Application for WaMHinPC Bursary

Category 5 of the Bursary
NSF Standards 1,2,3 and 4
Fulfills all 5 Attributes of WaMHinPC
Fulfils all 3 of the Hallmarks of WaMHinPC Gold Standards

Aim of Proposed project:

To develop therapeutic strategies for patients and carers living with cancer

Submitted by:

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Supported by Gavin Peake-Jones, Professor Mathew Makin, Lindsay Haveland and a consortium of patients, carers, third sector and NHS colleagues

Background

A simple 'distress thermometer' has been shown to identify clinically significant psychological disorders in cancer patients. 80% of patients who attended a drop in Macmillan Centre in the Wrexham Maelor Hospital requested information on emotional aspects to their care needs. Maintaining hope is of therapeutic importance but professionals report that they feel ill prepared and lack the necessary skills to respond to their patients' needs.

Can a simple psychological intervention ameliorate the distress experienced by cancer patients? The instillation of hope and the promotion of protective factors have been shown to reduce distress and ensuing suicide. The *Bank of Hope* is a set of simple coping strategies designed to instil hope and resilience and to decrease the potency of distress in individuals with emotional and physical pain. It was originally designed to help people experiencing suicidal thoughts. Its user friendly design makes it suitable for use by all types of carers both in statutory and voluntary sectors, including unqualified staff e.g. support workers and those with no specific mental health training. One of the key coping strategies in the Bank of Hope is the *Triple Whammy*, a novel cognitive restructuring technique inspired by Mindfulness-based stress reduction.

The *Triple Whammy* is where a patient's current experience of distress is exacerbated both by recollection of past experiences and by anticipated future suffering. This combination of past, current and anticipated suffering fills distressed people with an overwhelming feeling of despair and helplessness, even in the absence of a formal mental illness. The patient is helped to recognise the triple whammy within a therapeutic dialogue, which typically follows the following steps:

- Acknowledge the severe distress caused by thoughts of cancer/uncertainty/possible or actual physical pain that can be overwhelming at times.
- Help the individual see that the feeling of despair arises mainly from the re-experiencing of their past distress ('yesterday's pain') and their anticipation of future distress ('tomorrow's pain').
- Help the patient see that they are adding their past suffering and anticipated future suffering to their current experiences, so that they are effectively experiencing three times more than their actual current level of distress.
- Help the patient see that they may not always feel like this, and that their overwhelming fear and emotional pain are a transient symptom of their distress that, with help, can pass.
- Use the analogy of a viral illness and temperature.
- For proof, look at previous times when they felt like this but those feelings didn't last forever.
- Help the patient see that 'right now in the room' they are coping with their distress.
- The realisation that they are able to cope with their current distress and that things can change is what gives people 'the light at the end of the tunnel'.

This technique empowers patients and carers to break down their distress into manageable chunks, so increasing their sense of internal locus of control, autonomy and resilience.

Feedback on the original version of the Bank of Hope from professionals, users, patients and third sector experts in suicide prevention has been very positive (feedback available on request).

Feedback from cancer care specialists with a mean experience of 16-20 years (65% had more than 10 years experience in this field, with 21% of participants with more than 20 years experience):

- 84% (36/43) believed that the *Triple Whammy* would be a useful technique;
- **84%** (36/43) reported that they intended to use the *Triple Whammy* technique to reduce patients' distress.

Feedback from a cancer specialist who has been using the *Triple Whammy:*

'I, and I think more importantly the patients, have found it a very effective brief intervention; it's as though giving patients permission to normalise past and future fears is therapeutic in its own right. I would certainly get this out of the toolbox first...'

Proposed Project

To co-create a version of the 'Bank of Hope' and 'Triple Whammy' specifically for patients and carers living with cancer, and to undertake an initial qualitative evaluation of self reported effectiveness.

Proposed methods

An advisory group of representatives including researchers, practitioners, patients and carers will be recruited to advise on the design, implementation and evaluation of the use of the Bank of Hope in cancer care. Patients and carers living with cancer will be invited to share strategies that they have developed themselves or learnt from others. The evaluation will include both clinical and patient led outcomes. During the recent workshops at the North Wales Cancer Conference 25 out of 43 participants (patients, carers, cancer care specialists and GPs) indicated that they would like to be actively involved in this process and a further 5 said that they would like to be kept informed.

Anticipated outcomes

The main outcome will be a bespoke, user friendly psycho-educational intervention specifically designed for individuals living with cancer. It will be summarised in a short leaflet that patients, carers and practitioners will be able use and disseminate as a reminder of the coping strategies. This will be designed for use in both the NHS, Primary and Secondary Care and Third Sector organisations including Macmillan Foundation and Marie Curie.

How this project fulfils the Gold Standard approach

The whole of the process from inception of the idea to the final adapted Bank of Hope and the accompanying leaflet will be underpinned by all three Hallmarks; excellent communication, trust and person centeredness.

Patients and carers will included in the whole of the process, demonstrating a need for excellent communication and trust, so that patients and carers will feel empowered and safe enough to talk openly. This will be the first time that patients and carers have been invited to co-create a new therapeutic intervention in such a project, demonstrating the trust already invested in them by the author of the Bank of Hope. Further trust has also been shown by the interest already expressed by some practising cancer care specialists and GPs.

The coping strategies captured and developed in the project will by definition all have been of benefit to people already and therefore clearly person centred rather than created for a mass market by a researcher in isolation. All of the strategies will be most effective in a compassionate, therapeutic relationship which is already underpinned by the three Hallmarks. It is hoped that the use of the strategies and the leaflet may even enhance therapeutic relationships by empowering practitioners to be more ready to identify emotional distress by having additional clinically relevant strategies in their 'toolbox' and the confidence to use them.

Relevance of the proposed project to health and social care policy/practice

This project supports:

- Shared decision making;
- Treatment and services designed by citizens to meet their needs;
- Enablement;
- Recovery model;
- NSF targets;
- Promoting Mental Health and Preventing Mental Illness: Building the Economic case for investment in Wales;
- Rural Health Plan, WAG Consultation meeting the challenges of providing emotional support in a rural environment;
- The view of the CMO for Wales that mental wellbeing should be at the heart of everything we do.

Sustainability of outcomes

The therapeutic strategies will be distilled and captured on a simple leaflet which can be used in all sectors. It could also form the basis of further development of educational and training materials. The leaflet will also be made available online.

Investment and deliverables

The total amount being sought is £3,000. This will pay for the time input of the project clinical and organisational team leaders, who will undertake the majority of the work. The remaining team members will be contributing from their existing salaried hours.

The deliverables will be:

- 1. Background and research application (undertake literature review and gain ethics committee approval if required);
- 2. Design consultation process and facilitate with key stakeholders in up to six focus groups;
- 3. Design the adapted Bank of Hope and Triple Whammy;
- 4. Email consultation on the draft leaflet with relevant stakeholders;
- 5. Design leaflet and provide in electronic format to Macmillan to print as needed;
- 6. Support has been secured from RCGP to publish the leaflet on the RCGP Mental Health Forum website. It is hoped that the leaflet will be linked a prompt and aiming to link this in with GP's IT systems to create a computer generated suggestion that the leaflet should be printed and given to the patient in a similar way as a medication script.

Project Team

- Alys Cole-King, Consultant Liaison Psychiatrist (Clinical team leader)
- Gavin-Peake-Jones, Director, Open Minds Consulting (Organisational team leader)
- Lindsay Haveland, Senior Health and Social Care Facilitator, Denbighshire Voluntary Services Council
- Professor Matthew Makin, Chief of Staff Cancer Services BCU LHB, and Glyndwr University
- Macmillan Foundation: Alun Tandy and others
- Marie Curie
- Carol Evans, Manager, Conwy and Denbighshire Rural Outreach Service / Emotional Care for Chronic Conditions Programme, Vale of Clwyd
- Patients and carers living with cancer
- 25 Cancer care specialists and GPs from all over Wales (details available on request).

¹ Lowe J et al. Validating the disress thermometer as a tool to screen for psychological distress in the UK.

²Barbara J. Limandri and Diana W. Boyle. Instilling Hope (1978). *The American Journal of Nursing*, Vol. 78, No. 1 1978), pp. 78-80

³ Cole-King, A and Haveland L. (2009) Workshop feedback. The 'Bank of Hope': A therapeutic intervention for people living with cancer and their carers. Cancer Care North Wales, Glyndwr University, UK.

⁴ McLean J, Maxwell M, Platt S, Harris F, Jepson R. (2008) *Risk and Protective Factors for Suicide and Suicidal Behavior: A literature Review*. Edinburgh: Scottish Government.

⁵Cole-King, A. (2009) - *The Bank of Hope: Initial qualitative evaluation of a simple CBT type intervention*. Poster presentation - Royal College of Psychiatrists, Faculty of Liaison Psychiatry Annual Meeting, Prague, Czech Republic. SEE ATTACHED.

⁶ Triple Whammy. Copyright © Alys Cole-King 2009

⁷ Kabat-Zinn J *et* al (1992) Effectiveness of a Meditation-based Stress Reduction Program in the Treatment of Anxiety Disorders. American Journal of Psychiatry; 149:p936–943.