A Pilot Evaluation of Mindfulness-Based Cognitive Therapy (MBCT) for People with Huntington’s Disease (HD)

Friends’ and Family Members’ Perspectives
1 BACKGROUND FOR THE STUDY

Why interview friends and family members?
Not surprisingly, HD also affects families and friends.

Link between mood of person with HD and quality of life for family members. (McCabe, Firth, & O'Connor, 2009)

A lot of responsibility for support falls to friends and family members.

Psychological support for person with HD should have positive effect for friends and family too.
BACKGROUND FOR THE STUDY

- Friends and family members of people with HD experience their loved ones’ physical symptoms and emotional distress differently from those with HD. (Ready et al., 2008)

- Interviewing relatives/partners/friends provides a complementary perspective on the appropriateness and usefulness of MBCT for people with HD.
Research Question

What effect does attending an MBCT group have on mental wellbeing and relationships of both individuals with HD and the people closest to them, as perceived by their family members and friends?
2 METHODS

Participants
Analysis
MBCT Intervention
METHODS: PARTICIPANTS & ANALYSIS

Participants

- 9 individuals with HD recruited for MBCT group through regional HD clinic. (Leona’s study)
- 5 partners and 1 friend of a person with HD who attended the MBCT group. (This study)

Semi-structured interviews

Analysis

- Thematic analysis – looking for themes and patterns in interviews
METHODS: MBCT INTERVENTION

- 8-week group course based on MBCT protocol. (Segal, 2002)
- Each session (2 hours) involved a number of mindfulness practices, each with a particular focus, such as breathing, the body, walking, or eating.
- 40 minutes home practice per week.
- Attendees invited back for three ‘reunion sessions’.
3

RESULTS

Four Themes
THEME 1: Isolation and Insulation from HD – The Rarity of HD Creates Distance Between Partners/Friends and Other People Living with HD and the Experience of Removing this Distance by Attending the MBCT Group

Subtheme (a)
All in the same boat – Participants’ experiences of their partner/friend meeting other people with a lived understanding of HD

- Most group attendees had never met anyone with HD outside of their family.
- Some found social element more important than mindfulness component.
My partner felt comfortable because...he knew that people were in the same situation as himself....Because I think going into a group where...everybody’s issues are different and then being open...would probably be a bigger challenge.

Emma
THEME 1: Isolation and Insulation from HD – The Rarity of HD Creates Distance Between Partners/Friends and Other People Living with HD and the Experience of Removing this Distance by Attending the MBCT Group

Subtheme (b)
Participants’ partner/friend seeing his/her future self – Making the decision to meet other people with HD who might be symptomatic.

- Different to having met family members with HD – now a choice.
- Finding out that the group was for people with HD in early stages helped alleviate these concerns.
I mean he knew his dad with it [HD], but he doesn’t know anyone else who’s symptomatic...and he preferred it that way.

Bianca
THEME 2: Perceived Interpersonal Changes Following MBCT – Benefits of Attending the Group for Partners/Friends, Participants, and Families

**Subtheme (a)** Slowing down – Growing to accept silence and stillness.

**Subtheme (b)** Partners’/friends’ increased communication and connection with themselves and others.

**Subtheme (c)** Action and reaction – Partners/friends being able to notice themselves in situations, take a step back, and choose how to react.
THEME 2: Perceived Interpersonal Changes Following MBCT – Benefits of Attending the Group for Partners/Friends, Participants, and Families

- Slowing down
- Choosing how to react
- Communication & Connection

Mostly intrapersonal
Mostly interpersonal

Influenced by the ‘relating mindfully model’ (Bihari and Mullen, 2014)
I use this expression...that I follow in her [partner’s] wake...because I think the way I have to deal with things is determined by how she is. Her getting benefit from the group affects you quite a lot.

Simon
Participants reminded their partner/friend to practise mindfulness.

Mindfulness provided participants and partners/friends with an increased sense of hope and confidence in managing a scary and uncertain future.

‘Mindfulness as a skill’ also talked about by people with chronic pain and dementia. (Melunsky et al., 2015; Moore & Martin, 2015)
In the future, when she does get symptomatic and things do start creeping in, she can remember the techniques, she’s always going to remember them, she still tries to remember them, we still discuss them, so that she can use them in the future.

Tom
Participants were generally appreciative of the MBCT course; however they were also conscious of the need for further support.

There was a knowledge and dissatisfaction that there would be little else available to their partner/friend in the immediate future.

Reiterates the views expressed by family members of people with HD outlined in previous research. (Etchegary, 2011; Skirton et al., 2010)
It’s [MBCT group] been really good and beneficial, however you still have to live day-to-day knowing that you have that condition, that at some point in time it’s gonna manifest itself.

Simon
4 DISCUSSION

Strengths & Limitations
Clinical Implications
Future Research
First known study looking at any type of psychological intervention for people with HD.

Findings reflect just one particular group. However, themes fit well with previous research.

None of the participants were family members.
CLINICAL IMPLICATIONS

- Encouraging signs that MBCT is helpful and appropriate intervention for people with HD.

- Findings reiterate clear need for emotional support for people with HD and their support networks.

- Future groups should aim to match people with HD at similar stages.
This was just a pilot study.

Larger-scale research needed to create evidence-base so that HD services can offer MBCT.
Thank you

Any questions?
REFERENCES