Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities

Operating Grant Final Report

April, 2013 – Scott B. Patten
PLAIN LANGUAGE SUMMARY

Multiple sclerosis (MS) is a debilitating neurological condition. MS is very common in Alberta, which has one of the highest levels of MS in Canada. People who suffer from MS are prone to depression, which makes their life even more difficult than it would otherwise be. Approximately half of people with MS also struggle with depression. This project sought a better understanding of the ways in which these two conditions interact. In particular, we were interested in their effects on a person’s ability to function and whether we could identify practical ways to deal with depression, such as prevention or early detection. In order to accomplish this, we used a variety of sources of information. Some of the necessary data already existed but needed to be analyzed. In other instances we needed to collect the necessary data directly from people with MS.

We were able to confirm that depression and MS frequently occur together, and that they tend to co-occur in situations where people are struggling to function. In particular, we observed high levels of depression in people who were struggling to continue their career, or who were getting to a stage of their illness where they were no longer able to work. However, we determined that depression in itself was not a key factor contributing to the end of careers; rather it seemed to be a reaction to the stressful nature of this transition. The main reasons why people stopped working were the symptoms of their MS, especially: fatigue, problems with thinking clearly and trouble getting around. People were unable to work due to these physical symptoms, and this seemed to cause them to feel depressed.

Even though depression does not seem to be a major factor causing people to stop working, we found that it made people’s lives extremely miserable. People were very interested in finding ways to deal with the issue of depression. One way to deal with it is to detect it early using scales designed for this purpose. We found that the most widely used scales performed very well, suggesting that they can be used for early detection of depression in people with MS.

We collected a lot of information on the sorts of help that people with MS need (as assessed by themselves), and also on the sorts of help that people with are able to get (as reported by people with MS). As this is a very serious illness, it is not surprising that people reported a high level of need for medical and nursing support to deal with the health issues that they faced. On a positive note, they most often reported that these needs were met. They reported, however, a lot of unmet needs in the area of day to day activities. The areas that they reported the greatest unmet needs were: meal preparation, housework, shopping, and chores. An encouraging finding is that people with MS reported high levels of satisfaction with their life, in spite of all of the challenges that they face – which was an encouraging result. Their level of participation in Canadian society was good.

We also examined the causes of depression in MS. Our expectation had been that the troublesome neurological symptoms that go along with MS would be the main cause of depression. However, this turned out not to be the case. The factors most strongly associated with the emergence of depression were pain, fatigue and childhood abuse. This information will be very useful in devising ways of preventing depression. There are already good approaches available for pain and fatigue management as well as therapies that can assist people in coping with experiences of abuse from their past. These strategies may be able to prevent depression in MS, a possibility that we plan to explore in future research.
EXECUTIVE SUMMARY

Multiple sclerosis (MS) is the leading neurological cause of disability in young people, and major depression is now the leading single cause of disability in Canada. Nearly half of people with MS also struggle with depression. In this study, we used a variety of existing provincial and national data sources and also collected our own data through a study involving approximately 3000 interviews with Albertans having MS in order to better understand their concerns and needs. We found that levels of depression were high in this population, which is something that we expected. However, depression did not appear to play an independent role as a cause of disability. This means that a strategy sometimes adopted by income-support providers; the strategy of waiting to assess functioning after a depression is resolved (under the assumption that the disability may no longer exist at that point) will be ineffective in reducing disability claims. We also determined that instrumental needs were not being met in people with MS, suggesting that efforts to improve homecare should focus on day to day activities such as helping with shopping, chores and cooking. In terms of preventing depression in this population, we found that the management of pain and fatigue are potentially effective avenues, but also that childhood abuse, smoking and other depression risk factors seem to play an important (and modifiable) role along with disease-specific factors such as severe fatigue. There have been recommendations for depression screening in this population, but concerns that screening scales may perform poorly due to overlapping symptoms. We examined this issue and found that a standard scale actually performed very well.

RESEARCH OVERVIEW

Objective(s)

Our objective was to improve the planning and delivery of mental health services for people with disabilities due to MS by (1) providing a better understanding of the frequency, distribution and associated patterns of impairment and disability associated with depression in this population, (2) examining risk factor associations and (3) by examining the performance of a screening instrument in this population.

Background

MS is considered the most common disabling neurological condition in young people (Murray, 2006; Nicholas & Chataway, 2007; Evans et al., 2013). This disease is a particular concern in Alberta, which is a high prevalence region within Canada (Beck, Metz, Svenson, & Patten, 2005; Evans et al., 2013), a country itself having a high prevalence of this condition (Evans et al., 2013). A prevalence study conducted by our group in collaboration with Alberta Health and Wellness found that 386/100,000 Albertans have MS, representing more than 10,000 people within the province (Patten, Svenson, & Metz, 2005). The Canadian MS Society estimates that 55 to 75 thousand Canadians have this condition (2013). Mental illness is an important dimension of MS. People with MS have an elevated prevalence of anxiety disorders (Feinstein, O'Connor, Gray, & Feinstein, 1999) and psychotic disorders (Patten, Svenson, & Metz, 2005), but mood disorders are considered the most pressing mental health concern (Feinstein, 2003; The Goldman Consensus Conference Participants & National MS Society, 2005). Both Major Depressive Disorder and Bipolar Disorder occur frequently in MS (Joffe, Lippert, Gray, Sawa, & Horvath, 1987). The only population-based study of Major Depressive Episode (MDE) prevalence, conducted by our group, found an annual prevalence of 25% in the 18-45 age group, leading to an age and sex adjusted odds ratio of 2.3 and identifying MS as one of the chronic medical conditions that are most strongly associated with depression in community populations (Patten, Beck, Williams, Barbui, & Metz, 2003). These results were confirmed in a subsequent study conducted in collaboration with Alberta Health and Wellness, where a relative prevalence of 2.2 was found (Patten et al., 2005).

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transition to unemployment and occupational disability. In the NARCOMS database (a community cohort with MS in the US), more than half of people with MS under the age of 65 were not working at a baseline interview and of 3,881 who were working at baseline, 487 (12.5%) were no longer working after an average follow-up interval of only 1.6 years (Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008). Existing literature indicates that depression magnifies the impact of various chronic conditions on functional status (Stein, Cox, Afifi, Belik, & Sareen, 2006; Schmitz, Wang, Malla, & Lesage, 2007), so depression is a likely contributor to this high rate of transition out of employment. High suicide rates have also been reported in this population (Brønnum-Hansen, Stenager, Stenager, & Koch-Henriksen, 2005; Koch-Henriksen, Bronnum-Hansen, & Stenager, 1998; Stenager et al., 1992). The Burden of Neurological Diseases, Disorders and Injuries in Canada Report (2007) estimated that the total cost associated with MS in 2000–2001 was $950.5 million, which included direct costs of $139.2 million and indirect costs of $811.3 million (Canadian Neurological Sciences Federation, Canadian Brain and Nerve Health Coalition, & Canadian Institute for Health Information, 2007).

Our research team identified several opportunities to advance knowledge concerning the mental health of persons with MS. These consisted of an Alberta database called the Canadian Impact of MS (CIMS) database which was established as a component of a multi-million dollar CIHR Interdisciplinary Team Grant led by Dr. Wee Yong and Dr. Luanne Metz at the University of Calgary. The CIMS database contains (often longitudinal) records of more than 2000 people with MS, incorporating ratings of neurological impairment, employment, financial support, as well as depressive symptom ratings.

Another opportunity arose as a result of a national study by Statistics Canada called the Participation and Activities Limitations Survey (PALS) (Statistics Canada, 2010). Despite the availability of these data sources, we identified major issues that could not be addressed by them. For this reason, we identified a need to conduct a large-scale, Alberta-based study in order to address these issues. All of these projects received input from relevant stakeholders, including Alberta Health Services (AHS), the MS Society and the Alberta Innovates, Health Solutions (AIHS) Program and all were approved by the University of Calgary Conjoint Health Ethics Review Board. Details for the three studies are provided below using the sub-headings: “The PALS Study”, “The CIMS Study”, and “The Prospective Cohort Study”.

The Participation and Activities Limitation (PALS) Study: Approach and Methods
In a Canadian census conducted in 2006, 80% of households received a short-form questionnaire that contained eight basic questions. The remaining, randomly sampled 20% received a more detailed questionnaire containing 61 questions (the census “long form”) (Statistics Canada, 2010; Statistics Canada, 2010). The long form contained two questions concerning health-related impairments: 1) Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning, or doing any similar activities? 2) Does a physical condition or mental condition or health problem reduce the amount or the kind of activity this person can do: (a) at home? (b) at work or at school? (c) in other activities, for example, transportation or leisure? Affirmative responses to one or more of these items were used by Statistics Canada to develop a sampling frame for use in PALS. The selection of the PALS sample from this frame used stratified random sampling to ensure feasibility of estimation by both province/territory and age group. Severity of disability was also included as a stratification factor during sampling.

Because it is linked to a census, the PALS sampling frame covered people living in private and some collective households in the ten provinces and three territories of Canada. Populations living on First Nations reserves were excluded, as were residents of institutional collectives, military bases, Canadian Armed Forces vessels, merchant vessels, and coast guard vessels, as well as campgrounds and parks. Data were collected primarily by computer-assisted telephone interview. Deterministic imputation for missing data was carried out in specific circumstances by Statistics Canada, but only when sufficient information was available from related questions. Proxy responses were allowed. However, proxies were used only after “every effort” had been made to contact and interview respondents directly. If a respondent was not available when the interviewer called, multiple
follow-up attempts were made. The proxy rate among those aged 15 and above in the PALS was 12.1%.

The PALS interview included a questionnaire called the Comprehensive Health Status Measurement System (CHSMS), which was administered to all respondents. This questionnaire was originally designed to classify health status for the Health Utility Index (HUI) (Horsman, Furlong, Feeny, & Torrance, 2003). The HUI is a health utility measure (Furlong, Feeny, Torrance, & et al., 1998), but utility weights were not used in this project. The CHSMS items were used to produce impairment ratings in six health status dimensions: vision, speech, mobility, dexterity, emotions, and cognition. Two additional dimensions, hearing and pain, are also covered by the CHSMS but could not be included in this study because of low frequencies of reported impairment. A listing of the CHSMS items can be found in the PALS questionnaire (available at http://www.statcan.gc.ca/imdb-bmdi/indexIP-eng.htm).

The PALS inquired about the use of mobility aids, the extent of instrumental support received, and help with preparing meals. The survey also sought to evaluate aspects of participation in leisure activity using items with the following wording: “Now I will ask you some questions about activities you do. In the past 12 months, did you do any of the following activities within your spare time?” This was followed by a series of specific response choices, such as: exercise, watch TV or videos, and listen to radio or CDs. Endorsement of responses indicating participation was followed by items asking about the frequency of participation in each activity.

The PALS incorporated complex design features including stratified sampling (unequal selection probabilities) but as a post-census survey PALS is unique in not requiring clustering in the way that most large population surveys do. Statistics Canada develops sampling weights that account for the relevant design features and support unbiased estimation of statistical parameters and their associated 95% confidence intervals. Adjustments to these weights for nonresponse were also made by Statistics Canada, reducing the risk of bias due to non-response. All of the analyses reported here incorporated these sampling weights, helping to ensure unbiased estimation of population parameters despite unequal selection probabilities and nonresponse. Statistical analyses were performed using the survey commands in Stata, version 11.0 (Stata Corporation, 2009) at the Prairie Regional Research Data Centre on the University of Calgary campus (http://www.ucalgary.ca/IR/RDC/). Certain low-frequency estimates could not be reported in this article (e.g. CHSMS ratings for hearing and pain). The release of low-frequency estimates is prohibited because of data release rules intended to ensure the confidentiality of census respondents (Statistics Canada, 2010).

The PALS Study: Key Findings
A comparison of the frequency of reported limitations in respondents with MS compared to the remainder of the PALS sample found that the MS group had a higher frequency of limitation in each category of impairment. Predictably, MS was most strongly associated with impaired agility and mobility whereas depression was most strongly associated with pain and cognition. There were no remarkable interactions between MS and mental disorders either on the multiplicative or additive scales examined in the analysis (using log-transformed and untransformed models, respectively). Most categories of impairment (agility, vision, mobility, pain, memory and learning) are associated both with MS and also with mental disorders, but they do not provide evidence that either of these factors modified each other’s effects (Patten, Williams, Lavorato, Metz, & Bulloch, 2012).

As expected, the use of mobility aids was much more common in people with MS. The differences were most evident in the use of canes, grab bars, wheelchairs, walkers, scooters, and motor-vehicle modifications. People with MS were more likely to have one or more caregivers and to identify multiple caregivers. Similar proportions of people with and without MS identified family or friend caregivers, but those with MS were far more likely to report having a paid caregiver. The percentages of respondents with MS reporting that they either received no help or received inadequate was particularly elevated in four areas: meal preparation, housework, chores, and shopping. The differences between people with and without MS were substantial, with people with MS being twice as likely to fall into the “no help/inadequate help” category. In other domains of functioning, the
proportion of people with MS reporting that they either did not need help or received all the help they needed was very high, with no differences discerned from those without MS: caring for self (95.8%), specialized home care (96.3%), and moving around the residence (97.3%) (Patten et al., 2012).

Leisure activity is an aspect of participation in society. Of those activities evaluated in the PALS, the societal-participation percentages were generally similar between those with MS and the rest of the PALS sample. Exercising at home at least once per week was reported by a higher proportion of those with MS (57.1%; 95% confidence interval [CI], 41.9%–72.2%) than without MS (44.5%; 95% CI, 42.7%–46.2%), but imprecision associated with the MS estimate precluded statistical differentiation from the non-MS component of the sample. Watching television or listening to music was reported as a daily activity by 94.8% (95% CI, 91.3%–98.2%) of those with MS and 91.3% (95% CI, 90.6%–92.0%) of those without MS. Reading was less often a daily activity for people with MS, being reported by 62.9% (95% CI, 51.0%–74.7%), as compared with 76.1% of those without MS (95% CI, 74.9%–77.4%). Participation in activities outside of the home was also comparable between people with MS and those with other types of disability. Of those with MS, 53.7% (95% CI, 41.2%–66.2%) reported visiting with family or friends at least once per week, compared with 48.8% (95% CI, 47.4%–50.1%) of those with other types of disability. Participation in physical activities outside of the home at least once per week was reported by 39.7% (95% CI, 22.6%–56.9%) of those with MS, compared with 45.3% (95% CI, 43.8%–46.9%) of those without MS. In both groups, 40% to 50% reported attending sporting or cultural events or visiting museums, libraries, or parks. Only 4.5% (95% CI, 1.3%–7.7%) reported no participation in society in any of the above-listed domains of participation (Patten et al., 2012).

The PALS Study: Conclusions
People with both MS and depression have important needs for support in the community. However, these two conditions do not seem to interact with one another in a synergistic way. The extent to which these needs are being met is uneven – the health system seems to be effective in meeting many of the medical needs of people with MS, but is less so for activities such as meal preparation, shopping and chores.

The Canadian Impact of MS (CIMS) Study: Approach and Methods
Between 2002 and 2006 registrants at the University of Calgary MS Clinic were invited to participate in the CIMS project. Invitations were mailed to all patients registered at the Clinic. This MS Clinic is a population-based service covering the southern part of Alberta. The data collection was broadly based and not specifically focused on depression, mental health or employment. However, relevant items on these topics were included. Depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Rating Scale (CES-D) (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977; Radloff, 1977). This scale provides ratings on a scale of 0 (no symptoms) to 60 (highest possible rating on all 20 items). CES-D scores of 16 or higher are considered indicative of clinically significant depression (Radloff, 1977). The CIMS questionnaire also included a self-rated version of the Extended Disability Status Scale (EDSS), the most widely used MS-specific impairment/disability instrument (Kurtzke, 1983). CIMS also included the MSQoL-54 (an expanded version of the widely used Medical Outcomes Study Short Form, or SF-36 (Vickery, Hays, Harooni, Myers, & Dixon, 1995), that also includes a set of MS-specific items) and the Fatigue Impact Scale (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Fisk, Pontefract, Ritvo, Archibald, & Murray, 1995). Standard demographic items were also included. Working status was assessed using an item that asked whether the respondent had worked in the preceding eight weeks.

Between 2002 and 2006 CIMS asked respondents to complete annual follow-up ratings. A maximum number of four ratings were therefore theoretically possible, but as the cohort was a dynamic one, many of the respondents were only involved long enough to participate in 2 or 3 interviews, or only 1 interview.

After cross-tabulating the data, we used graphical and longitudinal data analysis methods to characterize the relationship between depression and occupational transitions with and without adjustment for covariates. We used grouped time proportional hazard models to explore the risk of
transition from working to non-working status. These models were fit as generalized linear models of the binomial family using the complementary log-log link function. The models were non-parametric in the sense that time (year of follow-up) was represented using an indicator variable such that no assumptions were made about the shape of the hazard function. The proportional hazards assumption was evaluated by examining the statistical significance of time by depression interaction terms using a likelihood ratio test. All analyses were carried out using Stata 11 software (Stata Corporation, 2005).

The CIMS Study: Key Findings

There were a total of n=2053 CIMS participants and 5620 questionnaires were returned by these participants. At the baseline time point 974 of these were employed. This group was taken to be population “at risk” for transition to non-working status. Of these, 759 returned more than one questionnaire and could be included in the survival analysis models. The working respondents had a higher level of education, a lower frequency of depression and were more likely to be ambulatory than the rest of the CIMS sample. The eligible subset (n=759) closely resembled the rest of the employed cohort at baseline.

Those who were working at baseline were slightly younger, with a mean age of 42.3 compared to 50.0 among those not working at baseline. Those who were working at baseline also reported lower levels of depression than those who were not working. The working subset also had higher MSQoL composite scores (both physical and mental) and lower fatigue impact across all domains than the overall CIMS cohort.

There was no convincing evidence over this time frame of diminishing health status, as assessed by median scores on the MSQol-54 physical and mental health subscales. Nor was there any clear evidence of an overall increase in depressive symptoms.

The hazard ratio for depression at baseline was 1.7 (95% CI: 1.3-2.3), a statistically significant association (Wald test p<0.001). No associations were observed between sex, age, marital status, nor education level with transition to not working status (data not shown). However, the use of an ambulation aid (HR 2.0, 95% CI: 1.4 – 2.9) and all three of the fatigue-impact subscales predicted this transition. The FIS subscales were included as continuous variables in the proportional hazards models, all p-values < 0.001.

There was significant collinearity between the subscales, such that the p-values were unstable when more than one of these subscales were included in the models. Spearman’s rho for the physical and social fatigue impact subscales was 0.82. The MSQoL was also treated as a continuous variable and both the mental (Wald test, p = 0.001) and physical (Wald test, p < 0.001) composite scores predicted the occupational transition.

Inclusion of depression along with age, sex, marital and educational status did not result in a change of the HR for depression, which remained at 1.7 after each of these adjustments individually. Similarly, inclusion of ambulation status and depression simultaneously in a model did not change the HR for depression. Inclusion of FIS and MSQoL subscales tended to weaken the effect of depression. For example, inclusion of the cognitive fatigue impact subscale reduced the depression HR to 1.4 (95% CI 1.0 – 2.0, p = 0.05). Inclusion of the physical fatigue impact subscale reduced it to 1.3 (95% CI 0.9 – 1.8, p = 0.13) and the social fatigue impact subscale reduced it to 1.1 (95% CI 0.8 – 1.6, p = 0.53). Simultaneous inclusion of both of the MSQoL-54 mental health composite scales reduced the depression HR to 1.2 (95% CI 0.8 – 1.9, p = 0.39). With adjustment for the mental health composite alone, the HR became 1.4 (95% CI: 0.9 – 2.0, p = 0.14) and with inclusion of the physical composite alone score the HR for depression became 1.0 (95% CI 0.7 – 1.4, p = 0.85).

In order to explore the impact of depression with simultaneous adjustment for these covariates, a model including all of the available covariates was fit. In this model, depression was not significantly associated with the occupational transition (HR 1.3, 95% CI: 0.8 – 2.0, p = 0.34). In this model, the
only variable attaining statistical significance was the MSQoL physical composite score (p = 0.01), included in the model as a continuous variable. The physical composite HR was 0.98, indicating a 2% increase in risk in association with one-point lower rating on the scale. These results are currently under review with the journal Functional Neurology.

The CIMS Study: Conclusions
The study was able to clarify temporal relationships by examining the predictive value of elevated depressive symptoms at a baseline time point when all of the respondents were working. Depressive symptoms did predict transition to non-working status in the absence of adjustment for other variables. However, after adjustment for other variables, both fatigue ratings and the composite scale scores of the MSQoL-54 resulted in substantial weakening or disappearance of the association. These results do not support the idea that the association of depression with transition to non-working status is an independent causal association. A qualification is that all of the predictive variables: depression ratings, MSQoL and FIS composite scores were correlated with one another and may reflect different ways of measuring more fundamental disease-related changes.

These findings validate the idea that depression may be a marker, or indicator, of subsequent transitions. This may occur because the stress associated with struggling to maintain functioning in an occupational role may begin to exact a toll on patients’ emotional status before the actual transition occurs or because depression and fatigue are closely intertwined with other symptoms and impairments in MS. However, as the analysis does not support a causal effect, it does not substantiate the idea that occupational functioning should be deferred while depression is present (a common practice currently), or that disability benefits should be withheld when depression is present.

The Prospective Cohort Study: Approach and Methods
This part of the project consisted of a prospective cohort study. A random sample of 182 people with MS were followed for six months, and were interviewed every two weeks during that time frame. There were a total of 19 contacts with each respondent during the follow-up interval. The contact could occur by phone, by internet or mail (and in a few cases in person), according to the respondents preference and circumstances. A validated depression instrument, the Patient Health Questionnaire - Brief (PHQ-9) (Spitzer, Kroenke, Williams, & The Patient Health Questionnaire Primary Care Study Group, 1999; Kroenke, Spitzer, & Williams, 2001; Kroenke & Spitzer, 2002) was administered at each contact, and a battery of measures of socioeconomic status, illness-related factors, childhood risk factors, stress-related and psychosocial factors and health behaviors were also administered.

Analysis of the data is ongoing, and is being led by a PhD student. We are using survival analysis method (life tables and proportional hazard models) to evaluate incidence, and factors determining incidence. Notably, this is the first-ever prospective study of depression epidemiology in MS. One of our goals was to examine the psychometric properties of the PHQ-9 in this population. We did this by examining psychometric indices, exploring different scoring procedures that have been proposed to adjust for “symptom contamination” due to MS (e.g. one of these involved leaving out the fatigue item and adjusting the interpretive cut-point accordingly) and by comparing these analyses to a PHQ dataset from the general population.

The Prospective Cohort Study: Key Findings
The sample was 27% male and 73% female, consistent with the known female preponderance in MS. The respondents ranged in age from 20-98 years old. The prevalence of probable major depression according to the PHQ-9 was 22% at baseline. Forty-nine respondents (27%) reported a past history of mental illness and 28% reported a family history of major depression. Strong associations of incident depression with major life events (OR=6.8), pain (OR=5.4), childhood emotional abuse (OR=4.9) were identified in the cross-sectional baseline data. All of these associations have been confirmed in our proportional hazard models. They do not appear to be due to confounding by age and sex.
In our examination of psychometric properties of the PHQ-9 in this population we identified corrected item-total correlations that were highest for anhedonia and depressed mood, the two symptoms considered essential to the syndrome of major depression as defined in DSM-IV (American Psychiatric Association, 1980). Depression, guilt and anhedonia produced the highest corrected item-total correlations for the general population sample. In both samples, conventional PHQ-9 scoring had high internal consistency (Cronbach’s α ≥ 0.82). Spearman’s correlation coefficients between total scores using the standard PHQ-9 scoring and 7 proposed adjusted scoring methods that we explored in this analysis ranged from 0.95 – 0.99. None of the scoring-adjustment methods that we explored displayed advantages over the traditional scoring of the scale (Sjonnesen et al., 2012).

The kappa coefficient was used as a measure of concordance between the different cut-point scoring methods. Kappa values are typically lower than percent agreement as they correct for random concordance; kappa values ≥0.81 may be considered “almost perfect” (Landis & Koch, 1977). Kappa coefficients produced from the various cut-point based scoring procedures in the MS sample ranged from 0.80 to 0.95, and ranged from 0.80 to 0.91 for the general population sample. The contribution of each PHQ-9 item to the total score was analyzed for differences between the MS and general population samples. In both samples, fatigue was the largest contributor to the total score, followed by sleep changes and appetite changes. The contribution of fatigue and concentration deficits to overall scores did not differ significantly between the two samples.

Using a logistic regression model we adjusted for age, sex and subsets of PHQ item scores both in the MS and general population datasets. The general population subjects were the reference group in these models. In other words, MS status was represented by an indicator variable assuming values of 0 (general population) or 1 (MS). The odds-ratio (OR) for anhedonia was found to be 0.47, indicating a lower frequency of endorsement in the MS sample. The MS sample had greater frequency of positive symptom endorsements for guilt (OR 2.17, p<0.03) and fatigue (OR 1.51, p<0.05). This model provides an assessment of the extent to which the symptoms of fatigue and concentration seem to be selectively over-reported in people with MS, after adjustment for other symptoms. There was no evidence of any greater frequency of endorsement of concentration deficits. The association with fatigue was statistically significant, but weak, which is consistent with the minor changes observed when excluding fatigue from the scoring, as described above (Sjonnesen et al., 2012).

**The Prospective Cohort Study: Conclusions**

A belief that depression in MS is “more biological” and less closely related to traditional depression risk appears to be wrong. The most important risk factors for depressive disorders, major life events and childhood adversity were at least as important, if not more important, in the MS population than what has been reported in the general population. Prevention and treatment of depression in this population is therefore likely to benefit from the skills and expertise of mental health specialists.

With respect to the screening option, we found no evidence that the most popular depression screener, the PHQ-9, was compromised in its performance or required specialized scoring methods when it is used in the MS population.

**Implications for Policy or Practice**

1. Depression is associated with functional transitions in MS. There is a need for services at these stages, but these can generally not be expected to prevent these transitions from occurring. Policies of organizations providing disability support can assess eligibility for such support even if depressive symptoms are present. Disability support programs should not defer their decisions about eligibility because depression is present.
2. The support needs of people with MS are considerable and generally greater than those associated with other medical conditions. These are met to a much greater extent in the medical/nursing spheres than within the sphere of day to day activities. Service providers, and the policies of the organizations within which they work, should not neglect these aspects of support.
3. The pattern of depression seen in MS resembles that seen elsewhere, emphasizing the value of the skill-set possessed by mental health professionals. Contrary to widely held opinion, psychosocial
issues such as childhood abuse are at least as important in MS as in the general population with
depression. Mental health services for people with MS should not focus their personnel and human
resources too sharply on “neuropsychiatric” expertise.

4. Service settings considering the implementation of screening can use a standard instrument (the
PHQ-9) without needing to use modified scoring procedures.

DIRECTIONS FOR FURTHER RESEARCH
This project has laid a foundation for intervention research, both in terms of secondary and tertiary
prevention. Intervention studies can now be pursued, ideally, these would use randomized study designs.
One of the major conclusions, that the PHQ-9 can perform as a screening scale in this population, should
be solidified by validation work that incorporates comparison to a gold-standard diagnostic instrument.

KNOWLEDGE DISSEMINATION AND TRANSLATION ACTIVITIES
So far, our main knowledge translation and exchange (KTE) methods have been a traditional one:
targeting the academic literature with peer-reviewed publications and conference presentations. We
have also participated in 2 of the 3 of the Found in Translation Events, making poster presentations in
each one. We have held a series of meetings attended by our Partners with the MS Society and AIHS
and have made sure that they have received copies of the publications. Another of our knowledge-user
partners is Dr. Mike Trew (Medical Director for Addiction and Mental Health with Alberta Health
Services), who involved the PI (Patten) in the development of clinical care pathways for depression,
which provides a conduit for this research to directly influence clinical practice. The PI (Patten) is the
Depression Network Lead for the Scientific Network of the Alberta Health Services Addictions and
Mental Health Strategic Clinical Network, which will be adopting depression in the medically ill as one of
its key themes and all of the knowledge generated in this project will therefore have a more or less
direct mechanism for translation into clinical practice through AHS and the Strategic Clinical Network.

PRINCIPAL APPLICANT (TEAM LEADER)

<table>
<thead>
<tr>
<th>Name</th>
<th>Position Title</th>
<th>Topics of interest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scott B. Patten</td>
<td>Professor, Department of Community Health Sciences, University of Calgary</td>
<td>Mood disorder epidemiology, comorbidity</td>
</tr>
</tbody>
</table>

PROJECT PARTNERS (TEAM MEMBERS)

<table>
<thead>
<tr>
<th>Name</th>
<th>Position Title</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sandy Berzins</td>
<td>PhD Student. One component of this study comprised Sandy’s PhD project.</td>
<td>She coordinated the prospective study, and is currently analyzing the data from it.</td>
</tr>
<tr>
<td>Luanne Metz</td>
<td>Director, U of C Multiple Sclerosis Clinic</td>
<td>Facilitated intellectual and operational aspects. Will be an important KTE partner – as a knowledge user.</td>
</tr>
<tr>
<td>Andrew Bulloch</td>
<td>Professor, University of Calgary</td>
<td>Assisted with graduate student supervision and operational oversight of projects.</td>
</tr>
<tr>
<td>Jennifer Rogers</td>
<td>Adjunct Professor, University of Alberta</td>
<td>Participated in teleconferences, provided feedback on project.</td>
</tr>
<tr>
<td>Carol Fredrek</td>
<td>MS Society of Alberta</td>
<td>Helped publicize the study, reviewed materials.</td>
</tr>
<tr>
<td>Krista Avery</td>
<td>Alberta Insured Income for the Severely Handicapped (AISH)</td>
<td>KTE Role with AIHS, a potential knowledge User</td>
</tr>
<tr>
<td>David Terriff, Kirsten Sjonnesen (Summer Student from Queens University), Kirsten Fiest</td>
<td>University of Calgary Students (PGME, Summer Student, PhD Students).</td>
<td>These students participated in analysis and presentation of results. K. Sjonnesen has since been admitted to the MSc Program at U of C. K. Fiest is extending the work to the domain of epilepsy.</td>
</tr>
</tbody>
</table>
**PUBLICATIONS AND PRESENTATIONS ARISING FROM THE PROJECT TO DATE**


This Poster received an award for the Best Poster Presentation at the CAPE meeting.

Fiest, K., Sjonnesen, K., Berzins, S., Williams, J. V. A., Bulloch, A. G. M., & **Patten, S. B.**, (2012). Depressive symptoms in multiple sclerosis patients versus the general population. *Canadian Academy of Psychiatric Epidemiology, Montreal, QC.*

**ABOUT THE ALBERTA MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM**

The *Alberta Mental Health Research Partnership Program* is comprised of a broad-based multisectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based mental health research in Alberta.

The mission of the Research Partnership Program is to improve mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta’s excellence and output of mental health research findings, and to better translate these findings into practice improvements.
REFERENCES


Spitzer, R. L., Kroenke, K., Williams, J. B. W., & The Patient Health Questionnaire Primary Care Study Group (1999). Validation and utility of a self-report version of the PRIME-MD. The PHQ Primary Care Study. *JAMA*, 282, 1737-1744.
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