# 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND)

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## ARTICLE INFO

## ABSTRACT

This paper explores attitudes to peer support among people with Motor Neurone Disease (MND) and their family carers. It reports findings from a secondary analysis of data from two UK interview studies conducted by the authors. The process of secondary analysis is reported in detail.

48 people with MND and 22 carers were interviewed in 2005–2007. The authors identified narrative extracts on peer support from their own datasets and exchanged them for independent thematic analysis. Subsequent discussion, drawing on literature on support groups and social comparison, led to an exploration of two overarching themes: valuing camaraderie and comparison, and choosing isolation.

Findings suggest that social comparison theory is a useful framework for analysing attitudes to MND support groups, but that on its own it is insufficient. 'Valuing camaraderie and comparison' explains how support groups offer practical and social support, as well as beneficial opportunities for social comparison. Seeing others coping well with the condition can provide hope, while downward comparison with those worse off can also make people feel better about their own situation. However, most people are also shocked and saddened by seeing others with the condition. Tension of identity can occur when group membership starts to define the individual as 'a person with MND, rather than the person I am that happens to have MND'. Choosing isolation can be a deliberate defensive strategy, to protect oneself from witnessing one's possible future. Levels of involvement may change over time as people struggle with their changing needs and fears.

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## Introduction

### Peer support groups and social comparison

Peer support groups offer contact with others who understand life with a particular illness. Goffman (1963) notes that someone with a stigmatised or 'spoiled' identity may seek out 'sympathetic others…who share his stigma' (p.31). Schachter (1959) observes that people faced with threatening experiences prefer to affiliate with others facing the same threat. Serious illness may literally threaten life and metaphorically threaten one's sense of self (Bury, 1982; Charmaz, 1983). When people are ill, therefore, they may seek the company of others with the same condition. This is also true of relatives of ill people, who find themselves in an unanticipated new role as carer.

These contacts provide practical and social support. 'Sympathetic others…provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person' (Goffman, 1963: 32). However, joining a support group can reinforce a sense of difference and isolation from normality: 'the stigmatised individual can use his disadvantage as a basis for organising life, but he must resign himself to a half-world to do so' (p.32). Persistent focus on 'the problem' and listening to the tales of fellow-sufferers can even become boring.

Much has been written on the benefits and harms of peer support, especially in cancer, often using social comparison theory. Wood (1996:520) defines social comparison as 'the process of thinking about information about one or more other people in relation to the self', and identifies three elements: acquiring social information; thinking about it in relation to oneself; and reacting to social comparisons. Wills (1981) identifies 'downward comparison' as one way of using such information: 'persons can increase their subjective well-being through comparison with a less fortunate other' (p.245). Taylor's (1983) interview study of cognitive adaptation in women with breast cancer found evidence to support downward comparison as 'a fairly robust method of self-protection against

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threat' (p.1165). Women compared themselves not only against real women whom they saw as less well-adjusted than themselves, but also against hypothetical women drawn from hearsay or media reports, illustrated by the quotation 'I know that there are just some women who aren't strong enough'. Taylor notes, 'If a comparison person who makes one appear well-adjusted is not available from personal experience, such a person may be manufactured' (p.1165).

Taylor found no examples of direct upward comparison (learning to cope more effectively by observing someone doing better than yourself). However, she did find examples of women selecting others for comparison who were worse off physically, but coping well. She describes this as 'the best of both worlds: the comparisons enable one to feel better about oneself, but one does not lose the advantage of having a successful model on which to pattern one's efforts at adjustment.' (p.1166).

Social comparison can do harm. The heroic or inspiring narratives which characterise some support groups may be difficult for some to live up to (Gray & Doan, 1990). Equally downward comparison can be distressing, as found in a randomised study of interventions to support women with breast cancer (Helgeson, Cohen, Schulz, & Yasko, 2001). The authors speculate, however, that peer discussion may bring longer-term benefits following initial short-term distress — their 8-week intervention may not have given enough time for this to happen.

Carmack Taylor et al. (2007) review whether to mix people with high and low levels of psychosocial distress in one group. They suggest mixed groups mainly benefit distressed people, who are helped by the effective coping presented by non-distressed participants. 'Patients appear generally and simultaneously to avoid interacting with worse-off others. For actual affiliation, patients instead prefer contact with others who are faring better than they are.' (p.266) Non-distressed patients may help others by their presence, but they themselves may get no personal benefit or may even be harmed by interacting with distressed people.

Patients who decide not to attend support groups have been less studied. Ussher, Kirsten, Butow, and Sandoval (2008) studied 87 people who left a cancer support group and 26 who never attended. The most common reasons given were practical (e.g. timing or location of meetings; clashes with family responsibilities), but others included no longer needing support; not wanting to be defined by a 'cancer identity'; dissatisfaction with the way groups were run; finding them 'boring and depressing'; wanting to avoid the exchange of problems and 'bad stories'; feeling unable to talk about one's own distress; not finding enough in common with other people at the group; and seeing oneself as not a group kind of person.

While cancer support groups have been widely studied, little evidence exists on the attitudes of people with Motor Neurone Disease (MND) to peer support. MND represents an interesting extreme case, because there is no prospect of recovery; social comparisons take place against a grim backdrop prognosis. This paper contributes new evidence of how social comparison functions in the context of a progressive and almost inevitably terminal condition.

## Motor Neurone Disease (MND)

MND is rare, serious and poorly understood. At any one time around 5000 people in the UK are affected. It is more common amongst men, and people aged over 50, but can occur at any age. (McDermott & Shaw, 2008; Talbot & Marsden, 2008).

MND affects each person differently. It can start with muscle weakness or spasticity in the limbs or the muscles around the throat and mouth. Sometimes breathing difficulties are the first sign. Early symptoms can be mild, but MND often progresses rapidly and is almost always terminal. The only proven treatment (the drug riluzole)

lengthens life by a few months. Commonly mobility is lost as muscle weakness spreads, and many people end their life in a wheelchair dependent on others for all activities and personal care. Some become unable to speak or swallow, and may have a tube for liquid feeding directly into the stomach. The most common cause of death is respiratory failure as the muscles supporting breathing fail.

Speed of progression is impossible to predict. People with the commonest form of MND starting with limb weakness (amyotrophic lateral sclerosis or ALS) usually survive 2–5 years from diagnosis. People whose symptoms start in the throat and mouth ('bulbar onset' MND) tend to deteriorate faster and may live only a few months. Rarer, more slowly progressing forms include PLS (primary lateral sclerosis) and PMA (progressive muscular atrophy). People with these forms generally live longer, and lifespan in PLS may be normal, but they share many of the same problems of increasing disability. An initial diagnosis of ALS may be revised to PLS or PMA when an individual survives longer than expected.

Given the lack of cure or effective treatment, and the prospect of rapid progression, a diagnosis of MND is an 'existential shock' (Brown, 2003), commonly received as a 'death sentence' (Locock, Ziebland, & Dumelow, 2009). Whereas many forms of cancer have become in effect chronic illness, with good prospects for cure or remission, Brown argues that 'MND lies astride the terminal and chronic categories', an 'uneasy interface' (2003:216). People know they will die, usually fairly soon, but in the meantime need to adapt to a series of progressively dependent states. Yet the variability of symptoms makes it difficult to know exactly what they need to adapt to. Some may remain fully mobile but unable to speak, eat or — eventually — breathe. Others may die still able to talk but otherwise paralysed, and some may end up unable to move or communicate at all.

## MND and peer support

The nature of MND has implications for support groups, especially seeing others with varying symptoms and often severely disabled. Despite (or perhaps because of) its rarity, there is a high level of involvement with peer support in various forms. In the UK, it is estimated that around 65% of people diagnosed are in contact at some level with the MND Association, the main voluntary organisation for England, Wales and Northern Ireland. A Tracking Survey by the Association found that 46% of respondents used branch or group meetings for support in living with MND (MND Association, 2005). This compares with recorded use of cancer support groups, for example, of 21.5% (Winefield, Coventry, Lewis, & Harvey, 2003) and 23.7% (Owen, Goldstein, Lee, Breen, & Rowland, 2007). The MND Association's wide network of local groups offers a range of events and support, and regional home visiting by trained volunteers. Many of these volunteers have had a family member with MND, and a few are people currently living with MND or caring for someone with it.

Not all choose to join face-to-face support groups, and indeed accessibility is an issue (both geographical and physical in terms of getting out of the house). Given the condition's rarity, meetings may be organised on a regional basis some distance away, compounding the problems of travelling with physical disability. Muscle weakness and breathing problems often cause fatigue and require frequent rests, making travel tiring. For people with speech and breathing difficulties, face-to-face interaction can also be difficult and exhausting.

For these reasons virtual MND support groups play a significant role. Two independent MND websites are the BUILD forum (www.build-uk.net), and PatientsLikeMe (www.patientslikeme.com). BUILD is a well-used, highly interactive forum which enables people to engage in direct peer-to-peer support. PatientsLikeMe allows people to store and share information about their symptoms,