



Pain is like a naughty pixie that gets in the way. Why should I have to stop doing things because it says no?

Natalie Bidad (Assistant Psychologist) & Lorraine Nanke (Principal Clinical Psychologist)

Introduction

- ACT is a principles-based approach which works with evidence-based processes in context to promote psychological flexibility.
- Much evidence supporting ACT-based group interventions in people with long-term health conditions (LTHC) analyses pre-post changes in outcome measures following a standardised intervention (for example^{1,2}). This research strategy does not directly address whether the intervention was associated with change in evidence-based processes.
- As flexibility-related processes are proposed to underlie human well-being, they are likely to be influenced by the whole range of interactions with healthcare systems, including formal intervention and informal communication.
- There is limited qualitative research investigating the efficacy of ACT delivered in a group setting to people with LTHC (for example³⁻⁵).
- The current service evaluation qualitatively explored service-users experience of either an ACT-based resilience or mindfulness 8-week course delivered in an outpatient group setting at Surrey and Borders Partnership NHS Foundation Trust, UK, in August and September 2018.

Method

- Semi-structured interviews (n= 10) were conducted in October and November 2018 with a self-selecting sample of participants who had attended either the ACT-based resilience or mindfulness course.
- Participants had a diverse range of LTHC. The topic guide explored participants' experience of their LTHC, what had led them to attend the course, and what they had found useful or otherwise during the course.
- Interviews were audio-recorded with participants' consent and transcribed verbatim.
- Grounded theory was employed for the thematic analysis.

Results

...when one of my kids had an issue at school and I had to go and deal with it...and I was rightfully very angry my daughter was having a hard time. And I kind of got there and I went, I've got 2 ways of handling this. I can go in and shout and scream, and stamp my feet. Or I can sit here and I can breathe for 2 minutes and then I can go in and deal with it. And I chose the latter, and actually having those 2 minutes just inside my own head to kind of put things where it needed to go so I could formulate what I want to say... I could go in and I could be calmer, but I could actually do what my daughter needed, rather than shout, scream and stamp my feet.

Participant 10

I started to think well perhaps let's try something else and see if we can't um find a way through [the pain]...I was hoping the course might somehow help me feel less pain. It hasn't. Actually since doing the course I'm in a lot more pain because I'm doing so much more, but it's how I'm handling it is the difference...**The pain is like this naughty pixie that gets in the way now... it's a bloody nuisance and it lives with me whether I want it there or not. It isn't going to go away, but I don't see why I should have to now stop erm doing things I want to do because it says no. I have to take it with me...**

Participant 2

I've been taking really small doses [of painkillers]. Umm cos I try and go through the day without having to but obviously, you know it gets to it gets to a limit. But I'm still not taking what I should be... But I think... I've managed to break free slightly in actually taking the step of taking them, which was such a huge huge thing for me in the first place.

Participant 3

Embedding flexibility in relationships

Embodied flexibility and self compassion

The main theme was participants' dynamic and ongoing shifts in their sense of agency, or their ability to do something to improve their health or well-being. Most reported an increased willingness to experiment with different ways of engaging with their body, other people and the healthcare system.

Getting to know or thinking about and putting myself first. Self-caring. I must admit it's something that I've never done never really thought I've had to do it, but during this course I actually umm, came to the conclusion that I actually need it. Um I do have to think about what I can do when I can do it.

Participant 5

yesterday I got really upset um about a carer not turning up on Saturday night. Um I was feeling really lousy on Saturday evening and I got a phone call saying that nobody would be able to come out until 9 o'clock. Um I got really quite angry about it saying 'Well I can't cook for myself, I can't do this, I can't do that' and I suddenly just said 'Stop. Just stop' to myself, from being angry, sat there, did a couple of breathing exercises, brought myself sort of down, down a level in the anger, and then actually thought well, they're not having an easy time either, they've got this and this and this, so why am I just focusing on myself thinking 'Poor me' rather than it's life it happens.

Participant 1

... obviously that sort of group of people who are very happy to talk got loads out of it and that was great for them ...but I felt that they needed to be in a different group, they weren't beginners, they should be in a different group, who've already got used to talking, who perhaps know each other well enough to not be embarrassed in front of those people, who are already knew what was wrong with each other and you know had coffee together and they had a relationship. And that, that's very difficult for anyone else trying to come into that... I felt it did intimidate me and, I went home to my son and then he said 'How did it go?'... I said 'God I just found it really irritating'. And he said 'Why?' and I said 'It's some people that just keep talking all the time then, no one else gets a chance'. And he said 'Mum' he said 'Do you think maybe that's why you should go on a mindfulness course?'

Participant 9

I s'pose it's helped me realise ... like for example seeing [group member's name] umm still working and at uni and, and she has a husband and she just keeps going and going, it kind of gives hope that I can like get back to work and run a normal life sort of thing um, I s'pose it's given me... sort of an idea of where I need to go next sort of thing

Participant 7

I'm just kind of used to jumping through hoops, if someone tells me to try medication or um to go to this specialist or to go to that specialist or to go to this group for example then I just kind of do them because otherwise you know you get told you're not complying blah blah blah, that you know you don't want to get better...I've just got jump through this hoop so to speak because otherwise I'm going to be seen to be not compliant

Participant 6

Flexibility in interactions with healthcare system

When I was going through the diagnosis with my back, umm, had one of the doctors here... get in my face and tell me it was all in my head, and I thought well I'm not having that because it's not in my head... and I thought...I've got to keep doing something to improve my lifestyle, to improve my you know, obviously my mentality. Um, so ... I was trying other things for my own personal use and also to, to put down on a basically on my notes you know '[Participant's name] is trying different things, she isn't you know what I mean just relying on medication' um and you know all the other things that go with that. It was just trying different things as well that didn't include medication.

Participant 8

I'd like to go and forget that I've ever been ill, but I can't because of the carnage it's wreaked on the poor old bod[y]. Erm so in some ways I want to totally break away from hospitals, um and another bit says 'Don't let me go because I'm scared it's [cancer] coming back'...And at the moment I'm trying to shift my thinking...I'm coming to terms with a much less hands-on approach...I only had a wobble for about 24 hours. Whereas before I would still be sitting in the corner sobbing going 'Nobody cares about me I could die' you know...I'm scared, ok it's ok to be scared...I'll chug along on the way I'm going. If it [pain] gets too bad I'll shout.

Participant 2

Discussion

- This study found participants' sense of agency in the management of their LTHC to be dynamic rather than fixed and 'all or nothing'. Participants showed an increased willingness to experiment with new ways of relating to their own body, to other people and to the healthcare system in order to better self-manage their LTHC.
- Participants 'starting positions' in terms of the different evidence-based processes of ACT were extremely varied, however the group intervention was able to 'meet' the individuals where they were such that they each experienced a meaningful increase in their behavioural repertoire. The ACT-informed group intervention therefore enabled individualised formulation and facilitated follow-up with targeted individual therapy.
- Attendance at the group formed one step in an ongoing process for participants, their engagement with the healthcare service being necessarily long-term. Their interaction with different aspects of the healthcare system sometimes had unexpected or unintended consequences on participants' sense of agency in the self-management of their LTHC.

Conclusion & Recommendation

ACT-informed interventions in a group setting offered an effective way of delivering individualised care to patients with LTHC to increase their psychological flexibility. Some interactions with healthcare services reported by participants had unintended consequences on evidence-based processes. Further research is needed to explore how self-management of LTHC is both facilitated and hindered by patient engagement with healthcare professionals and systems.

References

1. Whitney, S et al. 2017. Treatment of chronic pain for adults 65 years and over: Analyses of outcomes and changes in psychological flexibility following interdisciplinary acceptance and commitment therapy (ACT). *Pain Medicine*. 18(2): 252-264
2. Brassington, L et al. 2016. Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioural Science*. 5(4): 208-214
3. Whitehead, L et al. 2017. A nurse-led interdisciplinary approach to promote self-management of type-2 diabetes: a process evaluation of post-intervention experiences. *Journal of Evaluation and Clinical Practice*. 23: 264-271
4. Thompson, M et al. 2018. A qualitative analysis of patient-identified adaptive behaviour changes following interdisciplinary Acceptance and Commitment Therapy for chronic pain. *European Journal of Pain*. 22: 989-1001
5. Mathias, B et al. 2014. Individual experiences of an acceptance-based pain management programme: An interpretive phenomenological analysis. *Psychology and Health*. 29(3): 279-296

Acknowledgements

We would like to thank the service users that took part in this service evaluation, for their willingness, openness and time.