



An example of applied research in
Psychology:

Psychosocial research with cancer
populations: challenges faced and lessons
learned

DR CERI PHELPS

Session overview

- ▶ Range of psychosocial intervention for cancer populations
- ▶ Multi-disciplinary and collaborative approaches
- ▶ Ethical and recruitment challenges & boundaries
- ▶ Impact & Dissemination

Background

- ▶ Young people affected by cancer, or caring for family members with cancer, face many psychosocial challenges
 - ▶ Anxiety, depression, reduced self-esteem (e.g., Tulskey et al., 2011)
 - ▶ Poorer interactions with family and friends (Corey et al., 2008)
 - ▶ Guilt for causing parents to suffer (Cantrell & Conte, 2009)
 - ▶ Miss out on schooling (Pang et al., 2008)
- ▶ Young people reluctant to engage in face-to-face counselling (Prior, 2012) due to social stigma
 - ▶ effective therapeutic relationships with young people can be formed online (King et al., 2006; Skinner & Latchford, 2006).
- ▶ The use of avatars starting to be explored in counselling
 - ▶ familiar to most young people (e.g., Beattie et al., 2006; <http://www.Kooth.com>)

Background



- ▶ Online counselling provision increasingly popular alternative to face-to-face counselling (e.g., Barak et al., 2008)
 - ▶ Targets hard-to-reach groups
 - ▶ Removes constraints of travel, location and time
 - ▶ Greater sense of anonymity
- ▶ BUT concerns about:
 - ▶ Confidentiality, data protection
 - ▶ Ethical concerns – monitoring distress etc
 - ▶ Logistical/technical challenges



The C:EVOLVE Project: AIMS

1. To develop a virtual reality avatar-based counselling world for young people affected by cancer
2. To obtain pilot data on the acceptability, likely usage, and therapeutic value of the intervention
3. To evaluate the impact of the online counselling world from the counsellor's perspective
4. To make recommendations regarding the potential pitfalls and challenges in relation to the future delivery of such online interventions.

Phase 1

Initial development (March 13 – Feb 14)



- Development of virtual reality counselling world and avatars
- Recruitment of young people to Young Persons Panel to help design and pilot intervention.
 - 13 young people (age range 15-21)
 - Attended six monthly meetings and contributed to closed project Facebook Page
- Pilot measures and materials for Phase II (live pilot study)
- Identification of ethical and practical issues for Phase II

C:EVOLVE Young Persons Panel

- Brainstorming activities re: important elements of a virtual reality counselling world
- Voting on preferences for avatar design and related assets
- Identifying range of relevant emotions, emoticons and animations
- Testing and feedback
- Creation of “FAQ” page



The C:EVOLVE Team



Phase 1



- Development of virtual reality counselling world and avatars
- Recruitment of young people to Young Persons Panel to help design virtual reality counselling world and to test out an on-line counselling session.
- Pilot measures and materials for Phase II
- Identification of ethical and practical issues for Phase II

C:EVOLVE Young Persons Panel

- ▶ NHS ethical approval obtained
- ▶ 13 young people (age range 15-21)
 - ▶ Five current/past students at Swansea Metropolitan University
 - ▶ Eight pupils from Olchfa Comprehensive School, Swansea
- ▶ Attended monthly meeting and contributed to closed project Facebook Page

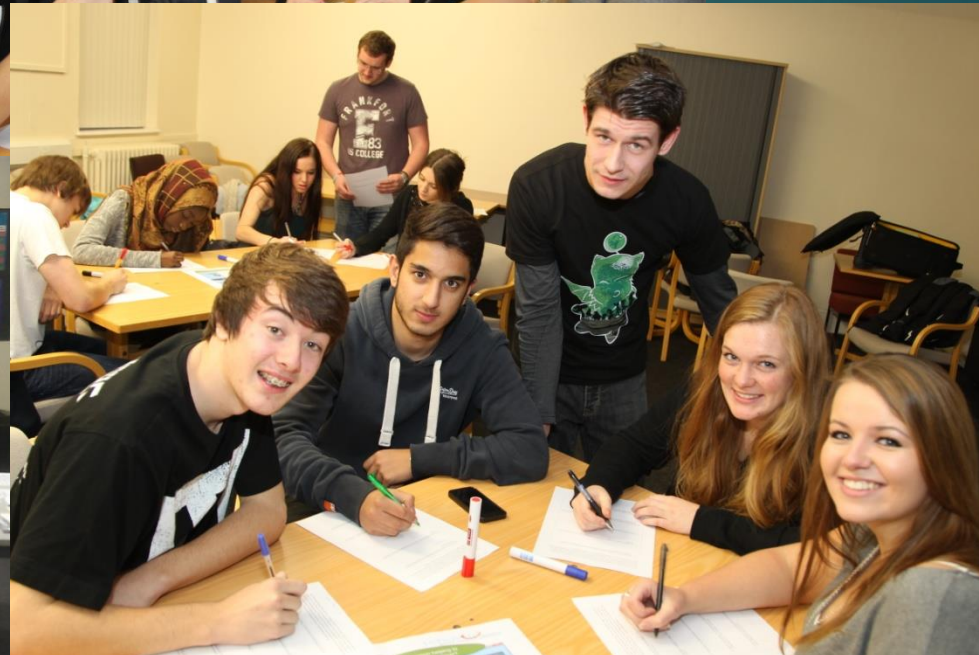
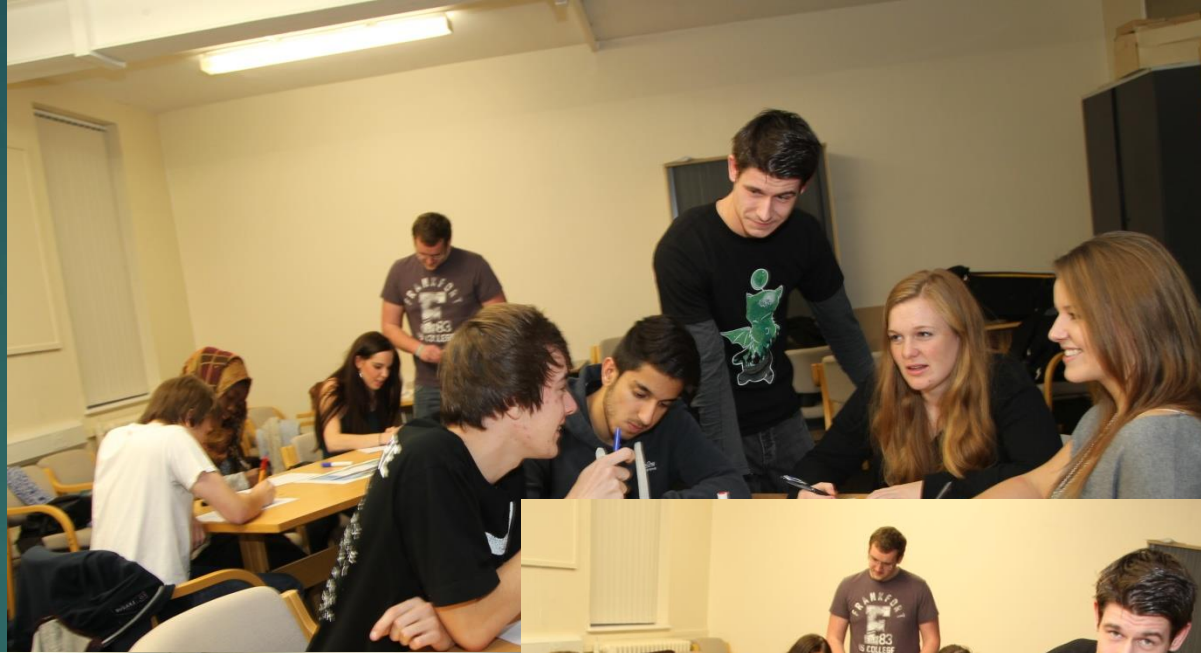
Testing out the C:EVOLVE world.....







Helping us develop materials for Phase II



Phase 1 Outcomes: Engaging young people....

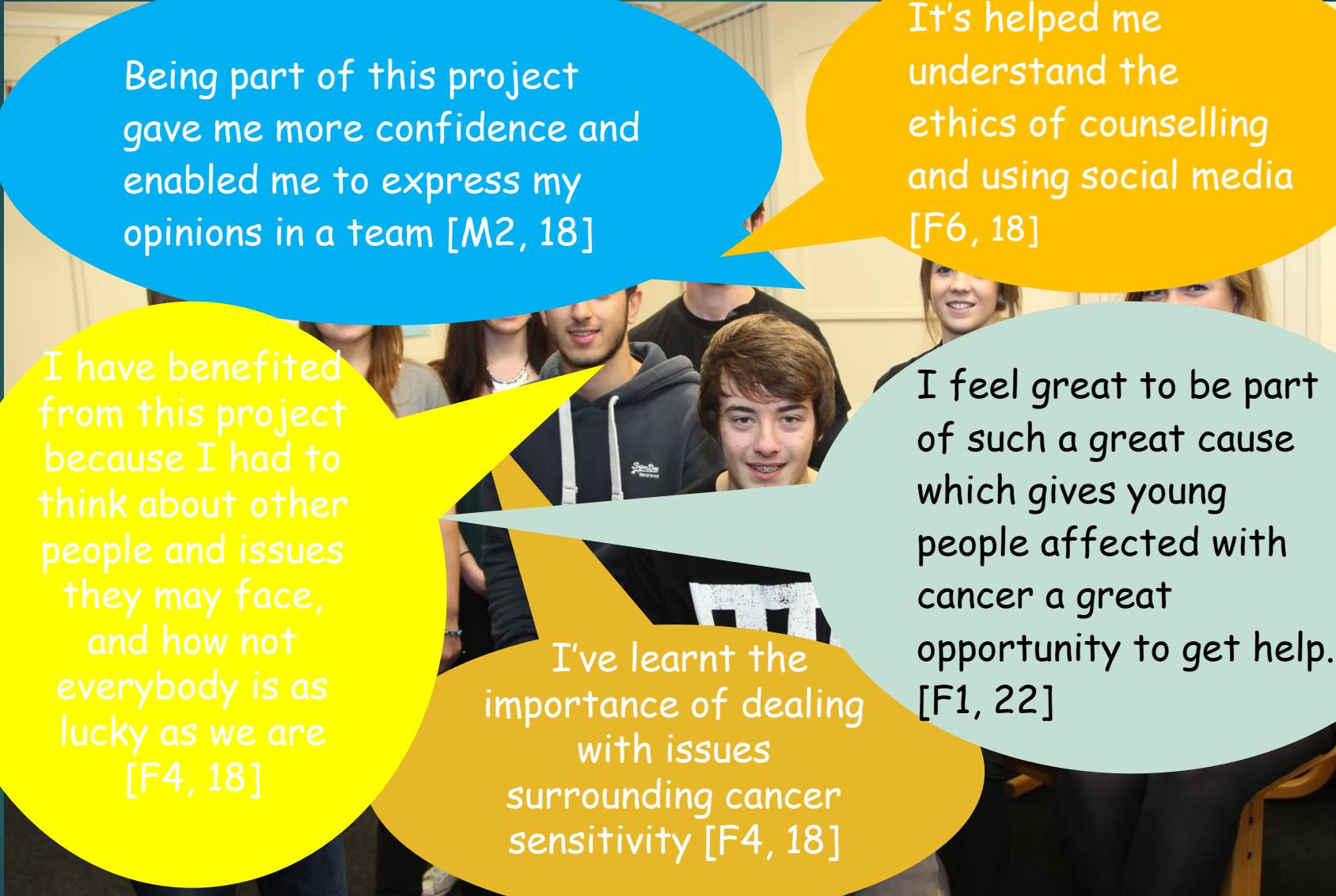
Being part of this project gave me more confidence and enabled me to express my opinions in a team [M2, 18]

It's helped me understand the ethics of counselling and using social media [F6, 18]

I have benefited from this project because I had to think about other people and issues they may face, and how not everybody is as lucky as we are [F4, 18]

I've learnt the importance of dealing with issues surrounding cancer sensitivity [F4, 18]

I feel great to be part of such a great cause which gives young people affected with cancer a great opportunity to get help. [F1, 22]



C:Evolve

Online counselling

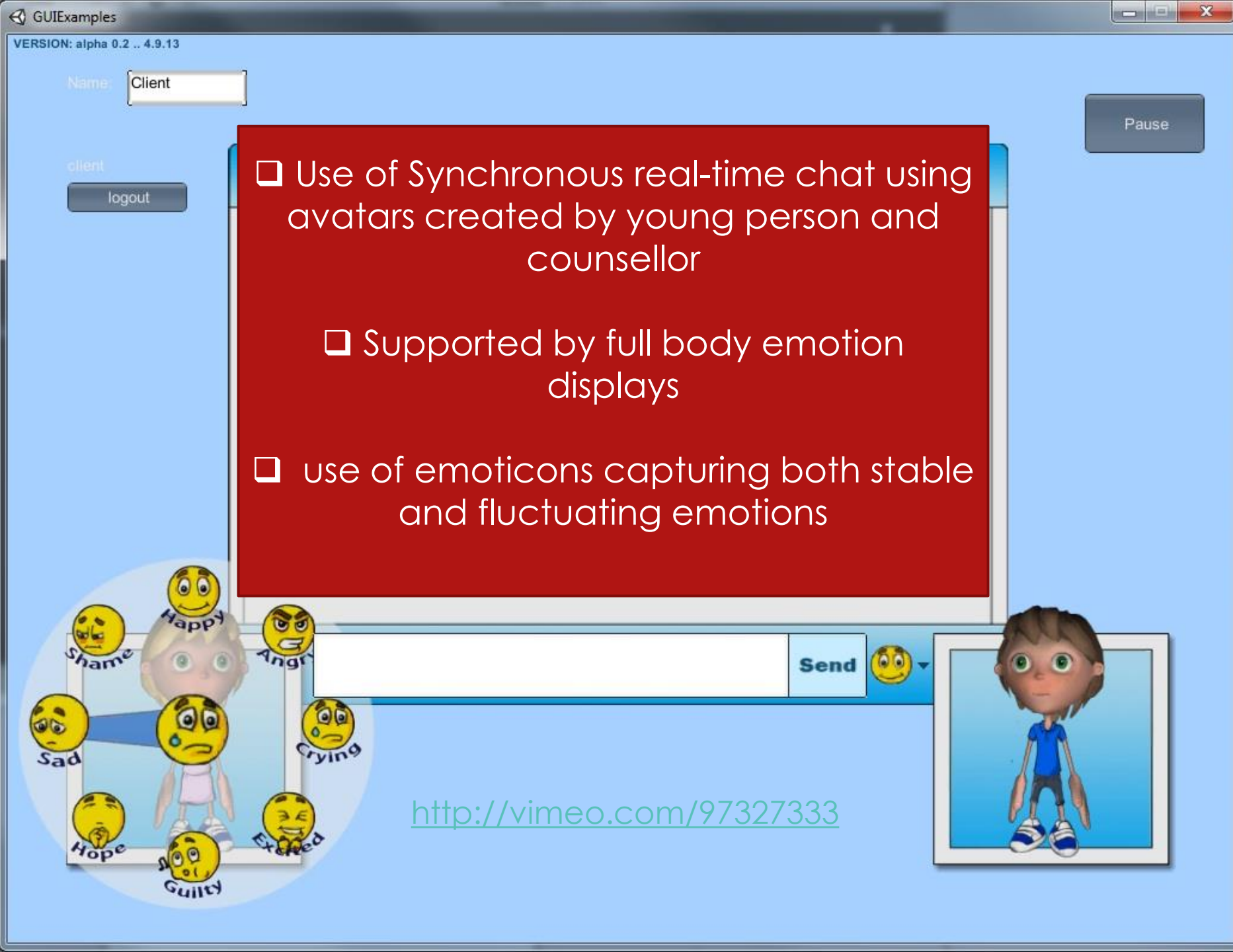


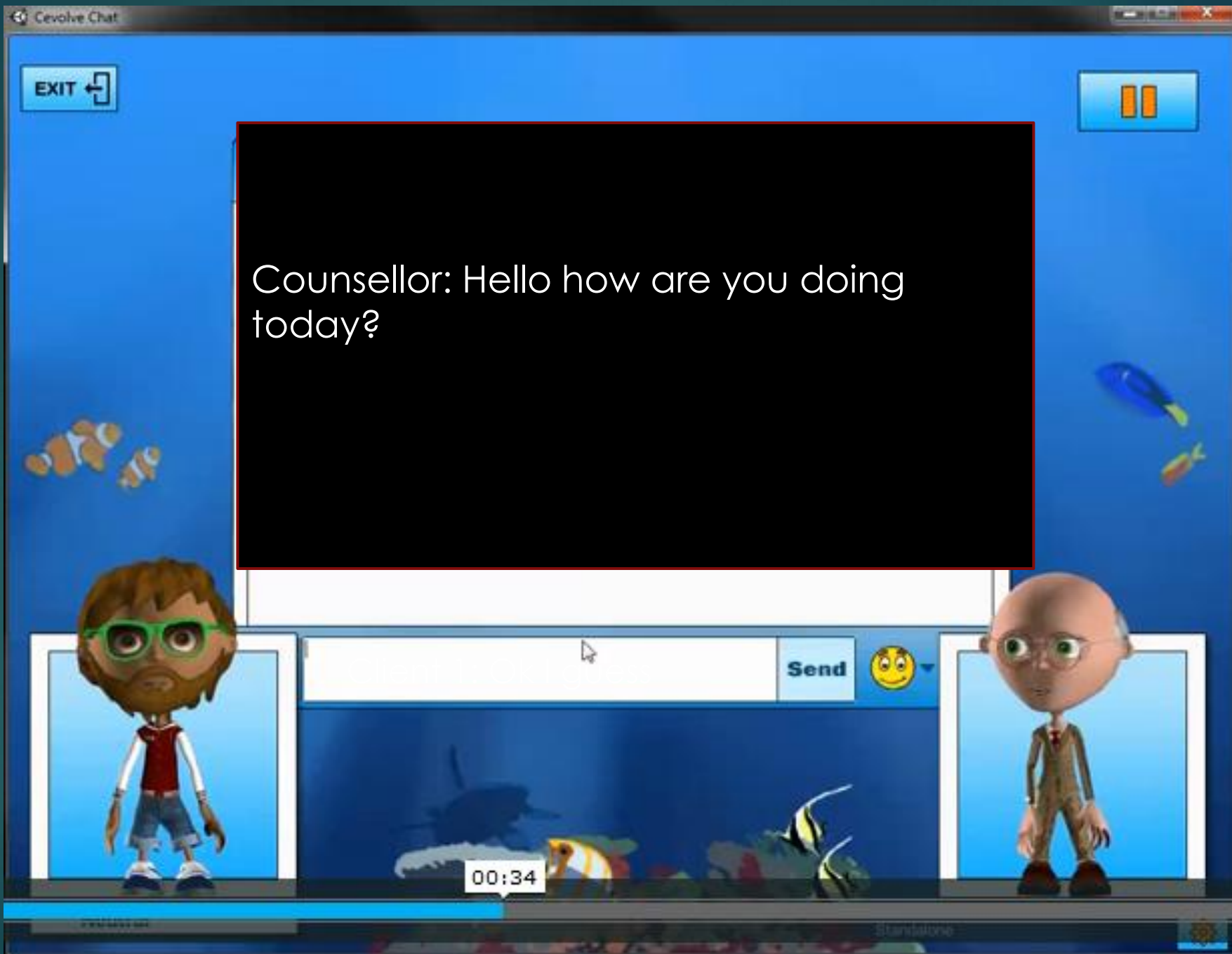
Start counselling session

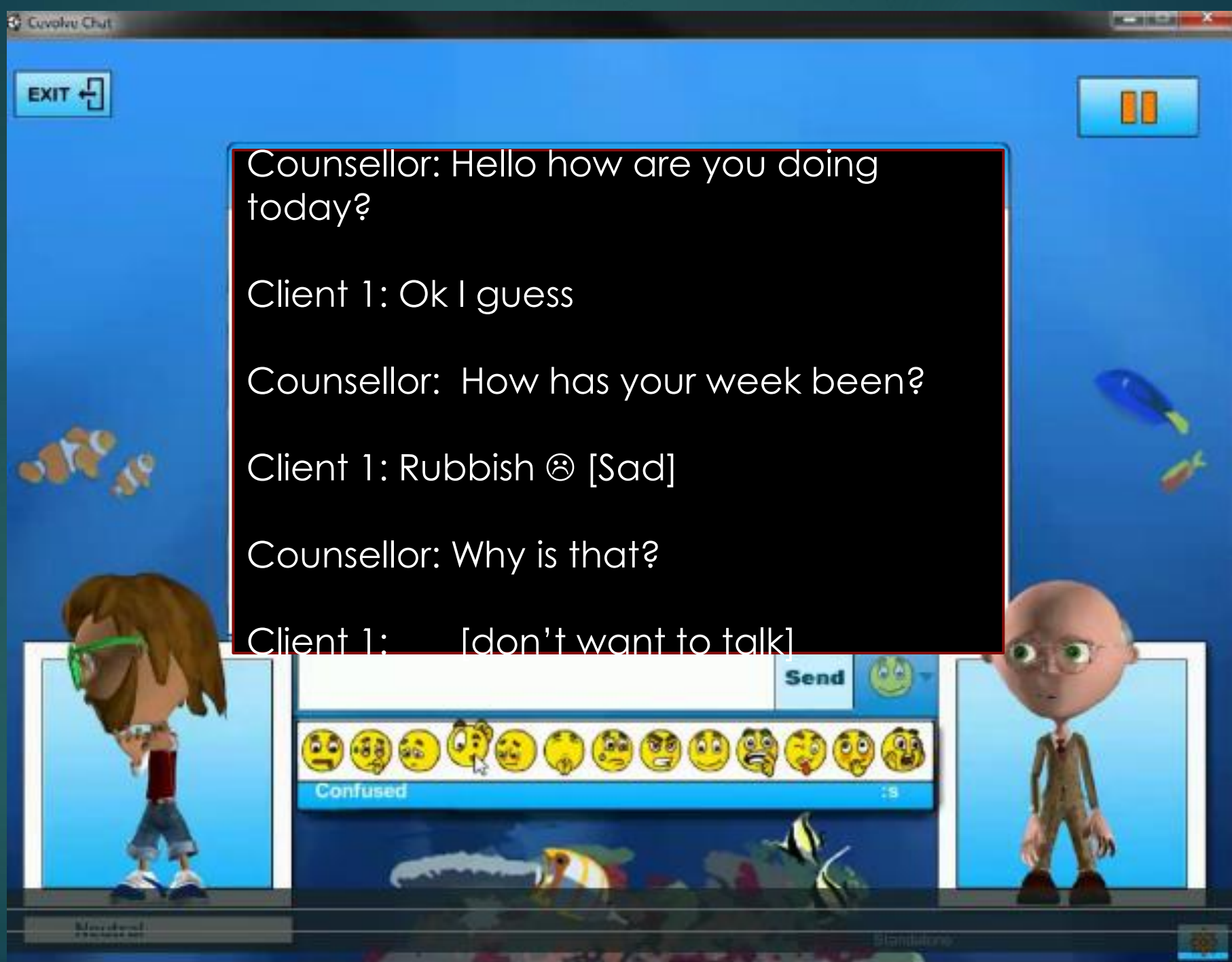
Avatar creator

Contact us

Log out







Phase II: Pilot feasibility study (March- August 14)

- ▶ Provision of six weekly online counselling sessions with qualified counsellor
 - Consent to pilot study including completion of online pre-and post measures

Participants:

- ▶ Up to twelve young people (15-25)
 - ▶ Personal diagnosis
 - ▶ Caring for someone with cancer in the family

Phase II Aims: Pilot feasibility study (March- August 14)

- ❑ **Uptake, drop-out and completion rates**
- ❑ **Changes in psychological functioning pre and post counselling (online measures via survey gizmo link)**
- ❑ **Demographic profile of those likely to use intervention**
- ❑ **Satisfaction with counselling**
- ❑ **Perceptions/reflections of online counsellor**

Are you a young person helping to look after someone with cancer?

Are you a young person affected by cancer yourself?

Would you be interested in having online counselling to talk about your feelings and worries??

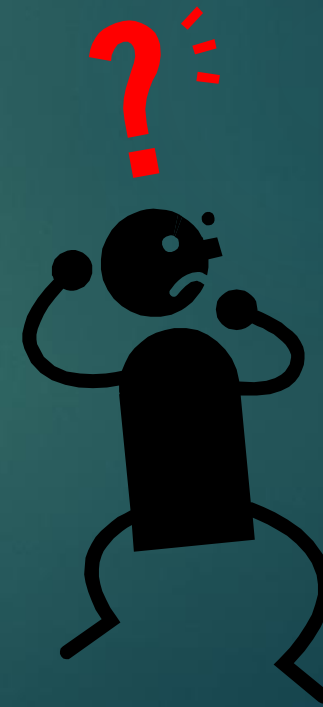
The C:EVOLVE project is seeking young volunteers to take part in a pilot study of a new avatar-based online counselling world.

- ☐ Are you aged between 13 and 25 years?
- ☐ Do you have access to the internet and are you familiar with using online games and social media?
- ☐ Would you be interested in taking part in a six week study of a new online counselling service?

If you have answered *yes* or *maybe* to the above questions and would like to find out more about the study, please email the study team at the School of Psychology and Counselling, UWTSD Swansea on c.evolve@sm.uwtsd.ac.uk or phone 01792 482084 for a study information pack.

The Recruitment Story

- ▶ Wide recruitment efforts over five months:
 - ▶ NHS, University, Tenovus, Press releases, Schools
 - ▶ C:EVOLVE blog, Twitter, Facebook
- ▶ Four expressions of interest
- ▶ One participant
 - ▶ Paused due to bereavement



Recruitment....why so poor?

- Flawed recruitment strategy?
- Parental reluctance/suspicion?
- Perhaps reluctance of young people to engage in counselling may stem from more pervasive issues than avoidance of face-to-face counselling
- Reluctance from service providers to promote recruitment to such an “untested” intervention?
- Lack of personal contact?
 - Online counselling as an addition/adjunct not sole intervention?



Considerations: Recruiting young people

- ▶ Further support for the role that young people can play in intervention development (Kime, McKenna & Webster, 2013)
 - ▶ 100% retention rate to YPP and
 - ▶ Valuable experience
 - ▶ *YPP Did not have cancer themselves*
- ▶ Poor uptake rates for online counselling documented elsewhere (Skinner & Latchford, 2006)
 - ▶ Reluctance and suspicion
- ▶ Intense ethical research framework may ultimately create obstacles to engagement/recruitment (Skelton, 2008)
- ▶ May be more acceptable if offered as an adjunct to face-to-face counselling (Dowling & Rickwood, 2014)

Considerations: Role of Gatekeepers

- ▶ Parents also important to target!
 - ▶ greater parental knowledge about online interventions predict more positive attitudes towards making use of such interventions for young people (Sweeney, Donovan, March & Laursen, 2015)
 - ▶ *should they have been involved in development of intervention?*
- ▶ Clinicians and nurses are a key and often trusted communication mechanism that can have a significant influence of study participation rates
- ▶ Established and trusted relationships with professionals an important facilitator in young people's help-seeking behaviour (Gulliver et al., 2010)
- ▶ Importance of training and support for counsellor crucial

Counsellor's Perspective...



The elusive counsellor/ elusive client

- ▶ Online counselling comes with a **large extra dynamic of insecurity**... Is the person seeing what is intended, practically seeing what you are seeing... Is it really the person?
- ▶ Challenging to work without body, facial cues, eye contact, tone of voice. **Difficult to provide reassurance.**
- ▶ It is my sense that **an online client would need to be quite robust** to start with.
- ▶ Time to build rapport by means of more small talk would be important. The felt sense of each other that comes by image, body presence etc needs to be achieved by words. Descriptions of each other, values, personality ... **Before any emotional vulnerability is explored.**

Acknowledgements: The C:EVOLVE Team

▶ Chartered Psychologists

- ▶ Dr Ceri Phelps
- ▶ Dr Paul B Hutchings

▶ BACP-registered Counsellors

- ▶ Carol Hughes
- ▶ Helen French
- ▶ Sarah Pozzi (online counsellor)
- ▶ Catherine Slade (counselling supervisor)

▶ Games Development Experts/Modellers

- ▶ Andrew Baker
- ▶ Wayne Hawkins
- ▶ Andrew Leeuwenberg

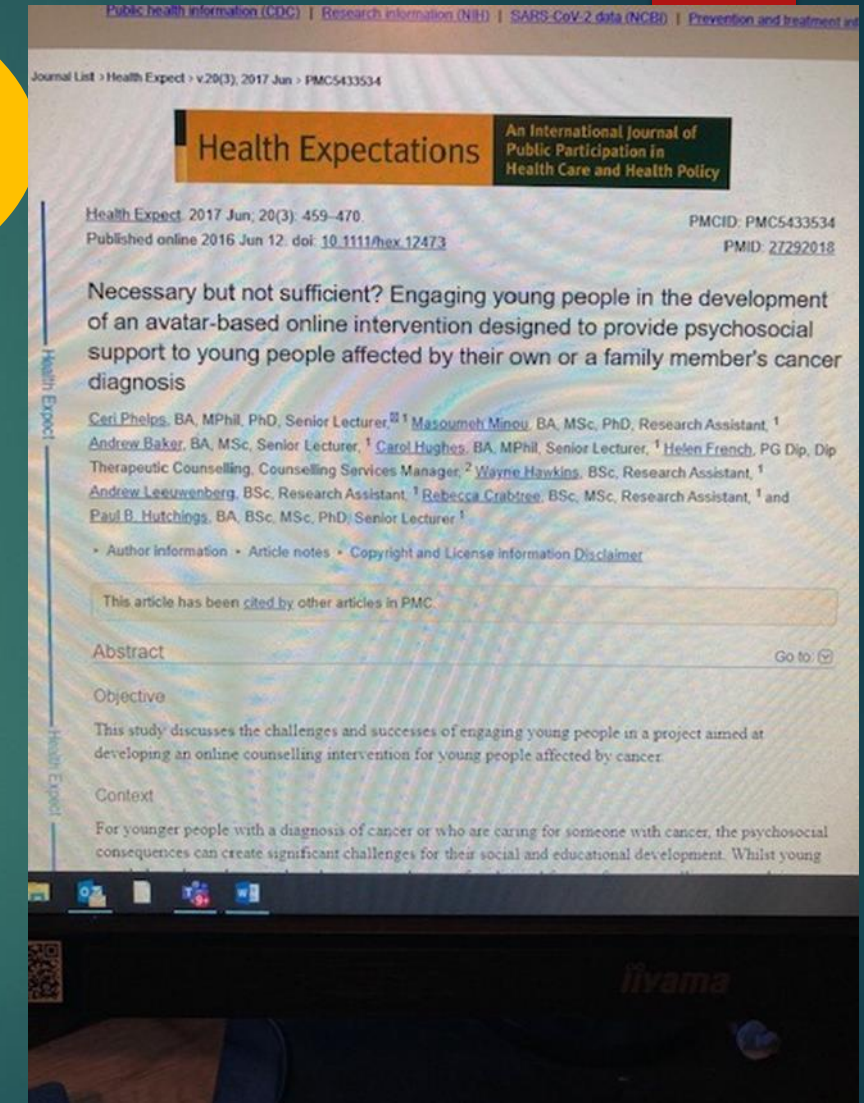
▶ Young People

- ▶ Olchfa Comprehensive, Swansea
- ▶ School of Psychology and Counselling, UWTSD Swansea

▶ Supported by Project Steering Group Collaborators and Project RA

- ▶ Dr Mas Minou/Rebecca Crabtree/Stacey Coleman
- ▶ Liws Kim Protheroe Davies
- ▶ Lorraine Sherman
- ▶ Ruth Groff

Changing the
face of
counselling
#Cthisevolve





Nature and Wellbeing

The Biophilia hypothesis

The biophilia hypothesis (Wilson, 1984) states that humans have an innate attraction to nature





Chalquist (2009, p.7) states that a variety of psychological symptoms such as anxiety, frustration, and depression are created by a 'disconnection from the natural world in which we evolved' and suggests that;

'reconnection to the natural world –whether through gardens , animals, nature walks outside, or nature brought indoors-not only alleviates these symptoms, but also brings a larger capacity for health, self-esteem, self-relatedness, social connection, and joy'.

Research regarding humans and nature shows positive physical and psychological effects from being in, as well as viewing, natural environments

These effects include :

Faster recovery from surgery

Decreased pain

Enhanced mood

Lowered stress

Increased ability to concentrate.

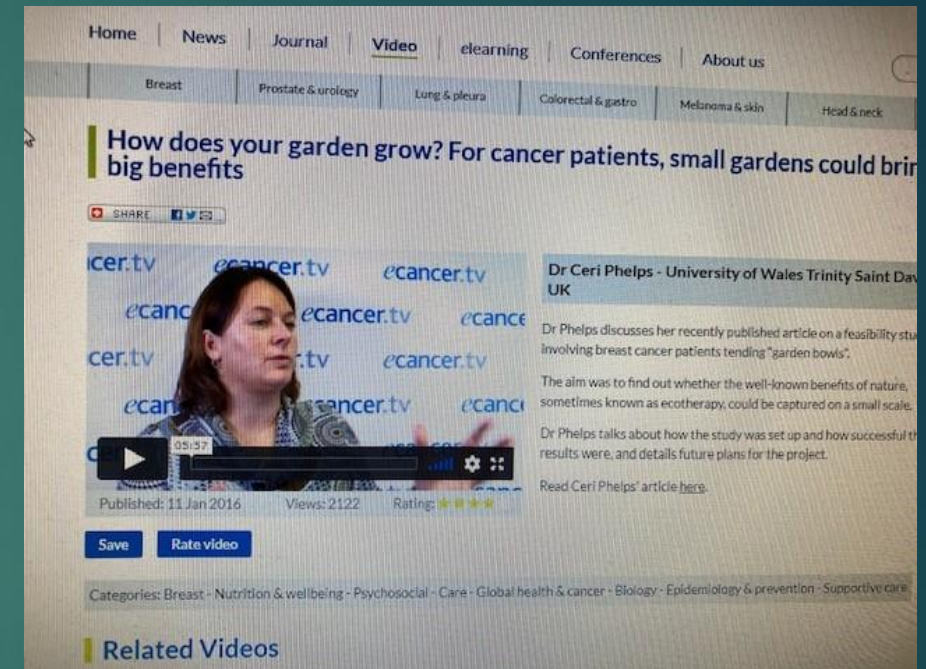






Publications/Impact

- ▶ <https://ecancer.org/en/journal/article/602-sowing-the-seeds-or-failing-to-blossom-a-feasibility-study-of-a-simple-ecotherapy-based-intervention-in-women-affected-by-breast-cancer/abstract>
- ▶ <https://ecancer.org/en/video/4550-how-does-your-garden-grow-for-cancer-patients-small-gardens-could-bring-big-benefits>







The ManVan Project

- ▶ The Tenovus ManVan was launched in March 2014 in partnership with the Movember Foundation and Prostate Cancer UK
- ▶ The UK's first dedicated mobile support service for men affected by prostate, testicular and penile cancer.
- ▶ Provides nursing advice, counselling for individuals and couples, group support and welfare rights advice directly to men in their communities across Wales.
- ▶ Travelled to more than 100 different locations across all seven Welsh Local Health Board areas.



Research reflections... a moveable (literally) feast....

- ▶ Evaluation of a completely unique “intervention”
 - ▶ Pragmatic, avoid burden
- ▶ Complex, difficult to control
 - ▶ Multiple services received
- ▶ Awareness-raising V engagement with services
- ▶ Buy-in from the ManVan team crucial

Conclusions II

- ▶ Clear potential value of the provision of mobile cancer service delivery in the provision of psychosocial support and care to men at different stages of their cancer journey and with different demographic, psychological and clinical profiles.
- ▶ Men still reluctant to engage with counselling services (V “tea and a chat”)
- ▶ Potentially important role in awareness-raising
 - ▶ E.g. Bridgend Ford Occupational Health day

Acknowledgements





Prifysgol Cymru
Y Drindod Dewi Sant
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GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

“I almost feel like a bit of a second class citizen”: A focus group study of the experiences of women diagnosed with secondary breast cancer and their support needs

MARGARET ANN BAKER,

**SECONDARY BREAST ONCOLOGY CLINICAL NURSE
SPECIALIST, ABMU**

**DR CERI PHELPS, REGISTERED HEALTH PSYCHOLOGIST,
UNIVERSITY OF WALES TRINITY SAINT DAVID**

Background

- ❑ Women with a diagnosis of secondary breast cancer have complex and often unmet needs
- ❑ higher level of psychological distress compared to that at receiving a primary diagnosis (Breast Cancer Care, 2009; Reed et al. 2010; Mahon et al. 1990; Parle et al., 2001)
- ❑ high levels of psychosocial morbidity (Cohen, 2002; Coristine et al 2003).
- ❑ Feelings of uncertainty, lack of control, stigma, abandonment, anger and isolation (Hanson-Frost et al. 2000; Krigal et al, 2014; Pollin; 1995; Mosher et al., 2013).

Methods

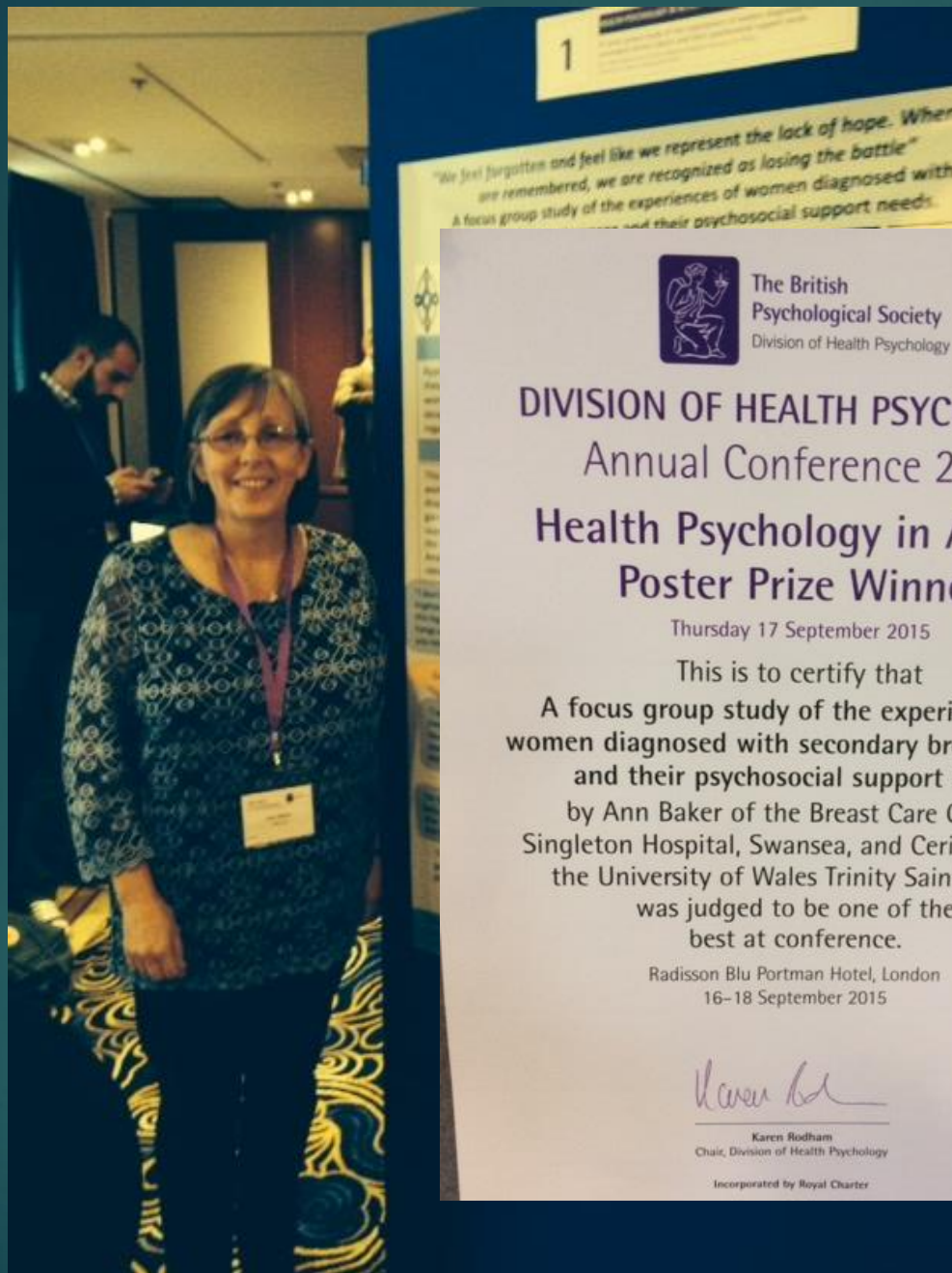
- ❑ Qualitative focus group methodology
 - ❑ ideal way of obtaining rich narrative information about shared experiences of health and illness (Wilkinson, 1988; McLeod, 2011)
 - ❑ previously used as an aid to exploring and planning future needs of women with a diagnosis of secondary breast cancer (Breast Cancer Care 2008) and other cancer patient groups (e.g., Hughes & Phelps, 2010).

Findings: Thematic Analysis

Table of superordinate and sub-ordinate themes

Superordinate theme 1: A loss of support	Superordinate theme 2: A changing identity	Superordinate theme 3: Living with no cure
Sense of abandonment	Self stigma	An uncertain future
Needing time to reflect	Walking in their shoes	Resilience
Perceived reluctance to explore the death question	A common identity through shared experience	Reluctance to seek psychosocial support
A missing link		

Impact....



"We feel forgotten and feel like we represent the lack of hope. When we are remembered, we are recognized as losing the battle"
 A focus group study of the experiences of women diagnosed with secondary breast cancer and their psychosocial support needs.



Bendith ydyd Pŵllygol
 Awtora'r Bôl Wnganannu

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Email: Margaret.baker@swansea.ac.uk

(2) School of Psychology, University of Wales Trinity Saint David, Swansea



Y Drindod Dewi Sant
 UNIVERSITY OF WALES
 Trinity Saint David
 SWANSEA - ABERYSTWYTH

Women are living with secondary breast cancer in the United Kingdom with 12,000 of in the last year of their life (Maher & McConnell, 2011). It is now acknowledged that breast cancer have a chronic condition and yet in some health boards there are no Specialists (CNS) to support those women (Reed et al 2003), and little is known needs during their experience of secondary breast cancer.

Participants

out to explore how such their experience of being breast cancer and to their needs for psychosocial Data was analysed using tative Phenomenological (7). Ethical approval was West Wales NHS REC.

A purposive sample of women with a diagnosis of secondary breast cancer was used. 16 women were approached through the Breast Care Centre at Singleton Hospital, Swansea. Of the 14 women who returned consent forms, 12 women then participated in one of two focus groups (6 women in each group). The women had secondaries in bone, brain, liver and lung. Ages ranged between 29 & 70 years.

Findings

Analysis of the two focus groups revealed themes that indicated the women felt unsupported by the care system in comparison to the levels of support received as primary breast cancer patients. Participants talked about the lack of formal support, the stigma of being diagnosed with secondary breast cancer, the impact of being informed that their cancer was not curable and the need for humour and resilience as part of their coping.

The lack of formal support

"I feel totally abandoned by you know any support what so ever since I got referred to oncology".

Humour & Resilience

"I just say yes I'm positive, positively pissed off".

"So I feel that nobody is treating me holistically because you can't separate parts of my body".

Stigma

"I had loads of support and everything but when we were given to oncology I feel I was treated like a statistic not as a person, and you do feel lost."

Conclusions

ons for the oncology/breast multidisciplinary team regarding the need to bridge the secondary breast cancer feel exists between themselves and their oncologist. There is state education training programmes to develop higher level communication skills to experience when patients with secondary breast cancer attend for their oncology the value of support groups has also been demonstrated through this project.

Thank you to all the ladies who took part in this focus group study, to Maggie's Caring Centre, Swansea for hosting the groups, and to the Breast Care Centre, Swansea and Mr MIB Chare Consultant Breast Surgeon for supporting this project. This project formed Ann Baker's Master's Dissertation in Counselling Practice at UWTSO Swansea.

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Pioneering conference sharing advice about life after secondary cancer diagnosis

Tuesday, 10 October 2017

Health professionals and cancer patients will be uniting in Swansea at a special conference to raise awareness of secondary breast cancer.

The event is being held on the same day as national Secondary Breast Cancer Awareness Day on Friday.

It is the first event of its kind to be held in Wales and features a packed agenda of expert speakers who will be sharing information about living with a secondary cancer diagnosis.

The conference, at the Village Hotel, has been organised by ABMU's Ann Baker (right) who has been supporting women with primary breast cancer for 26 years in her role as breast care specialist nurse.



However, she has since changed duties to take up her current post as Wales's first secondary breast oncology specialist nurse.

"The aim of the event is to increase awareness regarding secondary breast cancer, to educate and inform practice," said Ann, who is based at the South West Wales Cancer Centre, Singleton Hospital.



Prepared for submission to the journal *Cancer Nursing Practice* under the *Evidence & Practice: Research* stream

"I almost feel like a bit of a second class citizen": A focus group study of the experiences of women diagnosed with secondary breast cancer and their support needs

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Reflections & Conclusions

- ▶ Working with cancer population requires high levels of professional skills
 - ▶ Communication
 - ▶ Collaboration
- ▶ Moral and ethical standards
- ▶ Important to demonstrate impact of research on patient population
- ▶ Evaluation of psychosocial initiatives can be messy - essentially “complex interventions”.
- ▶ Often learn the most from the things that don't go to plan!