Intimate relationship quality, self-concept and illness acceptance in those with multiple sclerosis

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Lower levels of Intimate Relationship Quality (IRQ) have been found in those with Multiple Sclerosis (MS) compared to the general population. This study examined an MS sample to see whether IRQ was positively associated with self-concept, whether IRQ was positively associated with MS illness acceptance and whether IRQ was predicted by self-concept and illness acceptance. In this cross-sectional study, 115 participants with MS who were in an intimate relationship completed an online survey advertised on MS related websites. The survey assessed demographic variables, MS illness variables and levels of IRQ, self-concept and illness acceptance. Results revealed that IRQ was significantly positively associated with self-concept and with illness acceptance. Multiple hierarchical linear regression analysis revealed that, after controlling for illness duration and level of disability, self-concept significantly predicted IRQ but illness acceptance did not significantly predict IRQ. This study addressed several gaps and methodological flaws in the literature and was the first known to assess predictors of IRQ in those with MS. The results suggest that self-concept could be a potential target for individual and couple psychological interventions to improve IRQ and contribute to improved outcomes for those with MS.

Keywords: Intimate relationship quality, self-concept, illness acceptance, multiple sclerosis

Introduction

Multiple Sclerosis (MS) is a chronic, degenerative disorder involving problems transmitting nerve impulses throughout the brain and spinal cord, resulting in wide ranging physical and neurological impairments (Feinstein, 2007). The aetiology of MS is still unknown, the course of illness is unpredictable and at present there is no cure (Rao, Huber, & Bornstein, 1992).

Adjustment to MS involves positively assimilating the changes into one's life, continued psychosocial development and maintaining a positive life outlook (Antonak & Livneh, 1995; Marks & Miller, 1990). A better understanding about adjustment factors may contribute to improved outcomes for individuals with MS.

Intimate Relationship Quality (IRQ) is yet to be fully explored in those with MS. An intimate relationship involves two individuals predictably interacting with each other emotionally and physically, regardless of legal marital status (Prager, 1995, p. 23). High IRQ typically encompasses effective communication, problem solving, support, satisfaction and expressions of sensuality/sexuality while low IRQ may involve deficits in several of these areas (Ahlborg, Lilleengen, Lönnfjord, & Petersen, 2009; Baucom, Epstein & La Tillade, 2002).

Low IRQ has been associated with poorer mental and physical health in MS and other chronic illness populations (Coyne, Rohrbaugh, Shoham, Sonnega, & Nicklas, 2001; McPheters & Sandberg, 2010). Studies have shown lower relationship satisfaction and higher risk of relationship termination in those with MS compared to healthy controls (McCabe, 2002; Pflieger, Flachs, & Koch-Henriksen, 2010). This could be due to feelings of inequity, dependency, stress and caregiver burnout in the intimate relationships of those with MS (McCabe, McDonald, Deeks, Vowels, & Cobain, 1996; Ybema, Kuijer, Hagedoorn, & Buunk, 2002).

MS does not always lead to decline in IRQ and can bring couples closer together (Mohr et al., 1999; McCabe, 2004). It is important to explore why this is the case and to identify protective psychological factors associated with improved IRQ, so that these factors can be targeted in future research and psychological interventions. Employing a strengths-based approach (Saleebey, 2009), this study will examine whether self-concept and MS illness acceptance are protective factors for IRQ in an MS population.

Self-concept is a possible protective factor for IRQ. Self-concept is an individual's perception of their identity, adjustment, social skills and status, self-fulfilment, physicality and morality (Fitts & Warren, 1996). Self-concept and associated self-esteem has been found to be consistently low in MS populations (McCabe, 2005), consistent with the negotiation model of self and illness proposing that chronic illness inevitably results in a loss of self (Gerhardt, 1989). Other studies, however, show that MS can have positive effects relating to increased self-concept (Dutton, Simpson & Boot, 2012; Brooks & Matson, 2012).

The association between self-concept and IRQ has received little research attention. Qualitative research shows that romantic partners are important in dealing with self-concept changes linked with MS (Kralik, Koch & Eastwood, 2003). Dlugonski and Motl (2012) found that social support is significantly associated with positive self-esteem in those with MS, but did not focus specifically on IRQ. Nosek, Howland, Rintala, Young and Chanpong (2001) found that in women with disabilities, satisfying intimate relationships and having a job were related to high levels of self-esteem, however their study was not specific to MS. Much of the research has used measures examining self-esteem rather than self-concept in those with MS, which are different constructs in terms of domain-specificity (Arens & Hasselhorn, 2014). A better understanding of the relationship between self-concept and IRQ in those with MS is needed.

Another possible protective factor for IRQ is illness acceptance, which involves coming to terms with the illness course, emotionally internalising implications of impairments and social reintegration (Stuifbergen, Becker, Blozis, Beal, & Park, 2008). Acceptance of MS is linked with a variety of positive outcomes including improved satisfaction with life (Pakenham, 2007; Pakenham & Fleming, 2011).

It is, therefore, important to investigate the association between MS acceptance and IRQ. Harrison, Stuifbergen, Adachi, and Becker (2004) found that being married was

associated with greater disability acceptance. Pakenham and Fleming (2011) found that married participants showed higher MS acceptance than single participants and that higher levels of MS acceptance was associated with better marital adjustment.

Pakenham and Samios' (2013) results showed that MS acceptance was not associated with self-reported relationship satisfaction, but was associated with partner-reported relationship satisfaction. The study employed non-random sampling of couples with children from one community and the results may not be generalisable. The current study will recruit people from local and international MS-related sites to ensure that a wider range of ages and backgrounds is represented. Given the limited and conflicting literature on the relationship between MS acceptance and IRQ, further research is required.

It is clear that IRQ is an important adjustment factor for those with MS requiring further exploration. Some studies have used measures that only assess marital/relationship satisfaction, neglecting other aspects of IRQ such as consensus, cohesion, sensuality, and sexuality (Ahlborg et al., 2009) or have used very brief measures to assess IRQ. The current study will assess IRQ with an updated and comprehensive scale, the Quality of Dyadic Relationships Scale 36 (Ahlborg et al., 2009). Many studies have focused only on marriage when examining IRQ, failing to include unmarried individuals in committed relationships, which the current study will allow. There have been conflicting results about the presence of associations between IRQ and MS acceptance and there is a lack of research investigating IRQ and self-concept. Very limited information is also available about predictors of IRQ, especially examining self-concept and MS illness acceptance.

The current study will examine IRQ and its relationships with both self-concept and illness acceptance in those with MS. It is hypothesised that IRQ will be positively associated with self-concept and with MS illness acceptance. It is also hypothesised that, after

controlling for illness duration and levels of disability, IRQ will be predicted by self-concept and by MS illness acceptance.

Methods

Participants

Participants volunteered to participate via the electronic online survey link that was published on websites of Multiple Sclerosis Research Australia, Overcoming Multiple Sclerosis, MS Australia, CCSVI Australia, Shift MS, and Multiple Sclerosis Foundation. Individuals were required to have received a confirmed MS diagnosis from a neurologist and be in an intimate relationship to participate. 237 individuals participated in the online survey, however 122 withdrew before survey completion. Seven participants not currently in an intimate relationship were excluded. The final sample consisted of 115 participants with a mean age of 42.20 (SD= 10.87, range= 20-68). There were 18 males and 95 females and the majority of participants identified as Australian (45.20%) and North American/Canadian (21.70%). The sample consisted of predominantly married individuals (72.2%). The majority of participants were employed either full-time (40%) or part-time/casually (22.6%). Most participants had attained further education qualifications after finishing secondary school (88.2%). 87% of participants were diagnosed with relapse-remitting MS and 10.4% diagnosed with progressive MS, with 2.6% not answering this question. The mean MS illness duration was 7.81 years (SD= 8.09) and 71.3% were currently taking medication to treat their MS symptoms. The majority of participants (76.5%) did not need assistance when walking.

Procedures

The current study was cross-sectional. An online survey was created using the Qualtrics website and the survey link was posted on MS-related websites, which presented participants

with a plain language statement and consent from. Participants provided consent by selecting the ‘Yes, I agree’ option and providing email addresses. Participants were allowed one week to complete the survey and were able to withdraw their participation at any time by exiting the survey. The University of Melbourne Behavioural and Social Sciences Human Ethics Committee granted ethics approval for this study.

Measures

Participants provided information on age, gender, education history, relationship status, employment status and ethnic background. Participants provided data on the number of years and months since diagnosis, first MS symptoms experienced, history of symptom relapse and MS sub-type. The ‘Walking Distances’ scale of the Expanded Disability Status Scale (EDSS) (Bowen, Gibbons, Ganas & Kraft, 2001) was completed to assess degree of mobility impairment, which has previously been used with MS populations (Cao et al., 2013).

The 36-item Quality of Dyadic Relationships Scale (QDR36) was used to measure IRQ. It is a rating-scale questionnaire assessing 5 aspects of relationship quality: dyadic consensus, cohesion, satisfaction, sensuality, and sexuality (Ahlborg et al., 2009). Responses are on rating scales ranging from (1) to (6) with negatively worded items reverse scored. A score for each aspect of relationship quality and an overall score can be attained. QDR36 is an updated extended version of the widely used Dyadic Adjustment Scale (Spanier, 1976). Higher overall scores indicate greater relationship quality. The overall α reliability coefficient in the current study was 0.94. The QDR36 has not been used with an MS sample but has been used with a chronic pain sample (Edlund et al., 2015).

The Tennessee Self-Concept Scale (TSCS-2) was used to measure self-concept. It is an 82-item questionnaire producing two summary scores (Total Self-Concept, Conflict), six self-concept scores (Physical, Moral, Personal, Family, Social, Academic/Work), and three

supplementary scores (Identity, Satisfaction, Behaviour) (Fitts & Warren, 1996). Responses are on a five-point scale ranging from always false (1) to always true (5) with negatively worded items reverse scored. The total self-concept score combines the six self-concept scores. Higher scores indicate more positive self-concept, but high scores above 70 may indicate inflated self-concept, defensive attitude or distress. In the current study, participants completed all 82 items but only the overall self-concept scores were further analysed, which had α reliability coefficient of 0.90.

The 10-item Acceptance of Chronic Health Conditions Scale (ACHC), adapted for an MS population, was used to measure MS illness acceptance (Stuifbergen, Becker, Clozis, Beal & Park, 2008). Items are scored on a five point scale ranging from strongly agree (1) to strongly disagree (5) with reverse scoring for positively phrased questions. Higher overall scores indicate greater levels of acceptance of MS illness. The α reliability coefficient for the scale in the current study was 0.81.

Statistical Analyses

In Statistical Package of Social Science Version 22, Spearman correlations were used to examine the associations between IRQ, self-concept and MS illness acceptance. Multiple hierarchical linear regression analyses were used to examine whether self-concept and MS illness acceptance were significant predictors of IRQ.

Results

Missing data analysis

For the 115 participants, missing values analyses revealed minimal missing data. Little's (1998) test indicated that the missing data was missing at random and ignorable, $\chi^2(5227) = 609.64, p = 1.00$. For the TSCS-2, if more than eight replacements were required for overall

self-concept score then scoring did not proceed for that participant on that measure. If more than 20% of responses were missing on the QDR36 or ACHC then scoring did not continue for those participants on those measures. Missing values on all measures were estimated using the expectation maximisation technique.

Univariate analyses

For each measure the means, standard deviations, range, and number of participants completing the measure are reported in Table 1. To examine whether IRQ was positively associated with self-concept and with MS illness acceptance, correlational analyses between the psychological variables of interest were conducted and the results are shown in Table 2. Histograms and skewness statistics revealed slight non-normality in the distribution of IRQ, therefore, nonparametric Spearman's correlation coefficients were used. All correlation coefficients were statistically significant. IRQ was positively associated with self-concept and with MS illness acceptance. No variables were correlated at or above 0.90, which suggested the data may be suitable for multivariate analysis (Tabachnick & Fidell, 2007).

Multivariate analyses

To examine whether self-concept and MS illness acceptance were significant predictors of IRQ, after controlling for illness duration and level of disability, a multiple hierarchical linear regression analysis was conducted. The multiple hierarchical linear regression involved two steps and the results are shown in Table 3. The first step examined whether illness duration and level of disability predicted IRQ. Only level of disability significantly predicted IRQ. The second step involved including self-concept and MS illness acceptance, resulting in the model explaining an extra 19% of variance in IRQ. The only

significant predictor was self-concept, indicating that for every unit increase in self-concept there will be a 0.43 standard deviation increase in IRQ.

Discussion

In the sample of those with MS, we found that IRQ was significantly positively associated with self-concept and significantly positively associated with illness acceptance. We also found that self-concept was a significant predictor of IRQ but that MS illness acceptance was not a significant predictor. While this is the first study directly assessing the relationship between IRQ and self-concept, the positive association found between these variables is consistent with the trend found in the few previous studies indirectly examining these variables (Dlugonski & Motl, 2012; Kralik et al. 2003; Nosek et al., 2001).

The results showing a significant positive association between IRQ and MS illness acceptance are consistent with research by Pakenham and Fleming (2011) and by Harrison et al., (2004). The results are conflicting with Pakenham and Samios (2013) finding that MS patient illness acceptance was not related to self-reported relationship satisfaction, possibly because they used a different scale to measure only a portion of overall IRQ.

The first step of the multiple logistic regression revealed that level of disability was a significant negative predictor of IRQ, consistent with previous research showing a correlation between disability levels and mental health outcomes (Goksel Karatepe et al., 2011; Tsivgoulis, 2007). After controlling for illness duration and level of disability, the second step of the logistic regression revealed that self-concept was a significant predictor of IRQ but that MS illness acceptance was not. One explanation for this finding is that those with higher levels of self-concept may have more confidence in their worthiness and ability to initiate and maintain intimate relationships than those with lower levels of self-concept (Nosek, Hughes, Swendlunda, Taylora & Swank, 2003), which may contribute to more positive experiences and appraisals of their relationships.

The finding that MS illness acceptance did not predict IRQ is possibly due to the fact that MS illness acceptance may predict IRQ in isolation but not when self-concept is also included, because the two are moderately correlated and may share variance explained in IRQ. Alternatively, the direction may be different with IRQ instead predicting MS illness acceptance, which is a potential avenue for future investigation. Self-concept was the most important predictor of IRQ and was the most strongly correlated variable with IRQ, which suggests that self-concept may be a protective factor against impaired IRQ.

The current study successfully improved on several methodological limitations and research gaps in the literature. It is the first known study to quantitatively examine the relationship between IRQ and self-concept in those with MS and the first known to examine predictive relationships between these variables. The use of the QDR36 scale, a comprehensive and updated measure of IRQ improves upon IRQ measurement in most of the studies in this area. Furthermore, allowing unmarried couples to participate may have more accurately captured a more representative sample of intimate relationships than previous research. The sample included participants from a variety of cultural backgrounds, strengthening the generalisability of the results across different cultural groups, although the majority were from Western cultures.

The current results, however, must be viewed in light of some limitations. The cross-sectional nature of the study means the results cannot show whether these relationships are stable over time. Given the long term nature of MS and that the variables of interest are dynamic processes, future research should extend this study by conducting longitudinal research. The majority of participants were female (84%), and although females are more commonly diagnosed with MS than males (Ghezzi, 2004), there is a large gender imbalance in the current study.

The majority of the participants in the sample had relatively high and positive levels of IRQ, self-concept and MS illness acceptance, a conflicting profile with previous MS research profiles (McCabe, 2002; McCabe, 2005). This is possibly because the voluntary survey was more likely to appeal to and be completed by those with favourable adjustment profiles. It is also possible that by excluding participants who were currently single, the sample did not capture all of those with MS who have experienced intimate relationship breakdowns and difficulties. Replication of the current findings in other samples with MS is required. An extension of the current study could be to examine the profiles and perceptions of IRQ for both MS patients and their partners, which may differ. The regression model explained 25.5% of the variance in the IRQ, so there may be other factors outside the scope of this study that more strongly predict IRQ and responses and adjustment issues from the partner may be one such factor impacting patient IRQ and adjustment.

In conclusion, this study has contributed to our understanding of the relationships between IRQ and self-concept and between IRQ and MS illness acceptance. The current results suggest that IRQ is strongly related to both self-concept and MS illness acceptance. Furthermore, self-concept is a significant predictor of IRQ. The results suggest that individual and couple psychological intervention programs and strategies targeting adjustment to MS should focus on nurturing and improving self-concept. This may help to improve IRQ and contribute to a greater quality of life for those suffering from this debilitating illness.

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Appendix 1 (continued)

36. Which of the following statements best describes how you feel about the future of your relationship?

- ☐ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- ☐ I want very much for my relationship to succeed, and will do all I can to see that it does.
- ☐ I want very much for my relationship to succeed, and will do my fair share to see that it does.
- ☐ It would be nice if my relationship succeeded, but I can't do much more than I am doing now to keep the relationship going.
- ☐ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- ☐ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

Appendix 2

Tennessee Self-Concept Scale 2nd Edition

1= Always False

2= Mostly False

3= Partly False and Partly True

4= Mostly True

5= Always True

*= Reverse score

1. I am an attractive person	1	2	3	4	5
2. I am an honest person	1	2	3	4	5
3. I am a member of a happy family	1	2	3	4	5
4. I wish I could be more trustworthy*	1	2	3	4	5
5. I do not feel at ease with other people*	1	2	3	4	5
6. Math is hard for me*	1	2	3	4	5
7. I am a friendly person	1	2	3	4	5
8. I am satisfied with my moral behaviour	1	2	3	4	5
9. I am not as smart as the people around me*	1	2	3	4	5
10. I do not act as the way my family thinks I should*	1	2	3	4	5
11. I am just as nice as I should be	1	2	3	4	5
12. It is easy for me to learn new things	1	2	3	4	5
13. I am satisfied with my family relationships	1	2	3	4	5
14. I am not the person I would like to be*	1	2	3	4	5
15. I understand my family as well as I should	1	2	3	4	5
16. I despise myself*	1	2	3	4	5
17. I don't feel as well as I should*	1	2	3	4	5
18. I do well at math	1	2	3	4	5
19. I am satisfied to be just what I am	1	2	3	4	5
20. I get along well with other people	1	2	3	4	5
21. I have a healthy body	1	2	3	4	5
22. I consider myself a sloppy person*	1	2	3	4	5
23. I am a decent sort of person	1	2	3	4	5
24. I try to run away from my problems*	1	2	3	4	5
25. I am a cheerful person	1	2	3	4	5
26. I am a nobody*	1	2	3	4	5
27. My family would always help me with any kind of trouble	1	2	3	4	5
28. I get angry sometimes	1	2	3	4	5
29. I am full of aches and pains*	1	2	3	4	5
30. I am a sick person*	1	2	3	4	5
31. I am a morally weak person*	1	2	3	4	5
32. Other people think I am smart	1	2	3	4	5
33. I am a hateful person*	1	2	3	4	5
34. I am losing my mind*	1	2	3	4	5
35. I am not loved by my family*	1	2	3	4	5
36. I feel that my family doesn't trust me*	1	2	3	4	5
37. I am not good at the work I do*	1	2	3	4	5

38. I am mad at the whole world*	1	2	3	4	5
39. I am hard to be friendly with*	1	2	3	4	5
40. Once in a while I think of things too bad to talk about	1	2	3	4	5
41. Sometimes when I am not feeling well, I am cross	1	2	3	4	5
42. I am neither too fat nor too thin	1	2	3	4	5
43. I'll never be as smart as other people*	1	2	3	4	5
44. I like to work with numbers	1	2	3	4	5
45. I am as sociable as I want to be	1	2	3	4	5
46. I have trouble doing the things that are right	1	2	3	4	5
47. Once in a while I laugh at a dirty joke	1	2	3	4	5
48. I should have more sex appeal*	1	2	3	4	5
49. I shouldn't tell so many lies*	1	2	3	4	5
50. I can't read very well*	1	2	3	4	5
51. I treat my parents as well as I should	1	2	3	4	5
52. I am too sensitive about the things people in my family say*	1	2	3	4	5
53. I should love my family more*	1	2	3	4	5
54. I am satisfied with the way I treat other people	1	2	3	4	5
55. I ought to get along better with people*	1	2	3	4	5
56. I gossip a little at times	1	2	3	4	5
57. Sometimes I feel like swearing	1	2	3	4	5
58. I take good care of myself physically	1	2	3	4	5
59. I try to be careful about my appearance	1	2	3	4	5
60. I am true to my religion in my everyday actions	1	2	3	4	5
61. I sometimes do very bad things*	1	2	3	4	5
62. I can always take care of myself in any situation	1	2	3	4	5
63. I do as well as I want to at almost any job	1	2	3	4	5
64. I feel good most of the time	1	2	3	4	5
65. I take a real interest in my family	1	2	3	4	5
66. I try to understand the other person's point of view	1	2	3	4	5
67. I'd rather win a game than lose one	1	2	3	4	5
68. I am not good at games and sports*	1	2	3	4	5
69. I look fine just the way I am	1	2	3	4	5
70. I do not know how to work well*	1	2	3	4	5
71. I have trouble sleeping*	1	2	3	4	5
72. I do what is right most of the time	1	2	3	4	5
73. I am no good at all in social situations*	1	2	3	4	5
74. I solve my problems quite easily	1	2	3	4	5
75. I am a bad person*	1	2	3	4	5
76. I am satisfied with my relationship with God	1	2	3	4	5
77. I quarrel with my family	1	2	3	4	5
78. I see something good in everyone I meet	1	2	3	4	5
79. I find it hard to talk with strangers*	1	2	3	4	5
80. Sometimes I put off until tomorrow what I ought to do today	1	2	3	4	5
81. It's easy for me to understand what I read	1	2	3	4	5
82. I have a lot of self-control	1	2	3	4	5

Appendix 3

Acceptance of Chronic Health Conditions Scale (MS Adaptation)

I've come to terms with my MS.*

I'd give all my money to get rid of MS.

I think of MS as a curse

I can't conquer MS but I can adapt to it.*

My fondest dream is that I'll awaken without my MS.

Having a disease like MS is just a part of life.*

MS is a focal point in my life.

I spend a lot of time wondering why I have MS.

I think of MS as just part of who I am.*

I think a lot about what my life would be like without MS.

Note. *Reverse score this item.

Table 1. Descriptive Statistics for intimate relationship quality, illness acceptance and self-concept.

Scale	<i>M</i>	<i>SD</i>	Range	Possible Score
QDR36	22.16	3.70	10.00-27.16	6.00-36.00
ACHC	32.10	7.42	16.00-47.00	10.00-50.00
TSCS-2 Total	50.71	4.74	39.17-62.67	16.40-82.00

Note. $n = 115$. QDR36= Quality of Dyadic Relationships 36 Scale; ACHC= Acceptance of Chronic Health Conditions Scale, MS adaptation; TSCS-2 Total= Tennessee Self-Concept Scale, 2nd Edition.

Table 2. Spearman's correlations between psychological variables of interest.

	1.	2.
1. QDR36 total		
2. ACHC	0.28**	
3. TSCS-Total	0.45**	0.35**

Note. $n = 115$. QDR36= Quality of Dyadic Relationships 36 Scale; ACHC= Acceptance of Chronic Health Conditions Scale, MS adaptation; TSCS-2 Total= Tennessee Self-Concept Scale, 2nd Edition. ** $p < 0.01$

Table 3. Multiple Hierarchical Linear Regression Predicting QDR36.

	B	(SE)	β
<i>Step 1</i>			
Constant	23.12	0.58	
Illness duration	0.02	0.05	.04
EDSS	-0.47	0.19	-.26*
<i>Step 2</i>			
Constant	5.79	3.46	
Illness duration	-0.01	0.05	-.02
EDSS	-0.44	0.18	-.24*
ACHC	0.02	0.05	.03
TSCS-Total	0.06	0.01	.43**

Note: $R^2 = .06$ for Step 1, $\Delta R^2 = .19$ for Step 2 ($p < .001$). * $p < .05$, ** $p < .01$. QDR36= Quality of Dyadic Relationships 36 Scale; EDSS= Expanded Disability Status Scale; ACHC= Acceptance of Chronic Health Conditions Scale, MS adaptation; TSCS-2 Total= Tennessee Self-Concept Scale, 2nd Edition.

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