Psychological and Psychotherapeutic Approaches When Working with People with MND

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Aim

- To describe the different psychological/psychotherapeutic approaches used by therapists when working with people with MND

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- Dublin City University

Agenda

- Reason for the study
- Aims and objectives
- Results

Background and Rationale

- MND known to cause psychological distress and research highlighted emotional support priority for people with MND (Foley,Timonen and Hardiman2012)
- From literature appears no research on type of therapeutic intervention could support people with MND (Pagini et al. 2012)
- In line with IHF Strategic Plan (2012 – 2015) to ensure "continuous support of high-quality care for people with life-limiting illness and their families" and "to support the extension of palliative care to patients with life-limiting illnesses other than cancer"

Psychological Impact of MND

- **Anxiety** 0–30% average figures (70% individual studies) and **Depression** average figures 9–11% (57% individual studies) (Palmieri et al. 2010; Kurt et al. 2007)
- **Emotional Lability** 20–49% occurrence (Moore et al. 1997)
- **Hopelessness** linked to greater suffering and considerations of suicide (Whitehead et al. 2011, Ganzini, Johnston and Hoffman 1999, Ganzini et al. 1998)
- **Existential shock** as "*losing confidence in their bodies, recognising their physical vulnerability and being scared of facing their imminent death*" (Brown 2003, p.210)
- **Demoralisation** more related to people with MND than people with metastatic cancer (Clarke et al. 2005)
- Overall feelings of demoralisation, hopelessness, anger and loss of meaning has been argued to be **more than feeling depressed** (Blackhall 2012)

Aims and Objectives

- Aim
  - Examine counsellors, psychologists and psychotherapists experiences of different therapeutic approaches for people with MND
- Objectives
  - Review therapists' experience in Ireland
  - Gain insight into MND care centres in UK and Italy
  - Develop a map of therapeutic care, theories drawn on, interventions and perceptions of efficacy and outcomes, from a therapists perspective
  - Recommendations on what therapists perceive as future practice developments and directions for research

Results

“It is horrific; it is awful for me, it is one of the worst conditions from which to suffer. It’s an awful, debilitating, disabling, horrific disease and that still hasn’t lost me”

(Interview F, Psychologist Public Service)

Therapists' Emotional Affect and Tensions

Theme		Complementary Theme
Horrific disease	↔	Privileged
Loneliness of it (MND)	↔	Not wanting to do that (face death)
Energy low, sadness it brings	↔	Very energised, relationship with person
Feel nervous	↔	Going wherever she wanted to go
Cut off my nose	↔	Still came back for more
The frustration	↔	Hard work

People with MND Emotional Affect and Tensions*

Theme		Complementary Theme
Know what is going to happen	↔	Didn't want to know
Afraid of choking to death	↔	To have control
Really frustrated	↔	Resistant
Embarrassed he didn't want to be seen	↔	Blamed himself
Wasn't open to having people in home	↔	Interested in people around her
Busy trying to stay alive	↔	I have had enough
I don't blame them	↔	Do people really have a clue?

* As perceived by the therapists

Therapeutic Approaches

- **Supporting them in how they are now**

  *"So I really tried to work with him in **staying in the now**, right now what was he enjoying, right now what felt good, right now what could he do to make the most of where he was, particularly around children and things like that"* *(Interview H, Counsellor Private Practice)*

- **Adjusting rhythm and pacing** (Public Service Only)

  *"But we got through it anyway, it just took a long time and then she got very tired…. There was a lot of trying to **catch her at a good time;** you know it was not easy"* *(Interview C, Counsellor Public Health Service)*

- **Supporting them to self-direct**

  *"I was afraid he thought I was going to fix it and I had to be very clear, I am here to help with what is happening and it is **over to you, to see how it goes"*** (*Interview D, Psychotherapist Private Practice)*

Therapeutic Approaches

- **Exploring feelings**

  *"I keep going in but in a very gentle way you know, in a gentle way, but I haven't you could keep it at a very matter of fact level the whole time, and probably a lot of people have that with him, …. **but I have asked, I have pushed a little bit more"*** *(Interview C, Counsellor Public Service)*

- **Difficulty of working with dying**

  *"I wouldn't have huge **spiritual discussions** .. you know I would have asked them do they believe in an after life, do they believe in God, they all said they did, … and I didn't really, it didn't go any further than that you know, so it was more about the **fear of the process**"* *(Interview B, Psychotherapist Private Practice)*

- **To keep them functioning and coping**

  *"A lot of the time actually it is small, number one it is **information giving to people,** have a chance to talk through and ask questions"* *(Interview F, Psychologist Public Service)*

Therapeutic Approaches

- **Seeing the individual behind the illness**

  "There is a person before the illness and there is a person after the illness so if you can ***try and get to who is the person before the illness*** *who are they, try and get it in your mind and have a sense of who they were" (Interview E, Psychologist Public Health Service)*

- **Psychological evaluation** (Public Service Only)

  Assessing for any cognitive or communication impairment

Prior to and Post Therapy

Therapy Pre-requisites

- **Timeframe**
  - scheduling of sessions to allow for extra time when working with a person with MND, due to fatigue or communication impairment
- **Environment**
  - providing a quiet space with appropriate access or therapy in the home, due to limitations in communication and mobility
- **Knowledge of MND**
  - therapists who have prior experience of MND, are able to understand the physical impact of MND better and also recognise a possible cognitive impact for the person

Perceptions of Outcomes

- Providing space for the person to talk and express feelings
- Supporting them to self-direct
- Ease them on their journey
- Supporting them in how they are now
- Improve QoL
- Coming to terms

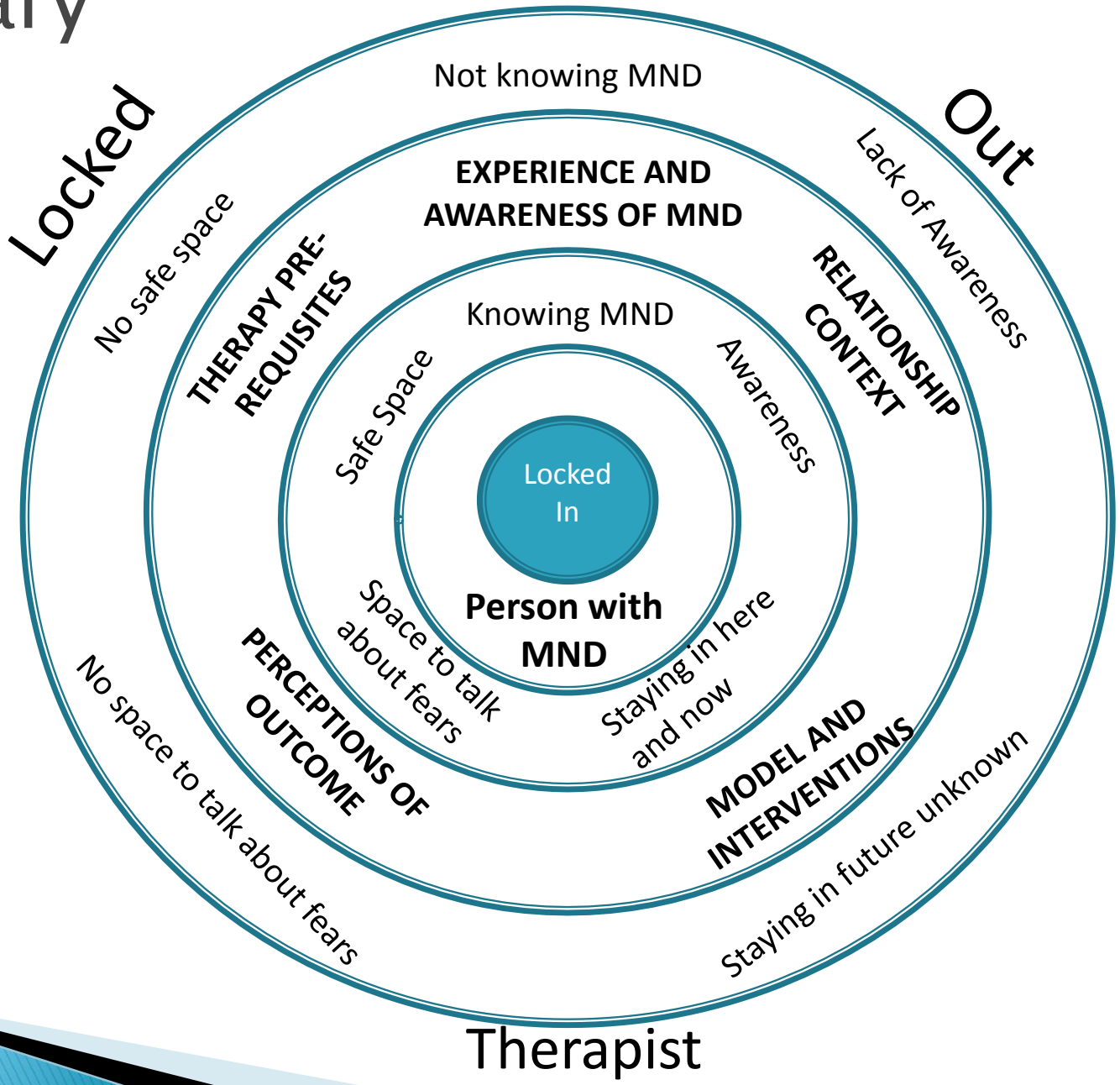
Insights from MND Centres in UK and Italy

- Different approaches and interventions are used from early diagnosis, to living with the disease to end-stage
- There is a difference in palliative care requirements for neurological conditions compared to cancer
- One centre, had a peer group for neurological conditions for patients to feel they were “normal”
- Another centre abandoned peer groups, as people who were coping felt more depressed when faced with what their future might look like

Summary

- No consensus about a specific approach for working with people with MND due to the complexity of the disease and variety of presentations
- Common approaches included supporting the person in the here and now, reaffirming their ability to have an active role in their life and supporting the person in exploring emotions
- Desired outcome being to provide the person with space to talk, express feelings and have an ability to self-direct
- The findings indicate that therapists should have experience of MND, the possible limitations in mobility, communication and cognitive processing

Summary


Not knowing MND
Locked
Out
Lack of Awareness
No safe space
EXPERIENCE AND AWARENESS OF MND
THERAPY PRE-REQUISITES
RELATIONSHIP CONTEXT
Knowing MND
Safe Space
Awareness
Locked In
Person with MND
Space to talk about fears
Staying in here and now
PERCEPTIONS OF OUTCOME
MODEL AND INTERVENTIONS
No space to talk about fears
Staying in future unknown
Therapist

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