

**Institution: University of St Andrews**



**Unit of Assessment: A1 – Clinical Medicine**

**Title of case study: Development and implementation of a new psychological intervention for cancer patients to alleviate heightened fears of recurrence**

**1. Summary of the impact** (indicative maximum 100 words)

Fears of recurrence (FoR) are the major concern for cancer patients. The Adjustment of Fear, Threat or Expectation of a Recurrence (AFTER) was initiated in Liverpool and developed significantly at the University of St Andrews by the originator (Prof. Humphris) and colleague Dr Ozakinci for general cancer patients, including an innovative validated Fear of Recurrence measure. The measure identifies patients with high FoR in NHS oncology services to enable psychological therapeutic treatments to be targeted. AFTER is being widely employed with cancer survivors successfully in UK cancer services and international oncology centres to reduce their FoR and depression.

**2. Underpinning research** (indicative maximum 500 words)

Fear of recurrence is a major concern for many cancer patients<sup>1</sup>, as highlighted in a major review<sup>2</sup> conducted by Prof. G. Humphris (University of St Andrews since 2003) and Dr G. Ozakinci (Lecturer, University of St Andrews since 2004) with others, reported in 2013. Cancer survival has improved, to the extent that many health commentators now regard it as a chronic disease. This has strengthened the field of cancer survivorship to the extent that services are being developed to serve patient concerns more closely. We have shown that recurrence fears are related to psychological variables not clinical factors such as the severity of the treated disease<sup>3</sup>.

Over a third of patients find the prospect of a recurrence troubling and anxiety provoking to the extent that longer-term rumination of this concern results in mood change and depressive symptomology. The effects are insidious and can feature many years after active treatment<sup>2</sup>. Patients respond to high fear of recurrence by demanding multiple health checks and avoiding making future plans. The AFTER intervention creates a completely new approach based upon a cognitive behavioural theory developed by Howard Leventhal. The theory predicts that patients regard every unusual physical sensation as a signal for cancer return<sup>4</sup>. The novel feature of AFTER adopted in 2008 is that it makes this process explicit and encourages patients to reflect on other possibilities and how characteristic behaviours can be modified and communicated to close family members<sup>5</sup> and the clinical team. Other inaccuracies in thinking are elucidated in a personal approach to planning incremental changes. Fears are exposed, discussed and managed using therapeutic techniques that are built upon clinical skills of rapport building, reinforcement, sharing of concerns within a family context and explicitly engaged to change behaviour and management of anxiety and potential mood change. This work was published in leading international journal and highly cited.

Following his move to the University of St Andrews in 2003, Humphris with Ozakinci from a SUPAC NCRI grant (2007-08; £80k) developed a new AFTER intervention built upon the original to include detailed supervisory notes, aide memoires for specialist staff in the 'field' (i.e. clinics) with source materials referenced to explicate therapeutic procedures. AFTER consists of 6 structured sessions conforming to a close fidelity assessment to ensure that all elements of the intervention are delivered as intended, so that patients gain the maximum benefit. New materials were developed (2010) to train experienced clinical members with psychological expertise (counsellors, cognitive behaviour therapists and clinical psychologists).

We have shown (2008) that the intervention can be employed with a wider spectrum of cancer patients with disease located in areas in addition to head and neck, including breast and colorectal cancer. This study used the AFTER intervention embedded within nurse-led services. Humphris was consultant to this project (design and staff training stages) from St Andrews. Improvements in

depressive symptomology were significantly identified in cancer patients (n=200) at the one year assessment.

**3. References to the research** (indicative maximum of six references)

1. Rogers S, Scott B, Lowe D, Ozakinci G, Humphris G. Fear of recurrence following head and neck cancer in the out-patient clinic. *European Archives of Oto-Rhino-Laryngology and Head and Neck* 2010;267(12):1943-9. doi: [10.1007/s00405-010-1307-y](https://doi.org/10.1007/s00405-010-1307-y) (9 citations)
2. Simard S, Thewes B, Humphris G, Dixon M, Hayden C, Mireskandari S, Ozakinci G. Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. *J Cancer Surviv* 2013. September doi: [10.1007/s11764-013-0272-z](https://doi.org/10.1007/s11764-013-0272-z) (2 citations)
3. Llewellyn CD, Weinman J, McGurk M, Humphris G. Can we predict which head and neck cancer survivors develop fears of recurrence? *J Psychosom Res* 2008;65(6):525-32. doi: [10.1016/j.jpsychores.2008.03.014](https://doi.org/10.1016/j.jpsychores.2008.03.014) (33 citations)
4. Humphris G, Ozakinci G. The AFTER intervention: A structured psychological approach to reduce fears of recurrence in patients with head and neck cancer. *British Journal of Health Psychology* 2008;13:223-30. doi: [10.1348/135910708X283751](https://doi.org/10.1348/135910708X283751) (28 citations)
5. Hodges LJ, Humphris GM. Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncology* 2009;18(8):841-48. doi: [10.1002/pon.1346](https://doi.org/10.1002/pon.1346). (27 citations).

**4. Details of the impact** (indicative maximum 750 words)

There are 3 impacts from our new AFTER intervention research, namely:

- (1) A new readily attainable measure of fear of recurrence.
- (2) The delivery of training and implementation of the AFTER intervention into clinical practice.
- (3) Improvement in quality of patient care.

In the enhancement of the AFTER intervention, Humphris and Ozakinci designed a new readily attainable fear of recurrence measure developed at St Andrews in 2007. It has good psychometric qualities, is brief and is being used in a major case-control study (NIHR) known as the H&N5000 study which Humphris acted as a consultant. Over 1000 cases have been collected - the largest cancer patient sample with this assessment.<sup>S6</sup> The identification of high FoR patients is vital to enable efficient referral for important support services of which AFTER is the only dedicated intervention currently available for targeting this major clinical issue.

A **Clinical Service** is provided by Humphris (Consultant Clinical Psychologist) and Ozakinci (Cognitive Behaviour Therapist) who use the AFTER intervention in the internationally renowned NHS Lothian Edinburgh Cancer Centre for out-patients referred by clinical specialists. This case series has been applied (2009 to present) so that approximately a sixth of patients referred to the service will benefit from the therapeutic elements contained in the AFTER intervention. The success of this application has prompted the Head of Psychological Service at the Edinburgh Cancer Centre to report: “I have seen at first hand the benefit of their innovative research on AFTER with patients referred to my service.”<sup>S1</sup>

The intervention has generated both recognition and invitations to run training events for the North of England Cancer Network. Training workshops were conducted on the AFTER intervention with **UK Cancer Units:**

- o North East of England Regional Clinical Psychology Services (18<sup>th</sup> Feb 2013)
- o North of England Cancer Network (18<sup>th</sup> Mar 2013) for cancer service ‘roll-out’ in North of England.<sup>S7</sup>

Approximately 25-30 delegates attended each one-day workshop, run by Humphris, to: (i) translate the research, (ii) explain the intervention manual, and (iii) enable health professionals attending (psychologists, counsellors and specialist cancer nurses) to deploy the intervention. The Head of Cumbria Psychological Services’ Consultant Clinical Psychologist has employed a staff member (May 2013) specifically for AFTER intervention application has stated: “We are therefore able to use this work of the Health Psychology team at the University of St Andrews to deliver improvements in Health care in routine practice”<sup>S2</sup> Furthermore, the Consultant Clinical

Psychologist from the Northern Centre for Cancer Care provides additional support by saying: “*All of us ... are aware what a significant issue Fear of Recurrence is for our patients and their carers. Your work provides a very useful framework for enabling practitioners to address this with patients, in order to facilitate enhanced coping and reduce psychological distress*”<sup>S3</sup>

On the strength of these events, other **European and International Cancer Centres** are adopting the AFTER for use in the EU and North America for example:

- The Centre de Psycho-oncologie, Brussels, Belgium (6<sup>th</sup> May 2013) the only centre of its kind in Belgium, invited Humphris to train their 15 psychologists and specialist cancer nurses in the practice of using AFTER. This attracted 30 delegates and was strongly positively rated. The Head of the Unit of Psychosomatic and Psycho-oncology Research states that “*this intervention will have an impact on the care of cancer patients and reduce the distress many of them experience during recovery from treatment*”<sup>S4</sup>
- A similar event was held in McGill University, Montreal (5<sup>th</sup> April 2013), Canada. Within Quebec the internationally recognised Psycho-oncologist has stated recently that: “*...the AFTER intervention has made a great contribution to our efforts to attempt to assist cancer patients with high levels of fear of recurrence*”<sup>S5</sup>
- It has recently (2013) received independent support in a major randomised controlled trial conducted in the Netherlands.<sup>S6</sup>

These training activities across key centres has attracted a 12 month Innovation Grant Award in April 2013 from NHS Fife R&D (£20k) to develop further implementation of the AFTER intervention into cancer services. The grant includes resources for training workshops, and staff supervision to build a targeted service for NHS patients. These workshops were run locally (August-October 2013) and engaged multi-disciplinary staff. Currently, the intervention is being applied routinely in the breast cancer services under supervision from Humphris. License preparation is in final stages for health service users to receive downloadable copies of the AFTER manual for a small consideration to cover production costs and receive email supervision of use of material with oncology patients.

Finally, the Throat Cancer Foundation has endorsed the manual and provides support for this approach to be adopted in Cancer Units.

**5. Sources to corroborate the impact** (indicative maximum of 10 references)

- S1 Letter of endorsement of AFTER intervention: Consultant Clinical Psychologist, Head of Service for Physical Health and Neuropsychology, Honorary Senior Research Fellow at Coventry University, Chair for Division of Clinical Psychology in Scotland
- S2 Letter of endorsement from NHS Cumbria, where it is used as part of their job roles.
- S3 Letter of endorsement from Northern Centre for Cancer Care, stressing the importance of the intervention with cancer survivors.
- S4 Letter of thanks and endorsement from Head of the Unit of Psychosomatic and Psycho-oncology Research, The Centre de Psycho-oncologie, Brussels, Belgium, corroborates the importance of the intervention as used in Brussels.
- S5 Letter of endorsement from McGill University, Montreal, Quebec, corroborates the use of the intervention as part of their services in Quebec.
- S6.van der Meulen IC, May AM, Ros WJG, Oosterom M, Hordijk G-J, Koole R, de Leeuw RJ. One-year effect of a nurse-led psychosocial intervention on depressive symptoms in patients with Head and Neck Cancer: A randomized controlled trial. *The Oncologist* 2013 September vol. 18 no. 3 336-344. doi: [10.1634/theoncologist.2012-0299](https://doi.org/10.1634/theoncologist.2012-0299).
- S7 Head & Neck 5000 Protocol V2.8. 28<sup>th</sup> April 2010.pdf see Page 19, You and Cancer section for the 4 questions (one half page) psychometrically validated and designed.
- S8 <http://www.necn.nhs.uk/group/psychology-group/> link to notice of workshop run by Prof Humphris on AFTER and Fears of Cancer Recurrence (see Minutes 18<sup>th</sup> April 2013 page 4 Item 8; workshop presentation 18<sup>th</sup> March 2013 EVOLVE NECN.