through our project at the IBC and Pinehurst Centre we now have a good idea of the kind of support / clinic set up we should be providing for carers in the Hastings and St Leonards and surrounding villages area.
(Transport? Respite?)

“Very relaxing – time for myself.” Mrs ED

Carers were encouraged to feedback on our services through a detailed user questionnaire. The questionnaire provided them with a choice of responses, ranging from (i) ‘very satisfied’ to ‘unsatisfied’ or (ii) “improvement” to “no improvement” to each question enabling a detailed evaluation of their responses. Our aim was to elicit an average response of no lower than ‘satisfied’ or “small improvement”. See table 3 below for overall results (see appendix 5a and 5b for full details).

Table 3

Overall results of how carers found the efficacy of our service

How carers found the service was helping them to address the following;	Manage with stress related symptoms associated with caring	Help you cope with the emotional / psychological concerns associated with caring	Dealing with physical health problems that might be associated with caring	With helping you to relax and aiding with your general wellbeing	Your mood, motivation, confidence or ability in helping to deal with the person you care for
Improvement	50%	56.25%	75%	75%	56.25%
Small Improvement	37.5%	25%	25%	25%	31.25%
No improvement	6.25%	12.5%	0%	0%	6.25%
Worse	0%	0%	0%	0%	0%
N/A	6.25%	6.25%	0%	0%	6.25%

The result for overall satisfaction with the way the treatments were carried out was;
 Very satisfied = **93.75%**
 Satisfied = **6.25%**

“A very therapeutic therapy helping with physical and psychological wellbeing, wonderful! The best therapy I have ever received.” Ms SD

Unfortunately the low response rate to the feedback questionnaire of just **41%** (18 out of 44 carers) is very disappointing. This could be put down to a number of factors. These include;

- . the sudden move of premises from the IBC in Hastings Old Town and subsequent move to Pinehurst Centre in St Leonards resulting in a loss of contact with a number of carers,
- . the increase in costs (room rental and laundry) resulting in a 50% reduction of treatments,
- . the sudden deterioration of the condition of the cared for accounts for at least two of the carers that we know of and there may have been others that we don't know about.

Further considerations - discussion

Whilst CWI was set up with the view of offering treatments for relaxation and wellbeing, we recognise that carers can suffer from a wide range and variety of conditions including physical, emotional and psychosomatic disorders. Sometimes we need to offer a place where carers can learn to live with their condition and make peace with themselves.

“It’s given me much needed time out and look forward to my appointments.”

Mr JD

“Valuable as a carer having some “me” time”. Ms CA

“Really worthwhile de- stressor. Excellent idea to fund this. Thanks to Sarah for her time.” Ms MG

By conducting a consultation and completing a detailed life style questionnaire (evaluation and assessment) the first time carers attended the clinic and prior to carers receiving a chosen therapy, we were able to ascertain that **79.5%** of carers that came for us for treatment had a medical condition that was diagnosed either by their general practitioner, a hospital consultant or medical doctor. These included a wide variety of conditions. Some are briefly listed in box 1 below. Patient confidentiality prevents us from providing further details.

Box 1 – example of some of the variety of carers health conditions encountered

Physical – musculoskeletal systemic	Arthritis (knees, neck), sciatica, back pain, occipital neuralgia, hip displacement, ↓ ROM in various joints. Hypothyroidism, menopause, ulcerative colitis, ↑ BP, ↑ cholesterol.
Mental / emotional	Anxiety, depression, insomnia / sleep disturbance, grief.
Psychosomatic	Fibromyalgia, chronic fatigue, myalgic encephalopathy (ME), tinnitus

If our experience is an accurate study of a cross section of the carer population in Hastings and St Leonards, then the results above - especially Box 1, strongly suggests in favour of the need to use experienced, qualified and professional therapists.

“Helped control my pain, so enabled me to do more and cope better.” Ms CC

Charities for the last 15 – 20 years have more often than not relied on volunteers - significantly so on those volunteers who practice CAM. Whilst using volunteers has many cost effective benefits, there are also additional costs incurred through supporting volunteer therapists eg; supervision, training, regular clinical supervision meetings which include reflective practice, extra administration, vetting of potential volunteers etc, not to mention the cost of additional teaching insurance premiums. In our opinion and experience the disadvantages, both economic and clinical, of using volunteers, far outweigh the advantages of employing 2-3 experienced therapists to provide a professional, first class and sustainable service.

“I had approached the Carers’ Wellbeing Initiative because I suffer from nerve pain in my neck. Therapeutic massage has now made me very much aware that it can do much more than treat neck pain. As such I really wanted to answer “Improvement” to all the first five questions because on completion of my first treatment with Andy I felt quite wonderful – for the first time in 3 years. I recall I felt happy, my self confidence had returned. I went out to visit friends that same afternoon. I never go out! Disappointingly, the extended periods between treatments (6 sessions over 6 months) did not provide the ongoing relief and psychological benefits I believe I would have received if a massage could have been offered at least twice a month. This is a wonderful initiative for unpaid carers and deserves to be supported.” Ms EJH

As well as striving to raise awareness about carers health issues, CWI aims to respond effectively to health needs of family carers in the local community giving clear and accurate CAM health information and advice.

Consequently CWI places great emphasis and importance on experienced therapists who embrace the spirit of life long learning, as well as;

1. developing and promoting the habit of reflective practice. Reflective practice includes the concept of research-mindedness and taking responsibility for evaluating one's work and continuing professional development. It also includes mindfulness of self-care.
2. practitioners of complementary medicine to be able to discuss disease processes in terms of orthodox medicine, who recognise the strengths and limitations of their own therapy and other systems (complementary, alternative, holistic, allopathic), as well as being able to work collaboratively with other health-care practitioners.
3. being aware of the possible need to refer clients to orthodox medicine under certain circumstances and advise accordingly.
4. therapists to have a comprehensive understanding of anatomy, physiology and disease processes through an understanding of health sciences and to develop a style of working that involves the patient in decisions about their care, which means there is considerable focus on communication and ethical working.

CWI expects all therapists to share a commitment to these values, which are inherent in a patient-centred approach.

“I found the treatment very relaxing and it was wonderful to be the centre of attention for a short while.” Mrs JL

The incidence of physical and mental health problems suffered by carers is disproportionately higher when compared to the rest of the population. Carers Wellbeing Initiative strongly believes that objective and subjective evidence supports our service can help reduce many of the above mentioned health conditions. This in turn could result in a significant increase in carers' capacity to provide care, and ultimately in the quality of life of both the carer and the person receiving care.

We hope that in future all of these questionnaires and their responses can be reviewed and used to guide and further tailor our future services to carers' needs. We also plan to formally appoint individuals (service users and members of representative organisations) to our Trustee Board in due course so as to better inform us on their needs and our strategic direction.

“The treatments I received made me make time for myself, something that I find difficult as a carer. They were also therapeutic and relaxing and they did me good.” Mrs MB

Our vision is for 2 - 3 therapists to work 4 hours (plus extra hours if needed) at least once a week. At the same time we would also hope to encourage more carers into group work and movement therapies such as tai chi, yoga etc, to help reduce social isolation and provide informal peer support.

It has been shown that group relaxation / exercise classes can encourage the development of social support, for example by forming friendships outside of the class and through sharing of similar problems (Crook P et al, 1998). Group relaxation / exercise programmes such as qigong, tai chi or yoga could counter social isolation and maintain good mental health (Wienfield HR, 1994).

(Cost strategy add here eg free for carers on benefits, low cost for others eg; £15)

Together with the use of relaxation and wellbeing promotion techniques such as acupressure, anti arousal breathing techniques and other lifestyle adjustors, a programme of combined individual treatments and group relaxation classes can be an important addition to the current wellbeing service repertoire for carers (Lorig KR et al, 1993)

“Very impressive. I wish there was something similar in Rye.” Ms YH

“Pleasant relaxing “me” time, that helped with the physical aspects of caring.” Mrs MC

We expect our service to enable carers to:

- better address and overcome restrictions in their ability to care due to problems caused by stress, emotional problems, and musculoskeletal problems.
- improve their ability to relax, improve their mood and their motivation to care.
- improve their ability to form relationships with individuals outside their immediate circle by reducing isolation.
- consider themselves better able to care

“Caring can at times be a lonely place to be – thanks for caring about us.” Mr EP

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The **Carers Wellbeing Initiative**
Ltd Company 8260659

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If you would like further information or have any questions then please email Andy at; carers.wellbeing@gmail.com

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