UNIVERSITY OF Southampton

Understanding and perceptions of mindfulness-based interventions and development of an adapted mindfulness intervention for breast cancer patients (MABCan)

Rachel Ryves, Geraldine Leydon, George Lewith, Deborah Fenlon, Ellen Copson, Caroline Hoffman, Claire Foster, Adam Geraghty, Gail Davies, Lesley Turner, Alison Richardson, Caroline Eyles

5 July 2014

breast cancer campaign
Research that saves lives

UNIVERSITY OF Southampton

Background.

UNIVERSITY OF Southampton

Living with breast cancer

- Living with breast cancer can cause considerable psychological suffering
- Approximately 50% of all breast cancer patients experience some emotional distress including anxiety and depression
- Psychological interventions such as CBT or psychotherapy can improve psychosocial outcomes such as mood or quality of life
- BUT there is little evidence that these outcomes are sustained or specifically address the cause of on-going distress

Mindfulness-based interventions

- Mindfulness-based interventions can improve symptoms of:
  - Distress
  - Menopausal symptoms
  - Fear of recurrence

- Mindfulness interventions are increasingly being used in clinical settings

What is mindfulness-based stress reduction?

- Developed by Jon Kabat Zinn
- Mindfulness meditation training focuses on the self-regulation of emotions
- Emphasises a moment-to-moment, non-judgemental, non-reactive awareness to experience
- Aims to reduce the rumination of distressing experiences and intruding thoughts
- Essentially ***living in the moment***

"The help it gives me in connecting me to the present and grounding me – against the storms of emotion that strike, the waves of strong emotion, the fear of what's going to happen…"

The course

- One session a week for 8 weeks
- A one day, 6 hour retreat
- 45 minutes home practice a day

Mindful eating

- Raisin exercise

UNIVERSITY OF Southampton

Breathing exercises

Body Scan

UNIVERSITY OF Southampton

Previous research

- Feasibility study of women with advanced stage breast cancer showed benefits of taking part in the existing MSBR course
- RCT also showed benefits for early stage breast cancer patients
- However existing course may not be acceptable or accessible for all due to:
  - Length and intensity of the course
  - Travel
  - Health and treatment issues

What needs to be explored?

- How to adapt the mindfulness course to reduce contact hours or make it more accessible
- Whether other modes of delivery of the course are acceptable

UNIVERSITY OF Southampton

Current Study (MABCan).

UNIVERSITY OF Southampton

Methods

- Design: Qualitative study involving two stages
- Recruitment: Patients from UHS Breast Oncology Group
- Eligibility criteria:
  - Women >18 years old with early stage breast cancer and ≥1 month from final chemotherapy or radiotherapy treatment
  - Women >18 years old with advanced breast cancer at least 2 months post-diagnosis of metastatic disease and with stable disease
  - A score of ≥8 on either anxiety or depression scales of the HADS; an ECOG performance of 0-2

Study stages

Stage 1

4 focus groups of 5-7 patients. One focus group may include women who have previously taken part in a mindfulness course.

Focus groups will elicit interest in and views of mindfulness interventions and how they can be adapted for BC patients.

Thematic analysis of the data will inform the development of a mindfulness course designed specifically for the unique needs of BC patients.

Stage 2

5-10 patients from Stage 1 will take part in a 30 minute "think aloud" interview to provide feedback and suggestions on an adapted mindfulness course.

Thematic analysis of interviews will identify content to directly shape the development and design of the intervention.

Focus groups & Interviews

- Asking about understanding of mindfulness
- Asking for benefits of and barriers to the course
- Asking about structure and duration of course
- Asking about sharing the course with different patient groups
- Asking for opinions of mindfulness techniques

Progress to date

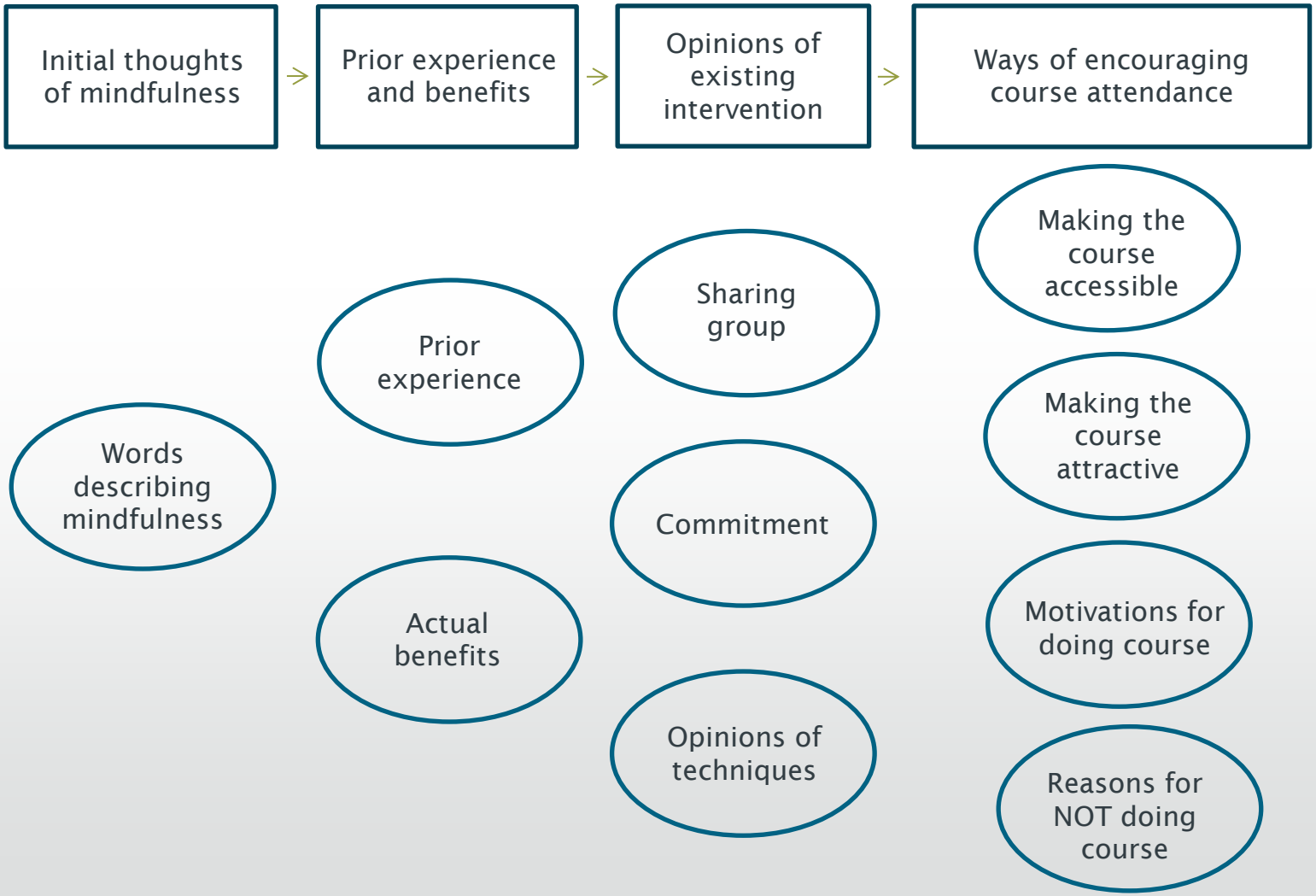
- 2 focus groups
  - 1 group with 4 metastatic breast cancer patients
  - 1 group with 6 early stage breast cancer patients

- 2 face-to-face interviews with metastatic breast cancer patients
- Pending: 1 focus group and 1 face-to-face interview

UNIVERSITY OF Southampton

Preliminary Findings.

Preliminary Findings



Commitment

- Most seem satisfied with structure and duration of the course, with little need for change

P4: *I think because* ***I really wanted to do it****. I think,* ***out of the eight weeks,*** *I think there was one week where I'd had the treatment and* ***I just couldn't get to it, I just felt really unwell,*** *that's the only time, but otherwise I did it all. I think it's because I really wanted to do it that I think you sort of push yourself a little bit, but it is quite hard when you're feeling really rough to, actually, to do it, because it's quite easy to lay in bed and think, 'Well I just don't want to get up', but, yes,* ***it is balancing out really****, isn't it? Yes, it is hard when you're feeling under the weather.*

I: *How does everyone else feel about that sort of length of time for the course?*

P1: *That sounds ideal to me if it's done, ideally, on the same day, it's* ***like a routine on the same day****, at the* ***same time****, in the* ***same place*** *and I have my own. So, I know that that Wednesday morning I won't be able to book any exercise classes, I won't be able to book work, that it's just specifically for that, and* ***for eight weeks that's what I do****, that Wednesday. If it comes to the point where it's like one week it's Thursday, then the other one's Monday, then* ***I'm more hesitant to commit*** *to that because then it's juggling everything else around it, whereas if I say, 'Right, Wednesday', that's it. Like today I'm here because I changed my work hours to yesterday.* (FG1, MBC)

Making the course attractive

- Patients felt that they would be more willing to take part in the course if they were shown the value of it

P2: *You know if you can present it in a way that* ***makes you feel you're going to really get something out of it****, then as you go through the course you can maybe reiterate that and* ***showing, telling us what we're getting out of it****. I think it would be something quite* ***valuable****. So you'd think well I'm going to do that because actually this is something - whereas if it's just positioned as, well you know we're doing this little course and - do you know what I mean?* ***It needs to have real value, doesn't it****? Because it is a big, I mean I know 45 minutes a day, but you know to set that aside and you know, it is a* ***commitment****.* (FG2, EBC)

Making the course attractive

- Some patients felt the course would be more acceptable if there was evidence to prove its value

P1: *For me, I would want to see* ***statistics****, I want to see* ***results****, I want to see* ***studies****, I want to see how other people felt, 'Out of a cohort of 1000 people, 900 said that they de, de, de.'* ***I want to see that it's worked****, that there is a* ***great benefit*** *in me gaining from it and* ***other people have gained from it****, maybe not 100 per cent, but a big, you know, like drugs, I wouldn't want to have anything that didn't really work for a lot of people. I want to see studies, I want to see graphs, I want to see results, I want to see how it felt to other people…*(FG2, MBC)

Motivations for doing course

- All participants thought the course would be of benefit

> ***P1:*** *It would give me a* ***tool*** *to* ***use*** *myself and to* ***help*** *myself.* (FG1, MBC)

Motivations for doing course

- Some patients thought mindfulness may help them regain some control in their lives

***P6**: I was just going to say, I don't know whether it would help with that **feeling of control** because it's that lack of control isn't it? And I think sometimes that's about the sleeping issue because actually you keep busy during the day and then **when you're stuck at night the different thoughts start intruding**. Actually if you've got **something that you can use**, as a kind of **focus**, that might help **control** some of those. But it's about that loss of control anyway isn't it?*
***I**: Yes.*
***P6**: You've sort of **lost control** over what's happened to us, people have done things, with the **best intentions** obviously but have done things to us. It's that lack of control I think.*
***I**: Yes.*
***P6**: And if it **helps** with that…*
***I**: Yes, that's a good point.*
***P6**: …that would be, it might be **useful**.* (FG2, EBC)

Reasons for not doing course

- Some patients were concerned that the course may focus too much on the illness

P3: So *you wouldn't be sat - that's one of the reasons I turned down counselling, because* ***I didn't want to just be talking about that*** *and that's all we had in common. So, no, as long as it was focusing more on this, the* ***healing side or coping side****, it would be fine.* (FG2, EBC)

Reasons for not doing course

- Some patients felt they did not want to spend time taking part in a course associated with their illness

***P1**: But I suppose I've, maybe I rationalised it and said to myself I just don't want to be - not - I mean this in a nice way. You know **I don't want to be associated with the ill** - if I meet someone who's got the illness, brilliant. But **I don't want to seek it out**, because like you say…*

***P2:** When my friend was first poorly we'd have a bit of a get together with a few of the mums, when everybody wasn't working, when we could catch up and have a coffee morning. She used to always joke that **we were in the C corner**, because there was only her and me going to the chemo.*

***P3**: It has been sort of a **club no one wants to belong to**.*(FG2, EBC)

Reasons for not doing course

- Some metastatic breast cancer patients expressed concerns about taking part in the course with other women at a different stage of their illness

***P2**: Because I find, and this maybe my protective factor, I find it quite hard to actually, **when you're in a mixed group**, it's almost like **you don't want to be negative** because you've got like a secondary and...*
***P4**: You mean somebody who might be cured?*
***P2**: Yes, because...*
***P4**: Yes, you might think, mm, that you know, they've got breast cancer, but **they'll be cured** and that's it, is that what you mean?*
***P2**: I think I'm trying to say it's like **you don't want to worry them**, because I got diagnosed quite quickly, with the secondary it was within a couple of months, so it was almost like I got that bit over, but there's other people, **people always have that fear that it's going to come back**. I find that I find myself protecting because I say, 'Oh, I've got secondary, but I've only got it in the spine, it's nothing.' Do you see what I mean? So, I'm probably **being more protective for other people than actually myself**.* (FG1, MBC)

Next steps

- Conduct further focus groups and face-to-face interviews
- Complete analysis of data
- Commence development and adaptation of mindfulness course
- Start stage 2 of study
- Study to be completed February 2015

UNIVERSITY OF Southampton

Summary

- Mindfulness-based interventions appear to be acceptable and accessible to breast cancer patients
- Some minor alterations to existing course may be of benefit to patients

Thank you

- Dr Caroline Eyles
- Breast Cancer Campaign
- Caroline Hoffman and other co-applicants