A Qualitative Study of Psychological and Psychotherapeutic Approaches for Motor Neurone Disease (MND) Patients

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1. Introduction

Motor Neurone Disease (MND) is an incurable, terminal, neurological disease characterised by progressive physical disability and is known to cause psychological distress and adversely affect Quality of Life (QoL) (Pagnini 2013). Psychological distress experienced as depression, anxiety, hopelessness, existential shock and suicidal ideation in some cases (Palmiert al. et al. 2010; Brown 2003). It is known that MND patients move their focus from physical health concerns to emotional support as the disease progresses and are often dissatisfied with the level of care provided (Foley, Timonen and Hardiman 2012). However there seems to be little or no research on the range and effectiveness of psychotherapeutic interventions that could support the patient (Pagnini et al. 2012). This study includes a review of current approaches by therapists in Ireland and an insight into MND care centres in UK and Italy.

2. Aim and Objectives of the Study

**Aim**

To examine counsellors, psychologists and psychotherapists experiences of different therapeutic approaches for MND patients

**Objectives**

- Review of therapists experience of different approaches for MND patients in Ireland
- Insight into approaches delivered by 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 therapist’s perspective (could be used as an input to a framework for therapeutic approaches for MND patients in Ireland)
- Recommendations on what therapists perceive as future practice developments and directions for research

3. Methods

Design: A qualitative study due to exploratory nature of research and lack of published literature.

Participants: In Ireland, 8 (6 female, 2 male) counsellors, psychotherapists and psychologists representing the public service (3) and private practice (5). Participants ranged in professional experience from 5 – 30 years (M = 15.5 years). The population size of therapists working with MND patients in Ireland is currently unknown, but is estimated to be in the region of 25-30*.

In UK and Italy, 2 (female) a counsellor and psychologist representing the public service.

*This is based on information gained from the Irish Motor Neurone Disease Association (IMNDA) and the National Centre for MND at Beaumont Hospital.

4. Results and Discussion

The principal categories and themes clarify the therapeutic approaches can be seen in Table 1.

**4 a. Prior to Therapy**

Therapy pre-requisites were identified in relation to time frame, environment and therapist’s experience of MND. The scheduling of sessions to allow for extra time when working with a patient, if there was communication impairment. Also providing an environment with appropriate access or therapy in the home, due to limited mobility. The findings show that 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 patient.

**4 b. During Therapy**

Therapist’s awareness of their own emotional affect or tension may impact their ability to see the patient’s range of affect or tension. Therapist’s ability to manage ambivalent feelings, such as existential angst, sadness, anxiety, powerlessness and frustration, from the results, may be linked to either embracing or closing down a similar affect or tension in the patient. The main affects for the patient being fear, anger and shame, and tensions between knowing or denying what is going to happen and busy trying to stay alive or wanting to give up. This confers with literature around known coping strategies for MND patients, varying between confrontation and avoidance (Matuz et al. 2010; Lee et al. 2001).

Therapists’ approaches include supporting the patient in the here and now by providing a “fine focus” on what they can still do, and empowering the patient by reassuring and affirming their ability to self-direct (see Figure 1). This confers with literature where an internal locus of control has been linked to higher QoL for MND patients (Matuz et al. 2010; Plasshau et al. 2002). Adjusting the rhythm and pacing of therapeutic interventions was important to therapists in the public service, who had overall more experience of MND. Talking about death and dying was frequently cited, and as an approach used less often. Information giving and psychological evaluation were only cited by those in the public service, this being seen as part of their role. The ability to see the individual behind the illness and meet the person was seen to be important. The interventions that supported each approach ranged from providing information, evaluating, supportive listening, working with emotions, and working at a deeper psychological depth.

**4 b. Post Therapy**

The therapists perceptions of the outcomes of therapy with MND patients, prioritise providing space for the patient to talk and express feelings, supporting them to self-direct and ease them on their journey.

4c. Additional Insights from MND Care 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 them as patients who were coping felt more depressed when faced with what their future might look like. This is in line with research that suggests MND patients express ambivalence to peer support groups (Lacock and Brown 2010).

5. Conclusion

There is no consensus about a specific approach for working with MND patients due to the complexity of the disease and variety of presentations. Common approaches included supporting the patient in the here and now, reaffirming their ability to have an active role in their life and supporting the patient in exploring emotions. The desired outcome being to provide the patient with space to talk, express feelings and have an ability to self-direct. The findings indicate that therapists should have experience of MND, the disease and patient experience. The person affected by MND sometimes considered to be “locked in”, and if the therapist is unaware may find themselves “locked out” of therapeutic relationship see Figure 2.

Insights from MND care centres outside Ireland, highlighted the shame and stigma of having MND as different to other palliative conditions; as are the differences in provision of palliative services. The benefits of using peer support groups is mixed. As part of this study a proposed map of therapeutic care for different stages of disease progression has been developed as can be seen in the handout.

Recommendations for future practice developments and research include an awareness and education program for therapists on psychological impact of MND and supportive approaches, information for people affected by MND on type of psychological services available and assessing effectiveness of therapeutic interventions.

Table 1: Grounded Theory Analysis of participants experiences of different approaches

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<tr>
<th>Category</th>
<th>Theme</th>
<th>Complementary Theme</th>
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<tbody>
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<td>Experience and Awareness of MND</td>
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<td>Therapeutic Context</td>
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<td>Therapeutic Content</td>
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<td>Therapeutic Theme</td>
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*Figure 2: Therapists’ Approaches (Model Themes) and Interventions

*It is horrific; it is awful for me, it is one of the worst conditions from which to suffer. It’s an awful, debilitating, horrifying disease and that still hasn’t lost me* (Illustrative Quote, Interview F, Psychologist Public Service)

References: