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Disability, depression and suicide ideation in people with multiple sclerosis

V.M. Lewis[a], K. Williams[a], C. KoKo[b], J. Woolmore[c], C. Jones[a], T. Powell[a,1]

[a] Department of Clinical Psychology, University of Birmingham, Birmingham, UK
[b] West Midlands Rehabilitation Service, Birmingham, UK
[c] Queen Elizabeth Hospital, Birmingham, UK

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ABSTRACT

Introduction: Depressive symptoms occur frequently in people with Multiple Sclerosis (MS) and rates of suicide ideation are higher than the general population. There is evidence for a direct association between disability and depression, disability and suicide ideation, and depression and suicide ideation in MS. However, the relationship between all three, i.e. the mediating role of depression between disability and suicidal ideation, has not been investigated. Exploring this relationship could highlight risk factors, alerting clinicians to the need for timely intervention.

Method: Seventy five people with progressive MS attending two out-patient clinics took part in this cross-sectional study. Participants completed the Beck Suicide Scale, Beck Depression Inventory, Multiple Sclerosis Impact Scale and Guy's Neurological Disability Scale.

Results: Depressive symptoms mediated the relationship between perceived and actual disability and suicide ideation. Different types of disability were associated with suicidality, including: 'tremors' and 'taking longer to do things'. A small sub-group of participants were identified who reported suicide ideation in the presence of only mild levels of depression.

Limitations: There may be a sample bias in this study as all participants were attending out-patient clinics and receiving support which may not be available to everyone with MS.

Conclusion: It is important for clinicians to screen regularly for both depression and suicide ideation, to be alert to specific types of disability for which a higher level of suicide ideation might be present and to consider the possibility of suicidal thoughts being present in people who show minimal or no depressive symptoms.

1. Background

MS is a progressive, neurodegenerative, immune-mediated disorder, characterised by deterioration of the myelin sheath (Pugliatti et al., 2006). The disease course is most often categorised into three different types referred to as: relapsing remitting MS (RRMS), primary progressive MS (PPMS) and secondary progressive MS (SPMS); irrespective of type, symptoms can vary considerably. Primary progressive MS (PPMS) encompasses increasing disability from onset with plateaus and possible minor improvements (Pugliatti et al., 2006). Secondary progressive MS (SPMS) is diagnosed if a progressive disease course follows a period of symptomatic relapses originally referred to as relapsing remitting MS (RRMS) (Tutuncu et al., 2012). Two thirds (approximately) of those diagnosed with RRMS will transition to SPMS, usually 10-15 years after diagnosis (Hooper, 2013). The rate of disease progression in both PPMS and SPMS has been found to be comparable (Kuhlman, 2013; Soldán et al., 2015). In progressive MS types, where there is a higher level of increasing disability compared to RRMS, this has been associated with higher levels of depression and suicide ideation (Chwastiak et al., 2002; Dennis et al., 2009; Sarısoy et al., 2013; Turner et al., 2006). For this reason, progressive MS types will be the focus of investigation in this research study.

Depressive symptoms occur frequently in people with Multiple Sclerosis (MS) (Dalgas et al., 2014) and are considered to be a significant problem in this condition (Gay et al., 2010). The risk of depressive symptoms in MS has been found to be as high as 50% (Chwastiak et al., 2002). This is four times higher than the risk of depression reported in the general population (Ayuso-Mateos et al., 2001). Suicide rates in the MS population have been found to be twice the rate of the general population (Bronnum-Hansen et al., 2005) and it has been reported that over a quarter of people with MS experience suicide ideation (Feinstein, 2002).

E-mail address: t.powell@bham.ac.uk (T. Powell).
[1] Dr Theresa Powell, Programme Director, Doctorate in Clinical Psychology, School of Psychology, University of Birmingham, Frankland Building, Edgbaston, Birmingham, B15 2TT, UK.

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Depression in MS has been shown to be highly correlated with suicidality (Carson et al., 2000) but depressive symptoms are often undetected and untreated (Feinstein, 2004; Patten et al., 2003). This may be due to a difficulty in distinguishing depression from the common symptoms of MS, for example, fatigue and cognitive dysfunction, both of which can be observed in MS without the presence of depressive symptoms (Siegert and Abernethy, 2005). Alternatively, Caine and Schwid (2002) suggest that suicide ideation in MS may not be identified because patients tend to minimise these thoughts during assessment in order to provide superficial reassurance to their clinicians that they will not harm themselves.

Suicide ideation in people with disabilities is a complex and imperative health concern (Giannini et al., 2010). Not only is depression a key predictor of suicide risk in MS (Paparrigopoulos et al., 2010) but the presence of depression is known to have a significant impact upon quality of life, general health (Feinstein, 2007; Lester et al., 2007) and adherence to treatment (Mohr et al., 1997). Attending to depression and suicidality in MS is therefore, a medical priority, to the extent that suicide may be an avoidable tragedy (Faber, 2003).

Disability (impairments in body structure or function and activity limitation, with one study measuring participation level, as defined by the World Health Organization, 2002) in MS has been found to have an impact upon both depression and suicide ideation when explored separately. No existing research has investigated the interrelationship between all three variables. Therefore, the present study will explore whether depression mediates the relationship between disability and suicidal ideation.

The direct relationship between depressive symptoms and disability was considered in a systematic review by Arnett et al. (2008) and resulted in equivocal findings. For the majority of studies included in the review, the measure of disability was the Expanded Disability Status Scale (EDSS) developed by Kurtzke (1983) which measures impairments in the following functional systems: pyramidal (ability to walk), cerebellar (coordination), brain stem (speech and swallowing), sensory (touch and pain), bladder and bowel, visual, mental and any other neurological symptoms caused by MS. Other measures utilised were the Sickness Impact Profile (SIP), physical summary subscale (Bergner et al., 1981) which measures somatic autonomy and mobility control; and the London Handicap Scale (LHS) (Harwood and Ebrahim, 1995) which measures mobility, physical independence, occupation, social integration, orientation and economic self-sufficiency. All measures provide a total score and the higher the score the higher the level of disability.

Null findings were reported in eleven studies but five of these had a small sample size (ranging from n=10–50). Five studies had a reasonable sample size (ranging from n=83–98) using standard measures of disability and depression. One other study used a non-standardised measure of disability. Conversely, eleven studies reported statistically significant findings, all suggesting a positive correlation between disability and depression, with effect sizes in the moderate range, suggesting increased disability is related to increased depression. All except one used standardised measures, and sample sizes ranged from n=76–1374 except for two (n=18 and n=45). Since this review, several other studies have confirmed this association (Anhoque et al., 2011; Arnett et al., 2008; Beal et al., 2007; da Silva et al., 2011; Gay et al., 2010; Sarısoy et al., 2013; Smith and Arnett, 2013).

With regards to the direct relationship between depressive symptoms and suicide ideation in people with MS, this has been explored in three studies (Feinstein, 2002; Viner et al., 2014; Turner et al., 2006); one did not find a significant association between level of depression and suicide ideation (Feinstein, 2002) and there are methodological weaknesses in the two which did find a significant association due to low to moderate response rates: 39.5% (Viner et al. 2014) and 43.7% (Turner et al. 2006) and the use of non-standardised measures. Feinstein (2002) measured suicide ideation by using just three self-report questions derived from the Beck Suicide Scale (Beck and Steer, 1993) and thus the psychometric properties of these three questions are unknown. Similarly, Viner et al. (2014) used a self-designed measure of disability rather than a standardised and validated measure and both Turner et al. (2006) and Viner et al. (2014) assessed suicide ideation by selecting a single item from the Patient Health Questionnaire (PHQ-9) (Kroenke and Spitzer, 2002), and although the measure itself is said to have good psychometric properties (Manea et al., 2015), these are unknown for a single item.

Looking at the direct relationship between disability and suicide ideation, Feinstein (2002) did not find a significant association. However, two more recent studies reported that self-reported bladder or bowel difficulties, and communication and swallowing difficulties were risk factors for suicide ideation (Viner et al., 2014, Turner et al., 2006) and in addition, Turner et al. (2006) found that mobility problems and a higher level of perceived disability was associated with suicide ideation. Assessing a person's own perspective of disability is important (Turk et al., 1995) and there are an increasing number of studies incorporating these measures (Freeman et al., 2001). For example, it has been found in a study exploring obesity related disability, that level of perceived disability can be different from actual physical limitation (Larsson and Mattsson, 2001). Therefore, the present study will explore both self-reported disability and the degree to which this is seen as a problem for the person.

Finally, two studies have explored the direct relationship between disability and completed suicide in MS during a study of risk factors. One found that those with a moderate level of disability were most at risk (Stenager et al., 1996) and one found that those who were more severely disabled were more at risk (Berman and Samuel, 1993).

As mentioned earlier, the interrelationship between disability, depression and suicide ideation has not been investigated in the MS population although, Meltzer et al. (2012) found depression to mediate the relationship between disability and suicide ideation in the general population. If increasing levels of disability are found to be important, or any specific type of disability, found to be a 'red flag' for depression and hence suicide, it emphasises the importance of screening for both in the future. Findings could also alert clinicians to the need for more timely interventions in order to ameliorate distress.

A related concept termed 'rational' suicide would also benefit from consideration within the interrelationship of these three variables. Although it is well recognised that suicide ideation is a core symptom of major depression (Pompili et al., 2012), it has been found that in the MS population, not all suicides have occurred in the context of depressive symptoms (Sadovnick et al., 1991). It has been suggested that people can freely desire suicide or a hastened death based upon a logical, carefully contemplated decision in the absence of depression or psychiatric difficulties (Onkay-Ho, 2014).

Criteria for 'rational' suicide have been defined as: "(i) the presence of an unremittingly hopeless condition, (ii) a suicidal decision made as a free choice and (iii) the presence of an informed decision-making process" (Werth and Cobia, 1995, p. 1). In a MS specific study by Gaskill et al., (2011) a perceived loss of control was found to be associated with suicide ideation suggesting that the ideation could provide a fall back means of still feeling in control for people faced with the burden of an unpredictable disease. There is no research to date exploring whether there is a sub-group of people with suicide ideation with only a minimal or mild level of depression in MS, therefore this will be examined in the present study.

The term disability in this study refers to disability as measured by Guys Neurological Disability Scale (GNDS) (Sharrack and Hughes, 1999) (which asks questions about: memory and concentration, mood and emotions, vision, speech and communication, swallowing, use of the arms and hands, mobility, bladder and bowel function, sexual function and fatigue) or perceived disability as measured by the Multiple Sclerosis Impact Scale (MSIS-29) (Hobart et al., 2001) which assesses the physical and psychological impact of MS.