Exploring how practising mindfulness affects people’s experiences of living with a long-term condition

RESEARCH SUMMARY

This qualitative research was undertaken for a PhD in the School of Healthcare at the University of Leeds, and was supervised by Prof Felicity Astin, Prof Michelle Briggs and Prof Andrew Long. It explored the question: “How does practising mindfulness affect people’s experiences of living with a long-term condition?” The PhD was successfully completed in September 2014.

Facts and figures

- I contacted Breathworks graduates from Leeds, Manchester and Bradford. I also contacted Breathworks trainers in the same region, and the Breathworks founders.
- There was a good response to my invitation to participate in the research. This meant I was able to recruit the number of people I wanted.
- During 2011-12, 41 people took part in the research. 27 people participated in a first interview, and 20 of these went on to complete diaries and second interviews. Later on, 14 people were involved in two focus groups.
- Participants had a wide range of physical and/or mental health conditions. Most had more than one long-term condition.
- People had attended Breathworks between one and nine years before taking part in the study. Most were women, of white British origin, aged over 45 and not working, often due to their health problems.

How the research information was analysed

- Each interview and focus group was transcribed to give me a complete record of our conversation.
- I then read each transcript to look for the themes in what people had said. I tried to work out how important the different themes seemed to be, and also looked at how often they came up in different people’s experience.
- I also tried to understand how these themes linked together to explain what happened to people with long-term conditions who practised mindfulness.
- From this process of analysis, I developed a ‘model’ of people’s experience, which is described in detail on the next page.
What people said, and what I found as a result

- Most people’s experiences were very positive, with some saying that practising mindfulness had been life-changing. Others had found it helpful, but hadn’t seen such a dramatic difference in their lives. For many, it had helped them cope better with their condition, and for some it had also improved their symptoms.

- Others had struggled, or not got what they hoped out of mindfulness practice. A lot of people described how it could be challenging and hard work, and took practice.

- When I analysed the experiences people described, one idea I had was that living with a long-term condition was like going on an unwanted journey to an unfamiliar place. Practising mindfulness helped many people with this journey, and to live more comfortably in the place they found themselves.

- The key thing mindfulness seemed to do was help people to *Start where they were.* When things are difficult, we may resist or ignore where we really are, and this can lead to problems. Mindfulness helped people be aware of and accept what was happening with their condition and how it was affecting them. They could then make appropriate decisions about what to do. *Starting where I am* is therefore at the centre of my model, which is shown below.

![Diagram showing the model of mindfulness](image)

- A number of things affected how much people were able to ‘start where they were’, and how easy or difficult they found it. These are shown in the boxes and arrows on the diagram, and each one is now described briefly.
• **Getting a new perspective** explained how mindfulness helped people view their situation differently. They learned to move towards the difficult reality of their situation, and to step back and see the bigger picture, including appreciating the pleasant aspects of experience. By focusing more on the present moment, they spent less time thinking about the past or future, and could see their current situation more clearly. They also saw how symptoms and thoughts came and went, and realised their illness was only a part of them, and not who they were.

• **Feeling equipped to cope** identified the resources Breathworks’ mindfulness training offered. These included practical tools, new ideas and support. All these things helped people feel more confident and competent in managing their long-term condition(s), and to have greater control and choice in life.

• **Doing life differently** described the changes people had made. Many had made mindfulness part of everyday life: some practised meditation regularly; others used it in other ways. Being more aware and accepting of their condition gave people greater understanding of how to work with it. They could act differently, both in everyday situations and in making bigger decisions about their lives. They could monitor and respond to their needs better. They also learned to focus less on the outcomes of activities, and just do the best they could. Making change was however often difficult, and people talked about the importance of kindness in helping them to value themselves and not push themselves too much.

• **Seeing a change** identified what differences people had or hadn’t seen in their experience. These included improvements in symptoms; more calm, clarity and optimism; better relationships with others, and sometimes more quality of life. For some, the changes had been dramatic, for others less so. These changes were important in helping motivate people to continue practising mindfulness.

• **Finding it difficult** described the opposite experience, of how people struggled with mindfulness in various ways – to become more aware of their symptoms and condition, to be kinder to themselves, or to keep up their practice. These difficulties made it hard for some people to benefit from practising mindfulness.

**What new things did the research discover?**

• A lot of the results of this study echoed what previous research into mindfulness has found. This is important, because some other courses are better known than Breathworks, and this research showed that people attending Breathworks can get many of the same benefits.

• The study gave more information about how people work with mindfulness over the longer term, which has not been very much explored before. It also showed that people can continue to benefit many years after attending mindfulness training. This is particularly important for those with long-term conditions, who frequently have to ‘learn to live with’ their health problems.
The research highlighted the importance of kindness within mindfulness practice, something Breathworks particularly emphasise. Being more kind to themselves helped people think more about their own needs, tell others how they were feeling, and look for the good things about themselves and their lives. These changes made it easier to practise mindfulness and care for themselves better.

This study also explored how people’s experiences related to other research about living with long-term illness, and what helps people to do this. One way this has been explored previously is looking at it as a process of “transition”. Transition describes how people come to terms with “disruptive life events”. It is the process of coming to terms with and adapting to change, and affects all aspects of life. Research has found that people need certain things, such as support, to make a transition. It has also identified certain ‘indicators’ which show transition has taken place, such as feeling connected to others and having more confidence and coping abilities. When people’s experiences of mindfulness were compared to the transition process, I found they were remarkably similar. As a result, my study concluded that practising mindfulness may help people make a transition and find ways to adapt to their changed situation. The idea of transition is used a lot in nursing, so describing mindfulness in this way may make it more relevant to healthcare professionals and help them to understand its value. Previous research has also suggested that transition is linked to improving people’s ability to manage their health condition, or ‘self-care’. A similar change was also described by many participants in this study. Improving self-care is a major concern within the NHS, therefore linking mindfulness to this issue should also help to emphasise its value.

What now?

I plan to publish the key findings from the research in relevant journals. This is important to ensure that the right people get to read about it, and that it adds to the existing knowledge about mindfulness and long-term conditions.

I also want to give information to health professionals and those who might benefit from learning mindfulness, particularly through Breathworks. This will hopefully make more people aware of it and encourage them to attend.

If you have any questions, you can contact me at hcjal@leeds.ac.uk until the end of October, or at the School of Nursing & Midwifery, Edith Murphy House, De Montfort University, Southgate, Leicester LE1 5RR from 3 November.

Jaqui Long, School of Healthcare, University of Leeds October 2014

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