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Mission statement
The Canadian Journal of Neuroscience Nursing (CANN) sets standards of practice and promotes continuing professional education and research. Members collaborate with individuals, families, interdisciplinary teams and communities to prevent illness and to improve health outcomes for people with, or at risk for, neurological disorders.

Le Journal canadien des infirmières et infirmiers en neurosciences

Les opinions, les points de vue, et les énoncés exprimés dans les articles, editoriaux et affiches publiques sont ceux des auteurs et commerçants. Ils ne reflètent pas nécessairement les idées et les politiques de l’ACIIN. L’éditeur et la maison d’édition n’acceptent aucune responsabilité reliée au contenu du matériel publié dans le journal. L’Association canadienne des infirmières et infirmiers en neurosciences est rattachée au Cumulative Index to Nursing and Allied Health Literature, International Nursing Index (INI) and Nursing Citation Index ISSN #1913-7176.

Énoncé de mission
L’Association canadienne des infirmières et infirmiers en neurosciences (ACIIN) établit les standards de pratique de la profession et fait la promotion de l’éducation permanente et de la recherche. Les membres collaborent avec les individus, les familles, les équipes multidisciplinaires et la communauté en général dans le but de prévenir les maladies neuroligiques et d’améliorer la santé des gens qui en sont atteints ou qui sont à risque d’en souffrir.
Editorial
Well, another year is about to wrap up and it has been a productive one for the Canadian Journal of Neuroscience Nursing. We have published abstracts and key papers from the 2012 CANN Conference, peer-reviewed papers from independent authors, and items of interest to the neuroscience nurse in clinical practice. In this issue of the journal, we have an international flavour in some of the manuscripts submitted for publication. One paper reflects the education and specialization of neuroscience nurses in Poland, while the second comes to us from Greece by way of the United Kingdom. This author reminds us, given multinational immigration trends, of the importance of considering CNS tuberculosis as a differential diagnosis for patients presenting with diffuse CNS symptomology.

We hope you enjoy the perspectives presented by these two authors around issues pertaining to neuroscience nursing in a global sense.

On behalf of the editorial staff and peer reviewers for the CJNN, we wish you and yours all the best for the coming New Year!

Theresa Green, RN, PhD
CJNN Editor

2013 CANN Conference Call for Abstracts
We will extend the call for abstracts until January 16, 2013. The 2013 CANN program will have more workshop content, thus limiting the amount of concurrent sessions. In order to ensure that your presentation/workshop is included on the program, please submit your abstract as early as possible. The time of submission will be one of the criteria considered by the scientific committee.

Regards,
Toni Vitale and Rosa Sourial

Appel aux résumés pour la conférence de l’ACIIN 2013
Nous repoussons la date de soumission des résumés au 16 janvier 2013. Le contenu des ateliers du programme de l’ACIIN 2013 sera plus conséquent, limitant ainsi le nombre de sessions simultanées. Soumettez votre résumé dès que possible afin de vous assurer que votre présentation / atelier soit inclus dans le programme. La date de soumission constituerà l’un des critères que le comité scientifique prendra en compte.

Cordialement,
Toni Vitale et Rosa Sourial

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A Prescription for Safer Care: Medication Reconciliation

Reducing medication-related errors is a priority for advancing safe, quality health care in Canada, and four national organizations are tackling it head on. Accreditation Canada, the Canadian Institute for Health Information, the Canadian Patient Safety Institute, and the Institute for Safe Medication Practices Canada released a report today entitled Medication Reconciliation in Canada: Raising the Bar.

Medication reconciliation is a formal process of identifying a complete and accurate list of medications a patient is taking, and using that list to provide correct medications for the patient at each transition of care. This new report identifies high-risk populations and effective approaches to medication reconciliation, as well as the challenges, trends, and advances toward ensuring drug-related errors are avoided.

Some of the insights found in the report include:

- In 2009–2010, the estimated economic burden of preventable patient safety incidents in acute care in Canada was $397 million. Medication reconciliation was identified as key to reducing this burden.
- One quarter of seniors have three or more chronic conditions that often need to be treated with multiple medications. These seniors are at higher risk of adverse events related to medication use, and unplanned visits to emergency departments and hospitals.
- Of the 288 health care organizations surveyed by Accreditation Canada in 2011, only 60% had a process for medication reconciliation at admission, and 50% had a process for medication reconciliation at transfer or discharge.
- Medication reconciliation practices showed the highest improvement from 2010 to 2011, yet continue to be one of the greatest patient safety challenges.
- The National Medication Reconciliation Strategy, co-led by CPSI and ISMP Canada, is actively developing a curriculum for health care practitioners, as well as tools, resources, and technology supports—including medication checklists, a mobile app to help patients better manage their own medications, and an interactive web-based map of innovative medication reconciliation resources by region.

The work of the four partners, including Medication Reconciliation in Canada: Raising the Bar, supports communication of medication information within the health care system, promotes consistent measurement, and ensures approaches are continually reviewed and updated. Together, this group will continue to advance the national medication reconciliation agenda, and will further support health care providers to make care safer for all Canadians.

Accreditation Canada www.accreditation.ca
Accreditation Canada is a not-for-profit, independent organization accredited by the International Society for Quality in Health Care (ISQua). Accreditation Canada provides national and international health care organizations with an external peer-review process, standards and tools to assess and improve the services they provide to their patients and clients based on national standards. Accreditation Canada’s programs and guidance have helped organizations promote quality health care for over 50 years.

The Canadian Institute for Health Information (CIHI) www.cihi.ca
CIHI is an independent, not-for-profit corporation that provides essential information on Canada’s health system and the health of Canadians. Established in 1994 and funded by federal, provincial and territorial governments, CIHI’s vision is to improve Canada’s health system and the well-being of Canadians by being a leading source of unbiased, credible and comparable information that will enable health leaders to make better-informed decisions.

The Canadian Patient Safety Institute (CPSI) www.patientsafetyinstitute.ca
CPSI is a not-for-profit organization that exists to raise awareness and facilitate implementation of ideas and best practices to achieve a transformation in patient safety. CPSI envisions safe health care for all Canadians and is driven to inspire extraordinary improvement in patient safety and quality. The Canadian Patient Safety Institute would like to acknowledge funding support from Health Canada.

The Institute for Safe Medication Practices Canada (ISMP Canada) www.ismp-canada.org
ISMP Canada is an independent national not-for-profit organization committed to the advancement of medication safety in all health care settings. ISMP Canada works collaboratively with the health care community, regulatory agencies and policy makers, provincial, national and international patient safety organizations, the pharmaceutical industry and the public to promote safe medication practices. ISMP Canada’s mandate includes analyzing medication incidents, making recommendations for the prevention of harmful medication incidents, and facilitating quality improvement initiatives.

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Une prescription pour des soins plus sécuritaires: le bilan comparatif des médicaments

Réduire les erreurs liées aux médicaments constitue une priorité pour faire progresser la qualité et la sécurité des soins de santé au Canada, et quatre organismes pancanadiens s’y attaquent de front. En effet, Agrément Canada, l’Institut canadien d’information sur la santé, l’Institut canadien pour la sécurité des patients et l’Institut pour l’utilisation sécuritaire des médicaments du Canada ont publié aujourd’hui un rapport intitulé Bilan comparatif des médicaments au Canada: hausser la barre.
Le bilan comparatif des médicaments est un processus structuré servant à établir une liste complète et exacte de tous les médicaments que prend un patient. On utilise ensuite cette liste pour donner au patient les bons médicaments et ce, à chaque point de transition des soins. Ce nouveau rapport cerne les populations à risque élevé et établit des méthodes efficaces pour effectuer le bilan comparatif des médicaments, en plus de présenter les défis, les tendances et les progrès accomplis en vue de s’assurer que les erreurs liées aux médicaments soient évitées.

Voici certains faits saillants présentés dans le rapport :

- En 2009–2010, au Canada, on estimait à 397 millions de dollars le fardeau économique des incidents évitables liés à la sécurité dans les établissements de soins de courte durée. Il a été établi que le bilan comparatif des médicaments est essentiel pour réduire ce fardeau.
- Le quart des personnes âgées ont trois maladies chroniques ou plus, lesquelles doivent souvent être traitées en utilisant plusieurs médicaments. Ces personnes âgées présentent un risque plus élevé d événements indésirables liés à l utilisation de médicaments, ainsi que de visites imprévues au service des urgences et à l hôpital.
- Des 288 organismes de soins de santé visités par Agrément Canada en 2011, seulement 60% disposaient d’un processus pour établir le bilan comparatif des médicaments à l’admission et 50% disposaient d’un processus pour établir le bilan comparatif des médicaments au transfert ou au congé.
- Les pratiques relatives à l’établissement du bilan comparatif des médicaments ont démontré l’amélioration la plus marquée de 2010 à 2011, mais elles s’avèrent toujours l’un des plus grands défis liés à la sécurité des patients.
- Dans le cadre de la Stratégie nationale de mise en œuvre du bilan comparatif des médicaments, codirigée par l’ICSP et l’ISMP Canada, on élabore activement un programme pour les professionnels de la santé, ainsi que des outils, des ressources et un soutien technologique—notamment des listes de vérifications des médicaments, une application mobile pour aider les patients à mieux gérer leurs médicaments et une carte interactive sur le Web des ressources innovatrices pour le bilan comparatif des médicaments selon la région.

Le travail des quatre partenaires, y compris le rapport Bilan comparatif des médicaments au Canada: hausser la barre, appuient la communication de renseignements relatifs aux médicaments dans le système de soins de santé, favorisent l’uniformité de l’évaluation et s’assurent que les approches sont revues et mises à jour de façon continue. Ensemble, les membres de ce groupe continueront de faire progresser le programme global de bilan comparatif des médicaments et continueront d’appuyer les prestataires de soins de santé afin de rendre les soins de santé plus sécuritaires pour tous les Canadiens.

Agrément Canada www.accreditation.ca
Agrément Canada est un organisme sans but lucratif et indépendant, agréé par l International Society for Quality in Health Care (ISQua). Il fournit aux organismes de soins de santé nationaux et internationaux un processus d’examen externe mené par des pairs, de même que des normes et des outils, afin d’évaluer et d’améliorer les services offerts aux patients et aux clients en se fondant sur des normes d’excellence. Grâce à ses programmes et aux conseils qu’il prodigue, Agrément Canada aide les organismes à promouvoir des soins de santé de qualité depuis plus de 50 ans.

Institut canadien d’information sur la santé (ICIS) www.icis.ca
L’ICIS est un organisme indépendant, sans but lucratif, qui fournit des renseignements essentiels sur le système de santé du Canada et sur la santé des Canadiens. Mis sur pied en 1994 et financé par les gouvernements fédéral, provinciaux et territoriaux, la vision de l’ICIS consiste à améliorer le système de santé canadien et la santé des Canadiens en devenant une source majeure d’information impartiale, crédible et comparable pour permettre aux responsables de la santé de prendre des décisions plus éclairées.

Institut canadien pour la sécurité des patients (ICSP) www.patientsafetyinstitute.ca
L’Institut canadien pour la sécurité des patients (ICSP) est un organisme de sensibilisation sans but lucratif qui vise à améliorer la sécurité des patients en facilitant la mise en œuvre d’idées novatrices et de pratiques exemplaires. L’ICSP aspire à des soins de santé de qualité pour tous les Canadiens et s’efforce d’inspirer une amélioration extraordinaire de la sécurité des patients et de la qualité des soins. L’Institut canadien pour la sécurité des patients tient à souligner qu’elle a obtenu un soutien financier de Santé Canada.

Institut pour l’utilisation sécuritaire des médicaments du Canada (ISMP Canada) www.ismp-canada.org
L’Institut pour l’utilisation sécuritaire des médicaments du Canada est un organisme national indépendant à but non lucratif engagé à faire progresser l’utilisation sécuritaire des médicaments dans tous les secteurs de la santé. L’ISMP Canada travaille en collaboration avec les professionnels et les établissements de santé, les organismes de réglementation, ainsi que les responsables de la politique, les organismes de promotion de la sécurité des patients provinciaux, nationaux et internationaux, l’industrie pharmaceutique et le public afin de promouvoir des pratiques visant l’utilisation sécuritaire des médicaments. Les mandats de l’ISMP Canada sont les suivants : recueillir et analyser les déclarations d’incidents ou d’accidents liés à l’utilisation des médicaments, formuler des recommandations pour prévenir les accidents liés à la médication et porter assistance dans le cadre des stratégies d’amélioration de la qualité.

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The New England Journal of Medicine publishes pivotal data demonstrating efficacy and safety of oral BG-12 (dimethyl fumarate) in multiple sclerosis

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Results of Phase 3 DEFINE and CONFIRM studies support dimethyl fumarate’s potential as a strong option for MS treatment


Data from the Phase 3 DEFINE and CONFIRM studies show that dimethyl fumarate (240 mg), administered twice daily (BID) or three times daily (TID), demonstrated significant and clinically meaningful reductions in MS relapses and brain lesions in patients with relapsing-remitting multiple sclerosis (RRMS) compared to placebo, as well as showed benefit in slowing the progression of the disease. Dimethyl fumarate is currently under review by regulatory authorities in the United States, European Union, Australia, Canada and Switzerland.

“The publication of both dimethyl fumarate pivotal studies in NEJM is another achievement for this important investigational therapy,” said Katherine Dawson, M.D., senior medical director, Biogen Idec Neurology Research and Development and Biogen Idec lead author on both dimethyl fumarate manuscripts in NEJM. “The data from its clinical development program consistently indicate that dimethyl fumarate may provide tangible benefits and address existing treatment needs of people living with MS. We are working closely with regulatory authorities across the globe with the aim of making the review of dimethyl fumarate as quick as possible.”

DEFINE and CONFIRM efficacy results

Together, the DEFINE and CONFIRM manuscripts in NEJM summarize the positive Phase 3 clinical data set for dimethyl fumarate, which formed the foundation for its regulatory filings around the world.

DEFINE was a two-year global study that evaluated dimethyl fumarate (240 mg, BID or TID) compared to placebo in people with RRMS. Results showed that both dimethyl fumarate BID and TID met the study’s primary endpoint by significantly reducing the proportion of patients who relapsed by 49 percent and 50 percent (p<0.0001 for both; reported in NEJM as p<0.001 due to journal requirement that p-values smaller than 0.001 be reported as p<0.001), respectively, at two years compared to placebo. Both dosing regimens also met all secondary endpoints in the study.

“Because MS is a chronic disease, we look for treatment options that not only control relapses but also slow patients’ disease progression for as long as possible,” said Ralf Gold, PhD, Professor/Chair of the Department of Neurology at St. Josef-Hospital/Ruhr-University in Bochum, Germany, and lead author on the DEFINE manuscript in NEJM. “In DEFINE, dimethyl fumarate demonstrated efficacy, as well as positive safety and tolerability profiles, which is a very attractive combination for an MS treatment.”

Like DEFINE, CONFIRM was a two-year global clinical trial that investigated dimethyl fumarate (240 mg, BID or TID) versus placebo in people with RRMS. The study also included an active reference comparator of glatiramer acetate (GA; 20 mg subcutaneous daily injection) versus placebo. Results showed that both dimethyl fumarate BID and TID met the study’s primary endpoint by significantly reducing annualized relapse rate (ARR) by 44 percent and 51 percent (p<0.0001 for both; reported in NEJM as p<0.001 due to journal requirement that p-values smaller than 0.001 be reported as p<0.001), respectively, versus placebo at two years. In addition, both dosing regimens of dimethyl fumarate met all secondary relapse and magnetic resonance imaging (MRI) endpoints in the study. While not statistically significant, dimethyl fumarate showed a clinically meaningful reduction in 12-week confirmed disability progression as measured by the Expanded Disability Status Scale (EDSS).

The GA data versus placebo in CONFIRM were generally consistent with its product labelling.

“Results of the CONFIRM study were consistent with those of DEFINE, demonstrating that oral dimethyl fumarate significantly reduced MS disease activity compared to placebo and has a strong safety profile,” said Robert J. Fox, M.D., medical director of the Mellen Center for Multiple Sclerosis at Cleveland Clinic and lead author on the CONFIRM manuscript in NEJM. “I believe that these findings support the potential of oral dimethyl fumarate in RRMS for both treatment-naive patients and those not tolerating or sub-optimally responding to currently available therapies.”

* Dr. Robert Fox is a paid advisor for Biogen Idec for projects not related to dimethyl fumarate clinical development.
The CONFIRM manuscript in NEJM also includes data from a post-hoc efficacy analysis that directly compared dimethyl fumarate to GA treatment. While CONFIRM was not designed for a formal statistical comparison of GA versus dimethyl fumarate treatment, this post-hoc analysis was included because it may provide helpful information regarding dimethyl fumarate's efficacy compared to an approved therapy for MS.

**DEFINE and CONFIRM safety results**

In DEFINE and CONFIRM, the safety profile for the dimethyl fumarate BID and TID treatment groups was similar. The overall incidence of adverse events (AEs), serious adverse events (SAEs) and AEs leading to study discontinuation was similar among the dimethyl fumarate and placebo groups in both studies.

In both studies, AEs that occurred more commonly with dimethyl fumarate treatment were flushing and gastrointestinal (GI) events. Flushing and GI events had the highest incidence in the first month of the study and decreased thereafter. The most frequently reported SAE across all treatment groups in both studies was MS relapse.

There was no increase in serious infections or malignancies in the dimethyl fumarate groups compared to placebo in either study. There were no opportunistic infections in the dimethyl fumarate groups. Laboratory analysis in both studies found mean white blood cell counts (WBC) and lymphocyte counts decreased during the first year in dimethyl fumarate-treated patients and then plateaud, remaining within the normal range throughout.

The full manuscripts, called “Placebo-Controlled Phase 3 Study of Oral BG-12 for Relapsing Multiple Sclerosis” (DEFINE) and “Placebo-Controlled Phase 3 Study of Oral BG-12 or Glatiramer in Multiple Sclerosis” (CONFIRM), can be found on the NEJM website at http://www.nejm.org.

**About DEFINE**

DEFINE (Determination of the Efficacy and safety of oral Fumarate IN rElapsing-remitting MS) was a global, randomized, double-blind, placebo-controlled, dose-comparison study to determine the efficacy and safety of dimethyl fumarate (240 mg, BID or TID) and enrolled 1,237 people with RRMS. The primary objective was to determine if dimethyl fumarate was effective in reducing the proportion of relapsing patients at two years. Secondary endpoints included reduction in the number of new or newly enlarging T2-hyperintense lesions and new gadolinium-enhancing (Gd+) lesions as measured by MRI, reduction in ARR, and reduction of disability progression as measured by EDSS. Additional endpoints included the safety and tolerability of dimethyl fumarate.

Detailed results from DEFINE were presented at the 5th Joint Triennial Congress of the European and Americas Committees on Treatment and Research in Multiple Sclerosis (ECTRIMS and ACTRIMS) in October 2011.

**About CONFIRM**

CONFIRM (COmparator and aN oral Fumarate In Relapsing-remitting MS) was a global, randomized, double-blind, placebo-controlled, dose-comparison study to determine the efficacy and safety of dimethyl fumarate and enrolled 1,430 people with RRMS. The study evaluated two dose regimens of dimethyl fumarate, 240 mg BID and 240 mg TID, as well as a reference comparator of GA (20 mg subcutaneous daily injection). Both dimethyl fumarate and GA groups were evaluated versus placebo. The primary objective was to determine whether BG-12 was effective in reducing the rate of clinical relapses at two years. Secondary endpoints at two years included reduction in: the number of new or newly enlarging T2-hyperintense lesions and the number of non-enhancing T1-hypointense lesions (MRI scans were obtained at a cohort of sites); the proportion of patients who relapsed; and in progression of disability as measured by EDSS. Safety and tolerability of BG-12 were also assessed. Detailed results from CONFIRM were presented at the 64th Annual Meeting of the American Academy of Neurology (AAN) in April 2012.

**About dimethyl fumarate**

Dimethyl fumarate, also known as BG-12, is an investigational oral therapy in late-stage clinical development for the treatment of relapsing-remitting multiple sclerosis (RRMS), the most common form of MS. Dimethyl fumarate is the only currently known investigational compound for the treatment of RRMS that has experimentally demonstrated activation of the Nrf-2 pathway.

In 2011 and 2012, Biogen Idec announced positive data from DEFINE and CONFIRM, two global, placebo-controlled Phase 3 clinical trials that evaluated 240 mg of dimethyl fumarate, administered either twice a day or three times a day, for two years. Dimethyl fumarate is currently under review by regulatory authorities in the United States, European Union, Australia, Canada and Switzerland.

**About Biogen Idec**

Through cutting-edge science and medicine, Biogen Idec discovers, develops and delivers to patients worldwide innovative therapies for the treatment of neurodegenerative diseases, hemophilia and autoimmune disorders. Founded in 1978, Biogen Idec is the world's oldest independent biotechnology company. Patients worldwide benefit from its leading multiple sclerosis therapies, and the company generates more than $5 billion in annual revenues. For product labeling, press releases and additional information about the company, please visit www.biogenidec.com.
Safe Harbor

This press release includes forward-looking statements, including statements about the commercialization of BG-12 (dimethyl fumarate) in MS. These forward-looking statements may be accompanied by such words as “anticipate,” “believe,” “estimate,” “expect,” “forecast,” “intend,” “may,” “plan,” “potential,” “will” and other words and terms of similar meaning. You should not place undue reliance on these statements. These statements involve risks and uncertainties that could cause actual results to differ materially from those reflected in such statements, including obtaining regulatory approval, the occurrence of adverse safety events, product competition, the availability of reimbursement for our products, adverse market and economic conditions, problems with our manufacturing processes and our reliance on third parties, failure to comply with government regulation and possible adverse impact of changes in such regulation, our ability to protect our intellectual property rights and the cost of doing so, and the other risks and uncertainties that are described in the Risk Factors section of our most recent annual or quarterly report and in other reports we have filed with the SEC. These statements are based on our current beliefs and expectations and speak only as of the date of this press release. We do not undertake any obligation to publicly update any forward-looking statements.

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Les résultats des études de phase 3 DEFINE et CONFIRM appuient le bien-fondé d’ajouter le fumarate de diméthyle à l’arsenal thérapeutique pour la sclérose en plaques

Biol (fumarate de diméthyle) dans le traitement de la sclérose en plaques

Les résultats des études DEFINE et CONFIRM en matière d’efficacité

Les articles parus dans le NEJM résument les résultats favorables des études DEFINE et CONFIRM, deux essais cliniques de phase 3 portant sur le fumarate de diméthyle, sur lesquels reposent les dossiers soumis aux organismes de réglementation à travers le monde.
L'étude DEFINE était une étude mondiale de deux ans visant à évaluer le fumarate de diméthyle (240 mg, BID ou TID) par rapport au placebo chez des personnes atteintes d'une SEP rémittente. D'après les résultats, le fumarate de diméthyle, qu'il ait été administré deux ou trois fois par jour, a satisfait au principal critère d'évaluation en réduisant significativement, soit de 49 % et de 50 % respectivement, la fréquence des cas de rechute au bout de deux ans par rapport au placebo (p < 0,0001 pour les deux; la valeur signalée dans le NEJM est < 0,001 en raison de l'exigence de la revue selon laquelle toute valeur p inférieure à 0,001 doit être consignée comme suit : p < 0,001). Les deux schémas posologiques ont aussi satisfait à tous les critères d'évaluation secondaires de l'étude.

« Vu la nature chronique de la sclérose en plaques, nous recherchons des options thérapeutiques qui non seulement limitent les poussées mais ralentissent aussi la progression de la maladie le plus longtemps possible », explique Ralf Gold, Ph.D., professeur et chef du département de neurologie à l'hôpital St-Joseph affilié à l'Université de la Ruhr et situé à Bochum, Allemagne. Professeur Gold était le principal auteur de l'article sur l'étude DEFINE soumis au NEJM. « Dans le cadre de l'étude DEFINE, le fumarate de diméthyle s'est avéré efficace en plus de présenter des profils d'innocuité et de tolérabilité favorables, offrant un ensemble d'atouts très intéressant pour le traitement de la SEP. »

Tout comme l'étude DEFINE, l'étude CONFIRM était une étude mondiale de deux ans visant à évaluer le fumarate de diméthyle (240 mg, BID ou TID) par rapport au placebo chez des personnes atteintes d'une SEP rémittente ou cyclique. L'étude comportait aussi un médicament actif de référence, l'acétate de glatiramère (AG; injection sous-cutanée quotidienne de 20 mg), qu'on a comparé au placebo. D'après les résultats, le fumarate de diméthyle, qu'il ait été administré deux ou trois fois par jour, a satisfait au principal critère d'évaluation en réduisant significativement, soit de 44 % et de 51 % respectivement, la fréquence annuaire des poussées au bout de deux ans par rapport au placebo (p < 0,0001 pour les deux; la valeur signalée dans le NEJM est p < 0,001 en raison de l'exigence de la revue selon laquelle toute valeur p inférieure à 0,001 doit être consignée comme suit : p < 0,001). Les deux schémas posologiques du fumarate de diméthyle ont aussi satisfait à tous les critères d'évaluation secondaires de l'étude, notamment en matière de rechutes et de lésions décelables à l'examen par IRM (imagerie par résonance magnétique). Avec le fumarate de diméthyle, on a aussi obtenu une réduction cliniquement pertinente, mais non significative sur le plan statistique, dans la progression de l'incapacité (soutenue sur une période de 12 semaines) selon l'échelle étendue d'incapacité de Kurtzke (EDSS).

Dans le cadre de l'étude CONFIRM, les données sur l'AG par rapport au placebo correspondaient de façon générale à celles figurant dans la monographie du produit.

« Les résultats de l'étude CONFIRM concordaient avec ceux de l'étude DEFINE, démontrant que le fumarate de diméthyle réduisait significativement l'activité pathologique de la SEP comparativement au placebo et qu'il offre un profil d'innocuité favorable », fait remarquer Dr Robert J. Fox, directeur médical du Mellen Center for Multiple Sclerosis intégré à la Cleveland Clinic et principal auteur de l'article sur l'étude CONFIRM soumis au NEJM*. « À mon avis, ces résultats confirment le potentiel du fumarate de diméthyle oral tant chez les patients n'ayant jamais reçu de traitement pour leur SEP rémittente que chez ceux ne tolérant pas les traitements actuellement sur le marché ou y répondant de façon sous-optimale. »

* Dr Robert Fox est un conseiller rémunéré affecté à des projets de Biogen Idec non liés au développement clinique du fumarate de diméthyle.

L'article sur l'étude CONFIRM publié dans le NEJM comprend aussi des données tirées d’une analyse d'efficacité a posteriori comparant le fumarate de diméthyle directement à l'AG. Bien que l'étude CONFIRM n'ait pas été conçue pour dresser une comparaison statistique officielle entre l'AG et le fumarate de diméthyle, on a jugé que l'inclusion de cette analyse pourrait fournir des renseignements utiles concernant l'efficacité du fumarate de diméthyle par rapport à un traitement approuvé pour la SEP.

Résultats des études DEFINE et CONFIRM en matière d’innocuité

Le profil d'innocuité du fumarate de diméthyle administré deux ou trois fois par jour a été semblable dans les groupes de traitement des études DEFINE et CONFIRM. L'incidence globale des effets indésirables, des effets indésirables graves et des effets indésirables motivant l'arrêt de la participation du sujet à l'étude était semblable dans les deux études, que les sujets aient reçu le fumarate de diméthyle ou le placebo.

Dans les deux études, les effets indésirables les plus fréquents chez les sujets recevant le fumarate de diméthyle étaient les bouffées vasomotrices et les troubles gastro-intestinaux. La fréquence de ces effets était la plus élevée pendant le premier mois de l'étude et diminuait par la suite. L'effet indésirable grave le plus souvent signalé dans tous les groupes de traitement des deux études a été une exacerbation de SEP, c'est-à-dire une rechute.

L'incidence d'infections graves ou de tumeurs malignes n'a pas augmenté dans les groupes sous fumarate de diméthyle par rapport aux groupes sous placebo, et ce dans ni l'une ni l'autre des études. Les groupes sous fumarate de diméthyle n'ont présenté aucune infection opportuniste. Les analyses de laboratoire pour les deux études ont révélé une diminution du nombre moyen de globules blancs et du nombre de lymphocytes pendant la première année du traitement par fumarate de diméthyle puis ces numérotions se sont stabilisées, restant dans les limites normales par la suite.

La version intégrale des articles, intitulés respectivement « Placebo-Controlled Phase 3 Study of Oral BG-12 for Relapsing Multiple Sclerosis » (étude DEFINE) et « Placebo-Controlled Phase 3 Study of Oral BG-12 or Glatiramer in Multiple Sclerosis » (étude CONFIRM), est accessible dans le site web du NEJM à l'adresse http://www.nejm.org.
À propos de l’étude DEFINE
L’étude DEFINE (Determination of the Efficacy and safety of oral Fumarate IN rElapsing-remitting MS) était une étude mondiale, randomisée, à double insu, contrôlée par placebo et à comparaison de doses visant à déterminer l’efficacité et l’innocuité du fumarate de diméthyle (240 mg, BID ou TID) et regroupait 1237 personnes atteintes d’une SEP rémittente. Le principal objectif était de déterminer si le fumarate de diméthyle était efficace pour réduire la fréquence des rechutes au bout de deux ans. Les critères d’évaluation secondaires comprenaient la réduction du nombre de nouvelles lésions ou de lésions nouvellement croisant à hypersignal en T2 et du nombre de nouvelles lésions rehaussantes au gadolinium (Gd+) tel que mesuré à l’IRM, la réduction de la fréquence annuelleisée des poussées et la réduction de la progression de l’incapacité telle que mesurée à l’échelle étendue d’incapacité de Kurtzke (EDSS). L’innocuité et la tolérabilité du fumarate de diméthyle figuraient également parmi les autres critères d’évaluation. Les résultats détaillés de l’étude DEFINE ont été présentés lors du 5e Congrès triennal organisé conjointement par l’ECTRIMS et l’ACTRIMS (comités européen et américain pour la recherche sur la sclérose en plaques et son traitement) en octobre 2011.

À propos de l’étude CONFIRM
L’étude CONFIRM (COmparator and aN oral Fumarate In Relapsing-remitting MS) était une étude mondiale, randomisée, à double insu, contrôlée par placebo et à comparaison de doses visant à déterminer l’efficacité et l’innocuité du fumarate de diméthyle et regroupait 1430 personnes atteintes d’une SEP rémittente. L’étude a évalué deux schémas posologiques pour le fumarate de diméthyle, soit 240 mg BID et 240 mg TID, ainsi que l’acétate de glatiramère (AG) comme agent de référence (injection sous-cutanée quotidienne de 20 mg). Les groupes sous fumarate de diméthyle et sous AG ont été évalués par rapport à un groupe sous placebo. Le principal objectif consistait à déterminer si le BG-12 était efficace pour réduire la fréquence des poussées cliniques au bout de deux ans. Les critères d’évaluation secondaires comprenaient la réduction du nombre de nouvelles lésions ou de lésions nouvellement croisant à hypersignal en T2 et du nombre de nouvelles lésions à hyposignal en T1 non rehaussantes (IRM obtenues dans une cohorte de sites); de la proportion de patients ayant rechuté; et de la progression de l’incapacité telle que mesurée à l’échelle étendue d’incapacité de Kurtzke (EDSS). L’innocuité et la tolérabilité du BG-12 ont également été évaluées. Les résultats détaillés de l’étude CONFIRM ont été présentés lors de la 64e réunion annuelle de l’American Academy of Neurology (AAN) tenue en avril 2012.

À propos du fumarate de diméthyle
Le fumarate de diméthyle, aussi appelé BG-12, est un traitement oral expérimental à un stade avancé de développement clinique pour le traitement de la sclérose en plaques rémittente ou cyclique, la forme la plus courante de SEP. Autant qu’on le sache, le fumarate de diméthyle est le seul composé d’essai pour le traitement de la SEP rémittente à avoir démontré une activation de la voie Nrf-2 dans un contexte expérimental.

En 2011 et 2012, Biogen Idec a annoncé les résultats favorables des études DEFINE et CONFIRM, deux études cliniques de phase 3 mondiales contrôlées par placebo qui ont évalué le fumarate de diméthyle administré à raison de 240 mg deux ou trois fois par jour sur une période de deux ans. Le dossier du fumarate de diméthyle est actuellement à l’étude au sein des organismes de réglementation aux États-Unis, dans les pays de l’Union européenne, en Australie, au Canada et en Suisse.

À propos de Biogen Idec

Exonération
Le présent communiqué de presse renferme des énoncés prospectifs, notamment au sujet de la commercialisation du BG-12 (fumarate de diméthyle) pour le traitement de la SEP. On retrouve dans ces énoncés l’emploi de verbes au futur ou au conditionnel ou d’expressions telles que « le dossier est à l’étude », « en vue de », « le potentiel ». Il ne faut pas trop se fier à ces énoncés, car les risques et incertitudes qui y s’rapportent pourraient donner lieu à des résultats sensiblement différents, notamment en ce qui concerne l’obtention de l’homologation, la survenue d’effets indésirables, la concurrence, l’accès au remboursement dans les diverses provinces ou régions ou par les régimes d’assurance, la nature du marché et les conditions économiques, les problèmes de fabrication possibles et l’obligation de recourir aux services de tiers, la non-adhésion à des réglementations gouvernementaux et l’impact défavorable possible de la modification de ces règlements, la capacité de protéger nos droits de propriété intellectuelle et les coûts qui y sont associés, et les autres risques et incertitudes décrits dans la section « Facteurs de risque » du dernier rapport annuel ou trimestriel transmis par Biogen Idec à la Securities and Exchange Commission (Commission des valeurs mobilières des États-Unis). Tout énoncé prospectif dans les présentes représente les perceptions et attentes de Biogen Idec au moment de la diffusion du présent communiqué de presse. L’entreprise se dégage de toute obligation de mettre à jour publiquement les énoncés prospectifs, quels qu’ils soient.

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Specialist nursing training in Poland: Applications for neuroscience nursing

By Robert Ślusarz, RN, PhD, Sandra Ireland, RN, PhD, and Theresa Green, RN, PhD

Abstract

Background: Nurses have a pivotal role in providing, facilitating, advocating and promoting the best possible care and outcome for the client. To ensure decisions and actions are based on current standards of practice, nurses must be accountable for participation in ongoing education in their area of practice.

Aim: To present a description of the current state of Polish nursing education and specialized model for neurological and neurosurgical nursing that can be utilized for both undergraduate and postgraduate continuing education in Poland.

Data sources: The model of postgraduate training introduced in Poland in 2000 was taken into consideration in developing the framework for neuroscience nursing postgraduate continuing education presented here. The framework for neurological continuing education is also based on a review of the literature and is consistent with Poland's legally binding professional nursing regulations (normative and implementing regulations).

Conclusion: The model demonstrates the need for the content of pre- and post-undergraduate degree education in neurological nursing to be graduated, based on the frameworks for undergraduate education (acquiring the knowledge and basic skills for performing the work of nurses) and postgraduate education (acquiring knowledge and specialist skills necessary for providing advanced nursing care including medical acts on patients with nervous system diseases).

Implications for nursing: New and advanced skills gained in specialization training can be applied to complex functions, roles and professional tasks undertaken by nurses in relation to care of patients with neurological dysfunctions.

Key words: professional improvement, specialist, neurology and neurosurgery nursing

Introduction

The July 2011 Professions of Nurses and Midwives Act passed by the Polish Parliament states that nurses and midwives are obligated to routinely update their professional knowledge to maintain licensure. The Act also guarantees their right to postgraduate education. This law, combined with the availability of multiple post-graduate courses (e.g., obstetrics, mental health), allows nurses and midwives to enhance their professional practice by expanding their skill levels in specialty areas (e.g., obstetrics, mental health) to ensure competence. Continuing competence is the ongoing ability of a nurse to integrate and apply the knowledge, skills, judgment and personal attributes required to practise safely and ethically in a designated role and setting (Canadian Nurses Association, 2004). Maintaining and improving knowledge and skills in specialized practice contributes to the quality of patient outcomes and to the evidence base for nursing practice (Melnyk & Fineout-Overholt, 2011).
Nursing education in Poland

Consistent with international historical trends, transformation of nursing education in Poland has progressed from high school training courses for nursing assistants (1950s) to programs combining nursing education at the secondary school level in the form of two to two-and-a-half year programs after nine years of general education and identification as nurses (1960s), to undergraduate university degree programs instituted in the 1970s (Sztembis, 2006). Today in Poland, undergraduate education of nurses can also be accomplished as part of what is termed a “higher education system” (mainly a system of combined vocational and university education). To become a nurse, every candidate has to complete an educational program in either a higher vocational school* or a university.

*A higher vocational school is described as an institution that offers licentiate studies. In Poland, these were five-year secondary school nursing programs (1960s) or 2.5-year post-secondary nursing schools (1970s–1980s) or three-year university Bachelor’s programs (1990s).

Degree programs

Both higher vocational school and university programs offer nursing programs. Examples of university-based nursing programs include the Nursing and Health Sciences Faculty Medical University of Lublin, the Department of Health Sciences Collegium Medicum of Nicolas Copernicus University in Bydgoszcz, and the Medical University of Wroclaw. Generally, at the majority of universities in Poland, studies to specialize in nursing are divided into two degrees: a first degree (undergraduate licentiate studies; Bachelor’s Degree) and a second degree (Master’s Degree). After completing the first degree (BN, which is given after successfully passing theoretical and practical exams) the candidates are registered by an appropriate nursing association (e.g., District Association of Nurses and Midwives in Bydgoszcz) and deemed competent to practise.

At present in Poland this registration is valid all over the country. Once a BN is achieved, nurses are eligible to undertake Master’s degree studies. Doctoral (PhD) nursing degree programs are offered at only a few universities, none of which provide a degree specific to nursing. In addition to these postgraduate academic degrees, another option to expand nurses’ knowledge and skills is termed “specialization” training. In Poland there are two “Learned Societies” related to neurological nursing. These include a Nursing Section of Polish Neurosurgeons (established in 2002) and a Polish Society of Neurological Nurses (established in 2010). Efforts are being made to join these two societies into a single Polish Society of Neuroscience Nursing. This would be

![Figure 1: Compatibility of the pre- and post-degree teaching](image-url)
the leading nursing association in Poland with its principal task being regulation of qualifications and competence of neurological and neurosurgical nurses. While specialized training in the area of neuroscience nursing does exist in Poland, there is a gap in the knowledge base to support evidence-based practices in this specialty.

The aim of this publication is to present the current state of undergraduate and postgraduate "specialist nursing education" in Poland. Based on existing literature and author experience, a continuing education model is proposed for specialized neurological nursing. The model is consistent with legally binding regulations (normative and implementing regulations) concerning the nursing profession in Poland, specialist literature related to continuing education, and the model of postgraduate training introduced in Poland in 2000.

**Postgraduate education and regulatory requirements**

The postgraduate education system is regulated by the government in Poland. Undergraduate-level nursing training, often referred to as basic training, is a prerequisite to broadly define post graduate/continuing education (Wojnowska-Dawiskiba, 1999; 2001a; 2001b; Wojnowska-Dawiskiba et al., 2004; Wrońska et. al., 2001; Ślusarz, & Wojnowska-Dawiskiba, 2003; Opracowanie zbiorowe CKPPiP, 2000; Blak-Kaleta, 2001; Tułodziecka, 2001).

In 1998, the Centre for Post-basic Continuing Education of Nurses and Midwives (CPBCEDN) was created as a new unit in the Polish national Ministry of Health and Social Welfare infrastructure (Ordinance of the Health Minister of 29 October, 2003). The CPBCEDN is accountable for coordinating the work of organizing, operationalizing, and monitoring the quality of nurses’ and midwives’ continuing education and specialization programs. As well, regulations concerning nursing postgraduate education were addressed in several legislative acts passed between 2003–2007: a) on nursing and midwifery vocation (Ordinance of 15 July, 2011 on nursing and midwifery vocation); b) on postgraduate education for nurses and midwives (Ordinance of the Health Minister of 29 October, 2003 on postgraduate education for nurses and midwives—Journal of Law No. 197, item 1923); c) specifications of nursing domains and domains that have application in health protection in which a specialization and qualifying courses for nurses and midwives can be carried out (Journal of Law No. 197, item 1922); and d) the range and types of preventative, diagnostic, medical and rehabilitation services rendered by nurses independently (without a physician’s order), and on the range and type of services independently rendered by midwives (Ordinance of the Health Minister of 7 November, 2007).

Postgraduate education is specifically addressed in the regulation on nursing and midwife professions (Ordinance of 5 July, 1996 on nursing and midwifery vocation 1996, Act.10b. p.1). This ordinance states that nurses have the right to vocational improvement in different kinds of postgraduate education and they are obliged to constantly update their knowledge and vocational skills. Also specified in the regulation (Ordinance of 5 July, 1996, on nursing and midwifery vocation 1996), types of postgraduate education (including specialization; Art. 10c. p.1) coincide with the requirements specified in the Ordinance of the Health Minister of 7 November, 2007, on (a) the range and types of preventive, diagnostic, medical and rehabilitation services rendered by nurse independently, without the doctor’s order, and (b) the range and types of such services rendered by midwife independently (Ordinance of the Health Minister, 2007) where the rendering of certain services is conditioned by the particular kind of postgraduate training.

Post-basic specialist nursing education has developed under these regulations and legislation based on a “modular” type of professional education in which nurses are taught specific skills based on nursing specialization competency requirements. For example, family practice nurses and midwives (first groups to attain specialization status) are taught skills to improve or maintain their competencies and qualifications as community health nurses (Sztembis, 2006). At present, the new post-basic programs developed in 1998 to 2000 provide many nurses and midwives with improved skills through the completion of 1) two-year specialization training programs, 2) training courses, 3) specialization courses, and 4) upgrading courses (Sztembis, 2006) and receive either a certificate or diploma.

**Nursing specialization**

The Ordinance of the Health Minister (2003) specifies basic nursing domains in which a specialization can be carried out. The ordinance also outlines programs for the specialization of nurses and midwives including required courses and the specialization credentials obtained. Based on this ordinance, 22 nursing specialties and qualifying courses for nurses and midwives in Poland have been approved. These range from primary care and occupational health nursing to anesthesiology and intensive care nursing (see Appendix 1 for complete list). Among them is a specialization in neurological nursing ($1.1. of the Regulation). In creating a new postgraduate education system for nurses in neurology nursing, programs must be compatible with the existing undergraduate basic education programs and current regulations and legislation (Figure 1).

In accordance with program requirements (Ordinance of the Minister of Science and Higher Education, 2007) undergraduate students undertaking specialization classes for neurology and neurological nursing take 75 hours of theoretical classes, 80 hours of practical classes and 80 hours of vocational practice. Taking into account the number of classes for this subject (the total of 235 didactic hours), neurology and neurological nursing is classified as sixth among the core subjects (applies to undergraduate degree studies) after 1) nursing basics (485 hours), 2) pediatrics and pediatric nursing (410 hours), 3) basic medical care (395 hours), 4) general nursing (370 hours) and 5) surgery and surgical nursing (370 hours). Regulations require that the format of postgraduate education for specialization include both a theoretical component (210 hours) and an internship (490 clinical practice hours).

Postgraduate education in neurological nursing provides opportunities for nurses to improve their qualifications in different ways depending on the requirements of their practice or interest. Options include enrolment in second degree studies (i.e., a Master’s degree in nursing) or various post-basic (post-BN) certificate courses in neurology nursing.
Neurological nursing

Neurological nursing is currently one of the 22 approved specialty fields of nursing in Poland in which major changes in education and training are being made through post-basic education. At present in Poland, only 51 nurses possess neurological nursing specialization credentials (a register and list of specialists is kept in a Center of Postgraduate Education of Nurses and Midwives in Warsaw). Speciality training in neurological nursing at both undergraduate and postgraduate levels has potential to prepare nursing teams to perform a variety of expanded and advanced nursing practice roles (i.e., expert nurse, clinical specialist, decision-maker, educator, leader, manager). The additional training and education also provides neurological nurses with the advanced knowledge and skills needed to assume broader organizational roles in health promotion education and leadership.

Pre- and post-degree training in neurological nursing

When a nurse graduates from basic degree studies, including the non-university undergraduate stream, (first degree) and has at least two years’ practice experience, they can enter specialty neurological nursing training. Alternatively, they can complete the second degree (Master’s degree), practise for two years and then enter the specialty program. Although differences in the depth and length of study required to achieve specialty credentials previously described differ, the current curricula for neurology and neurological nursing at both post-basic (undergraduate) degree and postgraduate (Master’s) study levels include the following topics:

- etiopathogenesis of neurological disorders
- diagnostic methods used in neurology
- basic life functions disorders—circulation, respiration and mental confusion; their influence on the nervous system
- feeling, movement and muscle tension disorders
- congenital and acquired defects of the nervous system
- vascular diseases of the brain
- brain and spinal cord injuries
- demyelinating neurological disorders
- brain tumours
- muscle and peripheral nervous system diseases
- nursing patients who suffer from nervous system diseases.

Through completion of the above-mentioned curricula, students acquire theory and skills necessary for practising the profession of a nurse and become ready to independently perform the vocational role determined by these nursing functions. After completing the specialty training, the functions performed by the post-basic and Master’s level entry nurses are the same.

A graduate’s (Master’s degree nurse) acquired skills and qualifications result from program content within the scope of neurological nursing for first degree studies and include:

- understanding the etiopathogenesis of neurological disorders
- preparation of neurological patients for diagnostic tests
- care of patients undergoing tests
- assessment of patients’ basic life functions disorders
- application of scales used for assessment of patients’ consciousness level
- care of patients with dysesthesia, dyspraxia and muscle tension disorders
- care of patients with central nervous system disorders
- care of patients with nervous system trauma.

The above-mentioned skills and qualifications are compatible with standards of teaching and professional qualifications framework for nurses in Poland. Certainly, after obtaining specialization (described below), a different range (broader) of skills and qualifications of the candidate are acquired.

Title of specialist

In accordance with the established vocational nomenclature, current specialization training (Art. 66 and 67, Ordinance of 15 July, 2011 on nursing and midwifery vocation, 2011), has been defined as a type of postgraduate training. The purpose of this training is to provide a nurse or midwife with specialist qualifications (as previously described) in a particular nursing domain or in a domain that has application in health protection, and to provide a specialist title in this field.

The specialization training in neurological nursing is realized on the basis of the education program framework, which includes contents and skills put in two blocks:

- General vocational block, which is the same for all specializations in terms of realization time (i.e. 330 hours) and the scope of realized contents
- Specialist block, the purpose of which is to prepare the nurse to provide professional care to patients with nervous system diseases (700 hours: 210 theory hours and 490 practice hours).

In neurological nursing education six modules (see Table 1) are distinguished (Ordinance of Health Minister, 2003; enclosure 17 to the Ordinance). Each of the modules has its own objective, specification of skills (both theoretical and practical) and curriculum.

The objective of module I: acquainting the nurse with pathophysiology, diagnostic of the nervous system diseases, as well as the specifics of nursing and medical care to patients with neurological diseases.

The objective of module II: preparing the nurse to provide professional medical care to people with nervous system diseases under conservative treatment.

The objective of module III: preparing the nurse to provide professional medical care to people with nervous system diseases under surgical treatment.

The objective of module IV: preparing the nurse to provide medical care to children with central nervous system injuries and diseases, as well as to the families of the children in question.

The objective of module V: preparing the nurse to provide medical care to people after brain or spinal cord injuries.

The objective of module VI: preparing the nurse to provide professional care to people with mental disorders and diseases.

Pursuing professionalism in neurological nursing education should also take into account the training hours that are realized through other types of postgraduate education. Worth
mentioning, within the specialist courses and additional training, are other skills incorporated into the specialization such as: 1) urinary bladder training, 2) cardio-pulmonary resuscitation, 3) obtaining and interpreting EKG printouts, 4) wound treatment, and 5) enteral and parenteral nutrition (Ordinance of Health Minister, 2003; Ordinance of the Health Minister, 2007).

Professional training in neurological nursing is concluded by achieving the specialist title. The nurse who has completed the course curriculum (Table I) for specialization in neurological nursing takes an external state exam, which is carried out by an institution that has been appointed by the Minister of Health (e.g., Center of Postgraduate Education of Nurses and Midwives in Warsaw). After the nurses successfully pass the exam and acquire specialist skills confirmed by professional qualifications of a specialist in this domain, they receive a specialist diploma (Ordinance of the Health Minister of 29 October, 2003; Ślusarz et al., 2003).

Conclusion
It can be said that with pre- and post-degree education for nurses in neurological nursing in Poland, training is gradual and builds on prior knowledge and skills. The framework of undergraduate education (acquiring the knowledge and basic skills for basic nursing) and postgraduate education (acquiring knowledge and specialist skills necessary for providing advanced professional nursing care to patients with nervous system diseases) has become more comprehensive. In Poland, the model of professional development within the scope of neurological and neurosurgical nursing (mainly postgraduate training) will require significant changes in validation of nursing practice, licensure and introduction of legal acts pertaining to scope of practice, which are now being discussed.

Implications for nursing
Currently, nurses who receive specialty training after achieving their first or second degree are treated as equally well-educated specialists who can perform the same professional tasks. Many graduate nurses and nursing educators believe there should be consecutive stages in nursing education (pre, graduate and postgraduate training) in order to achieve professional competencies and advanced specialization. Continuity of professional improvement should be

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1 In the basic medical care: family nurse vocational training: 35 hours, social worker practice: 35 hours
2 Craniocerebral injuries ward or neurosurgery ward in which craniocerebral injuries are treated
3 Spinal injuries ward or trauma ward in which spinal injuries are treated
maintained to educate specialists in neurological and neurosurgical nursing. New specialist skills gained in advanced training programs can be applied to functions, roles and professional tasks related to care of patients with neurological dysfunctions.

Offering such an education system may help to produce highly specialized neurological nurses. In accordance with their specialist knowledge and skills, these nurses can individually contract their nursing services (making a range of entitlements broader). Finally, there is an opportunity to appoint a specialist learned society that will gather specialists in neurological nursing who will have a definitive say in establishing regulations concerning their profession.

References


Ordinance of the Health Minister of 29 October, 2003 on specification of nursing domains and domains that have application in health protection, in which a specialization and qualifying courses for nurses and midwives can be carried out. (Journal of Law No. 197, item 1922).

Ordinance of the Health Minister of 29 October, 2003 on postgraduate education for nurses and midwives (Journal of Law No. 197, item 1923).

Ordinance of the Health Minister of 7 November, 2007 on range and types of preventive, diagnostic, medical and rehabilitation services rendered by nurse independently, without doctor’s order, and on range and types of such services rendered by midwife independently (Journal of Law No. 210, item 1540).

Ordinance of the Ministry of Science and Higher Education of 12 July, 2007 on specification of education standards for the particular fields of study and education levels (Journal of Law No. 1164, item 1166), enclosure no. 80. Teaching standards for the field—nursing.


Appendix 1: List of nursing specialties (Ordinance of Health Minister, of 29 October, 2003, on specification of nursing domains and domains that have application in health protection, in which a specialization and qualifying courses for nurses and midwives can be carried out)

Nurses can specialize in 22 nursing specialties:
1. family nursing
2. occupational health nursing
3. teaching/school environment nursing
4. preventive nursing
5. geriatric nursing
6. cardiac nursing
7. nephrology nursing
8. diabetes nursing
9. pediatric nursing
10. surgical nursing
11. operating room nursing
12. anesthesiology and ICU nursing
13. oncology nursing
14. psychiatric nursing
15. long-term care nursing
16. neurological nursing
17. palliative care nursing
18. emergency care nursing
19. health promotion and health education
20. neonatal nursing
21. epidemiology nursing
22. management in health care institutions

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CNS tuberculosis: A review and illustration from an autopsy case

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Abstract

An estimated one-third of the world's population (2 billion people) is infected with the tubercle bacilli (TB), which is estimated to cause 6% of all deaths worldwide. Despite there being a decline in the incidence of tuberculosis seen in Europe, there are still some countries in the rest of the world where the estimated number of new cases is very high. When a person presents with persistent fever with or without neurological symptoms, the diagnosis of TB cannot be excluded. We present a case report of a 26-year-old male patient, who died of CNS tuberculosis. Such case studies will help keep neuroscience nurses alert to potential medical issues in multiethnic patient populations.

Introduction

Central nervous system (CNS) involvement is one of the most devastating clinical manifestations of tuberculosis (TB). It is noted in 5% to 10% of extra-pulmonary TB cases and accounts for approximately 1% of all TB cases (Cherian & Thomas, 2011). Definitive diagnosis of tuberculous meninitis (TBM) depends upon the detection of the tubercle bacilli in the CSF. Preferably, every patient with TBM should be evaluated by imaging with contrast-enhanced CT either before or within the first 48 hours of treatment. Similarly, an extra neural focus of tuberculosis should be sought clinically and radiologically in all patients with CNS TBM, as it may indicate safer and more accessible sites for diagnostic samplings. Tuberculosis continues to be an important cause of death worldwide, with 6% of all deaths attributed to TB. A reasonable worldwide estimation of the magnitude of TB is that 33% of the population is infected with TB (Mandalakas & Starke, 2005). The laboratory diagnosis of TBM is dependent upon an acid-fast bacillus (AFB) smear, with results generally obtained within 24 hours (Singh & Kashyap, 2012).

There are currently 30 million cases of active TB in the world, 10 million new cases annually and 3 million people dying of TB each year (Bang, 2005). Between 1990 and 1999 in the United States, a total of 7,686 deaths were attributed to respiratory TB in people (e.g., health care workers) who potentially had contact with infected cases (Bang, Weissman, Wood & Attfield, 2005). In the year 2000, an estimated 8.3 million new cases of TB occurred worldwide, of which 884,019 (10.7%) were children. Of this total, 659,379 (75%) cases occurred in 22 high-burden countries, most of which were found in resource-poor Asia and Africa (Mandalakas & Starke, 2005).

In the United States, 6% of the population is infected with tuberculosis bacilli and, in 2001, the number of TB cases was reported as 15,591 (Cesur, 2004). In Europe, the influx of immigrants and the emergence of resistant strains of TB, especially among drug addicts and AIDS patients, have created the potential for a surge in TB incidence. However, there are still countries in the rest of the world, such as Zambia and Zimbabwe, where the estimated number of new cases are as high as 290 to 300 per 100,000 people per year (Cesur, 2004). In many regions of Africa, one-third or more of the population is infected with TB and incidence rates of newly diagnosed TB are more than 300 cases per 100,000 subjects (Cesur, 2004). The global epidemiologic pattern of TB has also changed, as a result of the epidemic of AIDS and the development and spread of multiple drug-resistant TB strains.

Case report

A 26-year-old male refugee from Nigeria was brought to the neurologic emergency department with a recent history of headache, fever, neck pain fatigue, disorientation, impaired memory, strange behaviour and severe weight loss. His roommates brought him to the hospital and reported the patient had been experiencing symptoms for the last month, but had no knowledge of his past medical history. The mean duration of symptoms prior to admission, reported in the literature in pediatric patients suffering from CNS tuberculosis is 22 days (range five days to three months) (Titone et al., 2004).

Initially he was treated for purulent meningitis of unknown etiology. Later, his clinical course and laboratory findings, although in agreement with the results, suggested meningeval tuberculosis and treatment was changed accordingly. The patient responded well to treatment, but developed cholestasis (slowing of the flow of bile). This condition has been observed in patients with tuberculosis resulting from enlarged nodules in the lymph nodes, which compress the common bile duct in the retro pancreatic region, mimicking pancreatic cancer or drug-induced cholestasis (Obama, Kanai, Taki, Nakamoto, &
It was decided to transfer the patient to a hospital that specialized in the treatment of tuberculosis. He died four days after his transfer.

**Autopsy findings**

The pathologist report stated: “The body was that of a 26-year-old black male. The inspection of the body revealed no external trauma. Multiple needle punctures were found on both arms. Examination of the brain revealed thick and slightly yellow exudates in the subarachnoid space.” The exudates were likely made up of small and large mononuclear cells, including epithelia cells, which also act as macrophages and may fuse to form Langhan’s giant cells located mainly on the superior surface of the cerebellum and the right temporal lobe extending to the optical lobe and the right fissure of Sylvius (Lammie, Hewlett, Schoeman, & Donald, 2009). The exudates followed the course of the blood vessels, encasing them completely. Dissection of the brain revealed no other findings. The lungs showed no pathologic findings except a small degree of pulmonary edema, while the liver was intensely yellow. No other pathological findings were evident on gross examination of the body.

**Histopathological findings**

At the region of the occipital lobe and the cerebellum tubercules were found (Figure 1). They were located inside the gray matter near the brain surface with no involvement of the meninges (Figure 2). These were granulomas comprising epithelioid cells, lymphocytes and macrophages surrounding the core of caseous necrosis (Figure 3). Blood vessels around the tuberculoma showed vasculitis with thickened walls of inflammatory infiltrates. Tubercle bacilli were also observed in the cerebral tuberculomas by Ziehl Neelsen staining.*

Ziehl Neelsen staining is a staining procedure that specifically stains all myobacteria

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**Table 1: Classification of CNS tuberculosis**

<table>
<thead>
<tr>
<th>INTRACRANIAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuberculous meningitis</td>
</tr>
<tr>
<td>Tuberculous encephalopathy</td>
</tr>
<tr>
<td>Tuberculous vasculopathy</td>
</tr>
<tr>
<td>CNS tuberculoma (single or multiple)</td>
</tr>
<tr>
<td>Tuberculotic brain abscess</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>SPINAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pott’s spine and Pott’s paraplegia</td>
</tr>
<tr>
<td>Non-osseous spinal tuberculoma</td>
</tr>
<tr>
<td>Spinal meningitis</td>
</tr>
</tbody>
</table>

**Table 2: Classification of extra pulmonary TB severity**

<table>
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<th>Less severe</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Lymph node</td>
</tr>
<tr>
<td>Miliary</td>
<td>Peripheral joint</td>
</tr>
<tr>
<td>Pericarditis</td>
<td>Skin</td>
</tr>
<tr>
<td>Peritonitis</td>
<td>Unilateral pleural effusion</td>
</tr>
<tr>
<td>Bilateral or extensive pleural</td>
<td>Bone (excluding spine)</td>
</tr>
<tr>
<td>effusion</td>
<td></td>
</tr>
<tr>
<td>Spinal</td>
<td></td>
</tr>
<tr>
<td>Intestinal</td>
<td></td>
</tr>
<tr>
<td>Genito-urinar</td>
<td></td>
</tr>
</tbody>
</table>


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**Discussion**

The WHO estimates that eight to 10 million new cases of TB occur all over the world each year (WHO, 2012). China has 1.4 million new cases of TB every year, more than any country except India (367 cases per 100,000 population) (China Tuberculosis Control Collaboration, 2004). Generally, incidence varies from 9 cases per 100,000 people per year in the U.S. to 290 cases per 100,000 people per year in developing countries. Tuberculosis has always been a major problem in developing countries as compared to Western countries due to the spread of human immunodeficiency virus (HIV), epidemic poverty, homelessness and immigration from Asia and Pacific islands (Titone et al., 2004) (Table 1).

Extra pulmonary TB (EPT) is meant to include all forms of the disease other than pulmonary. Tuberculous lymphadenitis (36.5%) seems to be the most common clinical presentation of EPT. According to the 2011 WHO report (http://www.who.int/TB/), 47.2% of patients develop a severe form of EPT and 52.8% of patients develop the less-severe form (Table 2). A case history of pulmonary tuberculosis was found to be a risk factor for the development of EPT (Cagatay et al., 2004).

Interestingly, few patients have combined pulmonary sequestration with TB. Pulmonary sequestration is a congenital anomaly in which a portion of the pulmonary tissue is detached from the normal lung and is supplied by anomalous systemic arteries and occurs in 50% of patients with TB. Most patients suffering with sequestration become symptomatic after the second decade of life, although 15% of patients with this anomaly experience no symptoms (Huang et al., 2012). However, confusion arises when the terms respiratory and non-respiratory are used interchangeably with pulmonary and extra pulmonary. These
terms are not synonymous. Respiratory system disease is usually considered to include pulmonary miliary (small nodules or lesions resembling millet seed), pleural, primary laryngeal, and other respiratory disease (Public Health Agency of Canada, 2010), whereas pulmonary disease usually refers to just those cases that involve the lungs and conducting airways. However, the terms respiratory and non-respiratory are more practical, as they distinguish between all forms of the disease that are potentially communicable and those that are almost never communicable. In Canada, approximately 75% of cases are respiratory and 25% non-respiratory.

CNS TB, which is difficult to diagnose (misdiagnosis rate was 49.6% from 1952 to 1994), accounts for approximately 15% of extra pulmonary cases or about 0.7% of all clinical TB cases in the U.S. (Fan et al., 2007). Tuberculous meningitis represents 5% of extra pulmonary cases in the U.S., with the risk for tuberculosis increased six times for foreign-born persons (Carmichael, Thompson, Buttolph, & Hooke, 2003, pp. 266–9). CNS TB includes TB meningitis and brain tuberculoma. Meningitis with or without tuberculoma occurs in approximately 75% of patients; tuberculoma alone in 25%. Intracranial tuberculoma is typically located in the parenchyma (Hsu, Lin & Chang, 2004).

Tuberculous meningitis is frequently associated with devastating consequences: 25% morbidity (i.e., permanent neurologic deficit) and 25% mortality. It is believed that the initial lesion is a tubercle in the superficial cortex that ruptures into the subarachnoid space. Brain damage results from the effects of the granulomatous basal exudates, which causes raised intracranial pressure (attributable to obstructive hydrocephalus) and basal ganglia and brainstem infarction secondary to periarteritis of the blood vessels supplying these structures. Although tuberculous meningitis is well described, prominent encephalitic features are less commonly reported. Illness and death associated with neurotuberculosis are highly dependent on the stage of disease at diagnosis; early diagnosis and treatment correlates with better outcomes.

Although the TB cases reported here represent only a small percentage of chronic eosinophilic pneumonia (CEP) cases (<1%), CNS TB with an encephalitic picture warrants further discussion because of high morbidity and mortality rates and need for early diagnosis and appropriate treatment (Christie et al., 2008). Our case was a seronegative (HIV1 and HIV2) examined with both Elisa and western blot techniques. The brain MRI demonstrated extensive pathological and marked enhancement of the pia arachnoids, most notable at the region of basal ganglia, the tentorium and the fissure of Silvius. At the right thalamus and the right side tectum a pathological area of abnormal intensity was noticed. In conjunction with these diagnostic imaging markers, laboratory findings, especially the low glucose levels of the CSF, suggested the diagnosis of CNS TB. A unique laboratory finding suggesting immunosuppression was the CD4/CD8 (T cells) ratio of 286/313, likely due to his malnourished state. The CSF analysis showed: leucocytes 100/mm³, polymophonuclears: 65%, erythrocytes: 50/mm³, and protein 180 mg/dl glucose 20 mg/dl. Interestingly, the polymerase chain reaction (PCR) technique was performed twice on the cerebrospinal fluid (CSF), as the detection of TBM strain was negative. Conversely, the PCR method performed on the brain tissue samples was positive. Efforts to determine the genotype of the strain were negative. Coupled with the rapid evolution of this clinical course, hepatotoxicity caused by the anti-TB drugs, especially rifampicin, unfortunately, proved to be fatal. The individual had arrived from Greece only one to one-and-a-half months prior and we hypothesize that he transported the TBM across Europe from the area of origin (Nigeria), or contracted it in one of the countries he crossed.

Apriority, we have to underline one more important symptom of CNS tuberculosis: the brain abscess. Brain abscess formation is a rare manifestation of CNS tuberculosis. Tuberculous brain abscesses develop either from parenchymal tubercular granulomas or via the spread of tuberculous foci from the meninges. It is characterized by an encapsulated collection of pus containing viable bacilli without evidence of the classic tubercular granuloma and is distinguished from granuloma (a small mass of granulation tissue caused by chronic infection) with central cœstion (degeneration of dead brain tissue) and liquefaction mimicking pus. It must be emphasized that when a person presents with persistent fever, with or without neurological symptoms, the diagnosis of TB cannot be excluded, especially if this person is an immigrant or is related to immigrants from Asia or Africa. The possibility of non-respiratory TB always remains as a potentially life-threatening condition. Overcoming the considerable challenges that are inherent in diagnosing, treating, and managing CNS tuberculosis will require an equal measure of ingenuity and resourcefulness to improve outcomes.

Nursing implications for care

Every day nurses are caring for multicultural/multiethnic patient populations in the health care facilities where they work. As in Greece, where there are an increasing number of illegal immigrants whose health status is, therefore, not checked prior to entrance into the country, nurses may more frequently be facing cases like the one introduced here. It is essential, then, for nurses to be not only alert to patient symptoms, but also well educated for diseases that may be unrecognized in the clinical setting as requiring serious attention. As part of the multidisciplinary team in health care settings, nurses can play a crucial role in the differential diagnosis of diseases that could save patients lives.

Unfortunately, it is very difficult to create or maintain nurses dedicated solely to TB due to relatively low incidence and limited resources for the specific disease. For example, in Barcelona, the TB program had, from its inception in 1987, public health nurses (PHN) who provided follow-up to TB patients, but who were also in charge of other communicable diseases (Cayla & Orcar, 2011). Thus, the nursing profession was (and remains) immersed in offering quality care in public health and contributions to quality of life of the community.

More specifically with regard to TB, however, nurses play a crucial role in control programs (Duran, 1998) with patient outcomes and accountability of nursing practice (Pringle &
aware of current incidence and prevalence rates of TB, identify the risk factors for TB and be able to identify people at risk of TB, alert to signs and symptoms of this disease, treat patient symptoms appropriately, and attend to the well-being of patients living with CNS TB. Early diagnosis is important to help prevent further deterioration in patient status, deliver appropriate treatment, and realize a better prognosis. Given that CNS TB may present in many different ways, nurses need to be alert to the common signs of CNS TB such as headache, stiff neck, fever, weight loss, blurry vision, confusion, lethargy, nausea, vomiting, and/or spinal cord symptoms (Harris & Morris, 2007). It is also inherent, as part of good nursing practice, that nurses be alert to signs and symptoms of meningitis (e.g., altered mental status, fever, seizure and cranial nerve deficits) (Harris & Morris, 2007). As CNS TB may result from infectious organisms such as HIV, the nurse must also be sensitive to the psychosocial implications inherent in the underlying causative organism, as well as the physical manifestations of CNS TB.

References


Patients’ perceptions of their roles in goal setting in a spinal cord injury regional rehabilitation program

By Harriett Draistra, RN, MSnC, CNN(C), CRnRn, Mina D. Singh, RN, PhD, Sandra Ireland, RN, PhD, and Theresa Harper, RN, BSN, MSn

Abstract
Goal setting is a common practice in rehabilitation, yet there is a paucity of literature exploring patients’ perceptions of their roles in this process. This study was conducted using a qualitative descriptive methodology to explore patients’ perceptions of their roles in setting goals in a spinal cord injury regional rehabilitation program. Imogene King’s theory of goal attainment was used to frame the study. Data were collected through interviews and analyzed using a content analysis. The results revealed four themes: Visioning, Redefining, Brainstorming, and Rebuilding. Participants (n = 13) envisioned their roles as setting an overarching priority goal, defining detailed rehabilitation goals, sharing knowledge with the team, and rebuilding skills to attain goals. Implications for nursing practice include the need to understand patients’ experiences and perceptions, share knowledge, and support effective communication to promote collaborative goal setting. A need to enhance health professionals’ education to fully understand factors influencing patients’ abilities to set rehabilitation goals, and future research in methods to promote patients’ engagement in goal setting was also clearly indicated.

Introduction
Spinal cord injury (SCI) is life altering, resulting in varying degrees of paralysis for the individuals involved. The incidence of SCI in Canada is approximately 4,529 cases yearly, with 1,786 of those resulting from traumatic external injuries (Rick Hansen Institute, 2011). Most traumatic SCI injuries occur due to motor vehicle accidents, sports injuries, or falls, while other causes include compression of the spinal cord related to metastatic lesions, abscesses and various degenerative changes (Rick Hansen Institute, 2011). Rehabilitation following such a catastrophic injury is necessary to allow individuals to return to community living in as full a capacity as possible.

Literature review
A literature review was conducted to understand a) current directions from government health bodies regarding expected standards for the provision of care, b) current practice of rehabilitation teams, c) the psychological impact of spinal cord injury for patients, and d) patient perspectives of goal setting in rehabilitation.

Current directions from government health bodies
Government directions reviewed focused on the importance of involving patients as integral partners with their health care teams. Health outcomes are improved with increased levels of health literacy, treatment decision-making, and self-management of chronic disease (Coulter, Parsons, & Askham, 2008; Health Canada, 2007; HealthforceOntario, 2007; Ontario Ministry of Health Promotion and Sport, 2010). It is thus imperative for health care professionals to understand and recognize SCI and other patients’ roles in order to promote collaborative care and decision making.

Current practice in rehabilitation
In rehabilitation, the focus on decision-making and collaboration with the health care team has resulted in the promotion of active patient participation in setting and enacting their personal goals. Current literature has suggested wide support for this inclusive approach to the process of rehabilitation (Holliday, Antoun, & Playford, 2005; Hurn, Kneebone, & Cropley, 2006; Khan, Pallant, & Turner-Stokes, 2008). Care is provided by members of an interprofessional team who work individually with the patient and meet as a team in conferences with the patient to discuss the progress of rehabilitation goals (Pellatt, 2004; Sinclair, Lingard, & Mohabeer, 2009; Struhkamp, 2004).

La perception par les patients de leur rôle lors de la définition d’objectifs dans le cadre d’un programme de rééducation régional pour les patients atteints d’une lésion de la moelle épinière

Résumé
La définition d’objectifs est une pratique de rééducation commune. Toutefois, il n’existe que peu de documentation traitant de la perception par les patients de leur rôle dans ce processus. Cette étude a été menée à l’aide d’une méthodologie descriptive et qualitative et vise à explorer la perception par les patients de leur rôle lors de la définition d’objectifs dans le cadre d’un programme de rééducation régional pour les patients atteints de lésions de la moelle épinière. La théorie d’Imogene King sur la réalisation d’objectifs constitue la base de l’étude. Nous avons collecté des données obtenues lors d’entrevues, puis en avons analysé le contenu. Les résultats ont révélé quatre thèmes: visionner, redéfinir, réfléchir, puis reconstruire. Les participants (n=13) croient que leur rôle est d’établir un objectif prioritaire qui englobe les autres composantes, de définir des objectifs de rééducation détaillés, de partager leurs connaissances avec l’équipe, et de reconstruire leurs habiletés afin d’atteindre les objectifs. En ce qui concerne la pratique infirmière, cela implique de comprendre les expériences et les perceptions du patient, de partager ses connaissances, et de communiquer efficacement afin de promouvoir une définition collaborative des objectifs. Cette étude a aussi clairement indiqué le besoin d’améliorer la formation des professionnels de la santé afin de parfaitement comprendre les facteurs qui influencent les habiletés des patients à définir des objectifs de rééducation. Elle a également laissé paraître le besoin de recherches dans les méthodes de promotion de l’engagement du patient dans la définition d’objectifs.
Barriers to patient participation
While rehabilitation facilities promote goal setting as a collaborative practice involving the patient, as a partner with the team, actual practice often differs (Bloom et al., 2006; Holliday et al., 2005; Young, Mannathan, & Ward, 2008). An imbalance of power between patients and health providers often makes autonomous decision-making difficult, as patients transfer to rehabilitation and prepare for re-entry to the community (Bloom et al., 2006; Donnelly et al., 2004; Pellatt, 2004; Wagner et al., 2001). Emotional and physiological factors that affect patients during the period of inpatient rehabilitation may also impact on their ability to engage fully in a collaborative rehabilitation process (Belcug, 2001; Holliday, Cano, Freeman, & Playford, 2007; Lohne & Severinsson, 2005; Struikamp, 2004; Sullivan, 2001).

Seeking program efficiency
Efficiency of care is measured by the achievement of changes in patient functional independence within the shortest possible length of stay. This outcome measure is one component used by the National Rehabilitation Reporting System (NRS) for comparison of rehabilitation facilities in Canada (Canadian Institute of Health Information [CIHI], 2009). The focus on efficiency may affect the patient's involvement in goal setting, as health care professionals struggle to balance the provision of health expertise in a timely fashion, while encouraging patients to take an active participatory role in their rehabilitation.

Patient's perspective on goal setting
The review of literature identified limited information about the patients' perception of goal setting. Two journal articles described research of patients' perceptions of goal setting. Both research studies were conducted in the United Kingdom and involved a sample group with mixed neurological etiologies. Young et al. (2008) explored perceptions of goal setting from inpatients, discharged patients, lay caregivers and staff (n=40). They concluded that goal setting provided psychological benefit to both the patients and their caregivers. Holliday, Ballinger, and Playford (2007) used focus groups to conduct a study of patients' perspectives of goal setting. Six focus groups were conducted, with three focus groups attended by patients who used the facility's current standard of goal setting, and three attended by participants who had been involved in an approach that encouraged increased involvement on the part of the patient (n=28 participants). The researchers suggested there was significant importance attached to the "key worker" (p. 393) involved in assisting the patient with goal setting. They concluded there is a necessity for health professionals to explore patients' understanding of their experiences and expectations of goal setting to ensure that it is a meaningful activity. These two studies suggest limited evidence that goal setting is of benefit to patients and their caregivers provided the process is clearly communicated, and health professionals are aware of the patients' understandings and expectations of goal setting.

Nursing theoretical framework
Imogene King’s theory of goal attainment guided this research and provided a conceptual framework of “dynamic interacting systems” (King 1997, p. 180): personal, interpersonal and social. These systems represent the individual, dyad or larger group, and social organizations, all of which interact and are impacted by their environment. King’s theory explains the interpersonal system as the interaction between the nurse and patient that takes place during mutual goal setting (King 1981). When the nurse and patient share an understanding of the events and agree on mutually valued goals and the means of achieving those goals, a transaction results. King (1981) defined transaction as “a process of interaction in which human beings communicate with the environment to achieve goals that are valued” (p. 82), and stated that successful transactions result in goal attainment. King qualified perceptions of individuals as that which gives "meaning to a person's experiences and represents an individual's image of the real world" (King 1971, p. 87).

Research question
What are the patients' perceptions of their roles in goal setting within a SCI inpatient rehabilitation program?

Setting
The research setting was a regional rehabilitation facility offering inpatient and outpatient rehabilitation and associated with a tertiary care, academic teaching hospital.

Methodology
Study design
Qualitative descriptive was chosen as the research methodology as it allowed for a straightforward description of the phenomenon under focus (Sandelowski, 2000). The phenomenon explored was the SCI participants’ perceptions of their roles in setting and enacting goals as members of the rehabilitation team. Qualitative descriptive methodology allowed for validation of the participants’ perceptions of the interactive process occurring between the patient and rehabilitation team.

Recruitment and sampling
Following ethics approval participants were recruited in a face-to-face process. Purposive sampling using maximum variation, the sampling method suggested by Sandelowski (2000), was utilized. Eligible participants were patients admitted to the rehabilitation program following discharge from acute care who were > 16 years and had sustained either a traumatic or non-traumatic SCI within the last six months that was expected to result in a permanent disability.

Patients who were expected to be discharged from inpatient rehabilitation within a period of four weeks were excluded. Based on clinical experience, four weeks was determined to be the minimum amount of time required for an SCI patient to experience substantive interaction in a goal setting process with the health care team. The presence of language barriers and/or co-morbid neurological injuries resulting in significant cognitive impairments was also exclusion criteria.

Data collection
Data were collected through audio-recorded, semi-structured interviews conducted by the researcher with individual participants during their rehabilitation stay and before discharge. Demographics, including SCI level, etiology, age, gender, marital status, and last level of completed education, were collected to provide a description of the variations among the participants. Interview questions focused on the participant's perception of 1)
how they identified their goals, 2) how they visualized their role within the team, and 3) what promoted or inhibited their participation, as members of the team, in setting and enacting their rehabilitation goals. Following the completion of the interview, participants were asked if they would agree to be contacted at a later date should the researcher have further questions.

Data analysis

Data were transcribed and reviewed by the researcher for accuracy. Field notes were reviewed to note any observations not captured by the transcripts. Data collection and analysis were conducted simultaneously, and themes emerging from each new interview compared with those from preceding interviews, as suggested by Sandelowski (2000). Content analysis, using an inductive approach, was the method used for data analysis. Coding was completed in a process described by Elo and Kyngäs (2008) and Hseih and Shannon (2005) using NVIVO 8, a computer software program (QSR International, 2007). The codes were grouped under two sets of headings: 1) time of occurrence, and 2) association with the focus areas of the interview questions. Categories emerging from the two sets of headings were compared and merged or deleted to produce a final set of subcategories. Further levels of abstraction generated final themes that reflected the participants’ perceptions of their roles in setting and enacting their personal rehabilitation goals.

Results

Description of participants

The participants in the study included 13 patients who had sustained an SCI through a trauma, disease process, or degenerative condition. The sample included both participants with tetraplegia and those with paraplegia. Including participants with a wide variety of injury and etiology provided maximum variation of the various sequelae seen in SCI. Table 1 provides demographic and injury etiology of participants.

<table>
<thead>
<tr>
<th>Identifiers (removed)</th>
<th>Level of impairment</th>
<th>Etiology</th>
<th>Age category</th>
<th>Gender</th>
<th>Marital status</th>
<th>Level of education</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Disease process</td>
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<tr>
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Ensuring trustworthiness

Trustworthiness was established through credibility, dependability, confirmability, transferability and authenticity (Guba & Lincoln, 1994; Lincoln & Guba, 1985). Credibility and confirmability were met by the involvement of two members of the SCI peer community, and reducing the likelihood of personal bias by maintaining field notes. Seven participants agreed to second interviews for further clarification of collected data after they were discharged. These “repeated interviews” (Thorne, Kirkham, & MacDonald-Emes, 1997, p. 175) added credibility to the results, as their perspectives of the experiences did not appear to have changed between interviews.

Using maximum variation as the sample procedure allowed the concepts of dependability and transferability to be addressed. The use of maximum variation assured representation of a wide range of SCI etiologies and different levels of injury that are typical of this aggregate. Audio taping of interviews, verbatim transcription, and the inclusion of exceptions and “outliers” also addressed these criteria. Using participants’ quotes and the description of the context of the rehabilitation setting to which these quotes pertained addressed the provision for authenticity.

Emerging themes

Data analysis identified themes of the experiences of SCI participants in goal setting as Visioning, Refining, Brainstorming and Rebuilding. These themes can be seen as interconnecting facets of the participants’ perceptions of their roles in setting and enacting rehabilitation goals. Figure 1 is provided to allow a visualization of the themes and their relationship to the participants’ interactions with the rehabilitation health care team.

Visioning

Visioning occurred as participants identified their overall goals for rehabilitation prior to admission. These goals were articulated as those associated with regaining independence or self-sufficiency and were often described using words related to physical acts such as walking or transferring from one surface to another.
Important factors that were either helpful or created barriers to the fulfillment of the participants’ roles in this area were identified. Helpful factors included their ability to 1) set a priority goal for rehabilitation, and 2) have a level of hope. Barriers included 1) the degree of impact of the injury on function, 2) feelings of loss of control, and 3) lack of knowledge about rehabilitation. The priority goal of regaining a level of independence or self-sufficiency that was acceptable to them was the foundational step on which participants built their goal setting roles.

Hope for regaining independence was an important consideration influencing participants’ engagement in rehabilitation. One participant expressed this in terms of embracing the idea of rehabilitation with enthusiasm, stating, “because I thought that I was able to be … self-sufficient … I embraced the idea of coming here very, very enthusiastically” (P01).

Loss of control experienced through the injury and by processes within the hospital system was expressed by the participants. Lack of knowledge was seen as a barrier for some participants, while in one participant’s experience it was evident that having knowledge of what to expect in rehabilitation prior to admission was of benefit. He expressed his readiness for the requirements of rehabilitation and stated, “I was expecting a physically demanding regimen and was determined to work with it” (P07).

Redefining

Participants redefined what was needed to achieve an acceptable level of independence and self-sufficiency in greater levels of detail through collaborative goal setting with health care professionals upon their admission to rehabilitation. In redefining, helpful factors included 1) the ability to have input in setting goals, 2) the ability to prioritize goals, and 3) achieving a sense of accomplishment. Barriers were seen when they perceived 1) a lack of knowledge about personal prognosis, 2) discomfort in goal setting, and 3) a reality check created by goal setting. Participants acknowledged their ability to have input in setting their goals, but often articulated that their lack of knowledge or discomfort with goal setting prevented them from engaging in the task. Several identified the need to receive assistance in setting detailed goals. A participant used the term “crystallized” (P06) to describe the assistance given, stating, “I came up with three (goals) at least on my own and … (a staff member) sort of crystallized my thoughts, because I couldn’t put them into words per se” (P06).

Redefining needed adjustments to their lives gave an unwelcome reality check for some participants and created an emotional reaction to goal setting. One participant articulated this discomfort in stating:

> When you think about it, you’re scared (starts to cry). Thinking that I’m not going to be able to drive again is a killer. Because I love to drive. I can’t even imagine not driving. Well, when you break it down with all your goals, you just…it’s just more of a reality check to what’s happened (P10).

Hope to regain an acceptable level of independence or physical function was experienced in varying levels by study participants. Similarly, setbacks experienced in rehabilitation progress affected participants in different ways. One participant modified his hope by looking beyond rehabilitation for other means of achieving his goal, while another sought comfort from the team to help her handle the stress from her lack of progress. In both cases, the choice made to retain hope resulted in some action that brought comfort to the individuals.

Brainstorming

Brainstorming captured the theme of sharing knowledge with the entire rehabilitation team in patient conferences, as described by participants. Factors that promoted brainstorming included 1) the ability to share and to receive knowledge, and 2) a sense of familiarity with the team. Barriers were identified as 1) discomfort in the conference, 2) lack of resulting action, and 3) lack of communication. The patient conference was seen as helpful if the individual participant was able to feel that his or her concerns were heard and acted on. This concept was shared by a participant who said, “Well, they all listened to me. They all had their say in what I said. They kind of built off of it, too” (P07).

If participants felt no action resulted, or information was withheld, they saw this part of their roles as devalued and felt there was little purpose in meeting with the team to discuss and modify their goals. One participant identified this, stating:

> When I go to these meetings, of course I see people that are there. Everybody seems to be concerned. I appreciate that (long pause). The problem still remains. See, I was part of the team in terms of participating to the discussion, yeah. Sure. (long pause) Where is the action; basically where is the piff, you know? (P01).

Rebuilding

The theme of rebuilding could be identified in the descriptions of the participants, as they spoke of working on goal attainment through day-to-day therapy. Factors that promoted rebuilding

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**Figure 1: Themes relationship.** The figure illustrates the relationship of visioning with the themes of redefining, brainstorming, and rebuilding. The themes were interconnected. Redefining, brainstorming, and rebuilding are built upon the foundational theme of visioning. Redefining expanded on the overarching priority goal identified in visioning to set defined incremental steps to achieve mutually identified goals. Brainstorming and rebuilding are continued in cyclic interactions and transactions. Dashed arrows represent the interactions and resulting transactions that occurred between participants and health professionals in either individual or group venues in the rehabilitation interpersonal system (King, 1981). The arrows are dashed to represent the fluid nature of the interactive process.
were identified as 1) personal determination, 2) support from the team, and 3) the concept of community. Barriers identified included 1) lack of personal resources, 2) lack of timely communication, and 3) a sense of vulnerability. The role of rebuilding skills was seen primarily by participants as one of personal determination, supported by individual members of the rehabilitation team. Lack of personal resources and accessible housing was stressful for those who did not have this support and created an added barrier to role achievement. One participant articulated this struggle in rebuilding in saying:

Apart from the physical end... again, trying to build up strength, etc., but apart from that, it's the how to do or how to accomplish various things that, you know, need to be done, but I can't do anymore. And then, as I say, on top of all that is to find a place to live and worrying about money (teary) (P06).

Some participants identified a lack of communication as a barrier to engagement in their roles. One participant articulated this, stating: “Times I felt like I was drifting you know... I knew I was here and part of the program, but I was drifting, you know” (P09). A sense of vulnerability related to lack of understanding of the hospital protocols or created by actions of individuals in the health care team raised barriers for some participants’ roles in goal setting. Conversely, interactions and support from fellow patients and the health care team were identified as helpful. As one participant noted, “It’s been my family for eight weeks. That is what it is, it’s your family and I will miss everyone” (P13).

Discussion

King (1981) identified the personal, interpersonal and social interacting systems in health care and suggested that systems influence each other dynamically within the environment. The influence of each of these systems was evident, as participants spoke about their roles in rehabilitation goal setting.

Visioning

King (1981) suggested basic concepts required to understand the personal system, the human individual. These concepts include understanding of body image, growth and development, perception, self, space and time. It was evident that the traumatic event of sustaining a spinal cord injury can have a significant effect on all elements of the personal system. The impact of injury and loss of control described by the participants support the reviewed evidence (Sullivan, 2001). Participants clearly detailed personal experiences of losing physical function and expressed the confusion, shock and emotion involved with these losses. They identified loss of control either through their experiences in the intensive care unit (ICU), or in being moved from one hospital to another. During the acute care phase of health care for SCI, patients are typically asked to identify their goals for rehabilitation. However, the devastating impact of the injury, both physically and emotionally, may result in difficulty absorbing the consequences of the injury and, as a consequence, patients may struggle to identify and direct personal rehabilitation goals (Holliday, Cano, Freeman, & Playford, 2007; Strubkamp, 2004).

The influence of the interacting personal and social systems described by King (1981) was also evident. Literature reviewed provided an explanation for the difficulties experienced by participants early in the recovery experience in the ICU. Research exploring patients’ experiences in ICU revealed that loss of sleep, noise, and medications may all contribute to a psychological impact on the patient (Carr, 2007; Elliott, McKinley, & Cistulli, 2011; Hewitt, 2002). Patients who experienced trauma were found to have a sense of detachment, unreality, and difficulty with memory while in ICU (Carr, 2007; Hewitt, 2002). In addition, patients often continued to experience “cognitive impairment, depression, anxiety, and post-traumatic stress disorder” following their discharge from the ICU (Carr, 2007, p. 95).

Moves between the regional trauma centre and local hospitals are often due to health system issues. Consideration of efficiency, as an outcome measure monitored by the NRS, dictates that patients are generally not admitted to rehabilitation until ready to participate, as this would impact the program’s length-of-stay efficiency. The psychological impact of relocation between hospitals, as the participants waited for rehabilitation, and conditions causing consequences for individuals admitted to ICU are examples of the interconnection of personal system and the (health care) social system (King, 1981).

Lack of knowledge about the rehabilitation program was a barrier to the achievement of participants’ perceived roles in goal setting. Many participants in the study identified that they had limited knowledge of what to expect in the program at the study site. Holliday, Ballinger and Playford (2007) suggested that an understanding of rehabilitation is necessary for patients to engage in active goal setting. However, despite a reported limited knowledge of rehabilitation, most participants entered the program with varying degrees of enthusiasm and hope for regaining their goals of achieving an acceptable level of independence.

Hope has been identified as an important consideration for recovery in SCI (Dorsett, 2010; Lohne & Severinsson, 2005; Lohne, 2008). Personal meaning of a situation appears to be strongly attached to levels of hope for individuals. Lohne and Severinsson (2005) suggested that patients who had suffered an SCI perceived themselves as caught in a “vicious circle” (p. 287) of dependency, waiting and loss leading to suffering. In their study, hope was seen by participants as a choice to step out of this suffering and to look for options to move them forward within a difficult situation. Hope was also evident as a benefit in the current study. Regardless of whether goals were achieved during the inpatient rehabilitation phase of care or not, hope could be seen as bringing meaning to the situation and, as such, enhancing the participants’ roles of visioning.

Redefining

The interconnection of personal and interpersonal systems was seen in the theme of redefining, as participants described the experience of defining specific rehabilitation goals upon admission to rehabilitation. King (1981) described self, a component of the personal system, as a person’s conception of all that they are “capable of being and doing” (p. 28). Setting detailed steps to achieve rehabilitation goals could be interpreted as a redefining of personal strengths, abilities and needs and, as such, of self. Many participants spoke of the difficulty of setting goals and communicated their reliance on health professionals to assist in setting goals. Evidence that goal setting tended to be done by health professionals rather than by patients (Bloom et al., 2006; Holliday et al., 2005; Young et al., 2008) was supported in this study.
While the process of collaborative goal setting with health professionals was clearly of benefit to the participants’ role enactment, it is important to recognize that there might be incongruence between the goals of the health professional and the goals of the patient (King 1981). Health professionals must be aware that they bring their own meanings, based on personal perceptions, judgment, and convictions about required actions, to interactions with patients (King, 1981). Acknowledging these, while supporting the patient’s right to autonomy, will lead to more effective communication and will promote the role of the patient in mutual goal setting. The success of a transaction that leads to goal attainment and patient satisfaction relies on supportive interaction between personal and interpersonal systems (King, 1981).

Lack of knowledge about personal prognosis and fear of failure were seen as barriers to goal setting. Similar barriers to goal setting in rehabilitation were reported by Holliday, Ballinger and Playford (2007), and Young et al. (2008). They found that participants had difficulty setting goals because they did not know what could be achieved or because of past disappointments with progress. Young et al. (2008) stated that participants in their study tended to be passive in the process of goal setting, as a result of “lack of expertise in rehabilitation or prognosis” (p. 192). Understanding that lack of knowledge may have an impact on the individual’s ability to set goals is an important consideration for health professionals.

Several participants identified personal discomfort with the goal setting process. In understanding the difficulty in setting defined goals and breaking these goals into incremental steps, the concepts of body image, self, and growth and development identified by King (1981) must be considered. In SCI, functional tasks that were achieved in infancy, toddler, and preschool development stages, such as gross and fine motor control and control of bowel and bladder, are often lost. Body image is changed (Yoshida, Self, Renwick, Forma, King, & Fell, 2009; Bassett, Martin Ginis, & Buchholz, 2009). Identifying goals that provide alternative means to regularly evacuate the bowel and bladder and simple tasks such as feeding themselves may necessitate a redefining of self, and have detrimental impact on the individuals’ body images. Avoidance of addressing these goals may be related to a hope that these alternative methods would not be required.

The sense of self was evident in the personal pleasures described by participants as having been taken for granted before their SCI: driving, involvement in community, and sports activities. When participants defined these activities as future goals, it brought the realization of their loss into sharp focus and caused distress. The distress caused by articulating these activities may have been a factor in considering their roles in goal setting. In a study conducted with patients in SCI rehabilitation, Belciug (2001) found SCI patients used the “Cognitive Avoidance” and “Emotional Discharge” (p. 158), categories of coping identified by Moos in the Coping Responses Inventory-Adult assessment tool to assist in coping with their emotions. Responses indicated a tendency for patients with SCI to avoid thinking about the injury or to react to stress with anger. However, prioritizing goals may have provided an opportunity for some participants to regain a sense of self, as they identified priorities they saw as important for their emotional well-being and that of their loved ones. Yoshida (1993) suggested that the “reshaping of self” (p. 217) includes various aspects of life, including vocation and social interaction with family and others. This process was stated as dynamic, resulting in fluctuating perceptions of self, as individuals “interpret and take action” (p. 241) in a situation.

**Brainstorming**

Participants articulated their interpersonal roles in bi-weekly patient conferences as one of sharing knowledge, stating the team sought input about their progress in meeting their rehabilitation goals. When participants felt they were not heard or agreed-upon actions did not take place, the experience was perceived negatively. King (1981) stated that the “concept of role requires individuals to communicate with one another and to interact in purposeful ways to achieve goals” (p. 91). If interaction with the team did not result in action, both the goal setting role of the participant and that of the health professional was devalued. This judgment may have resulted in decreased potential for successful transactions and goal attainment.

Many participants identified personal discomfort with the first patient conference they attended. It was apparent that some participants did not understand what was expected of them at this first conference. Several participants articulated that their expectations of the patient conference were not congruent with the actual experience. Past experience, culture, personal beliefs and values determine perceptions individuals bring to interactions (King, 1981). Participants articulated increased comfort in the conferences, as they grew more familiar with the team and the routine. It could also be suggested that by the second and subsequent conferences, participants came to better understand their interpersonal roles and those of the health professionals. Therefore, placing a priority on building social interaction through increasing familiarity between the SCI patient and the team could promote the patient’s role in brainstorming and result in a successful goal setting transaction.

**Rebuilding**

Rebuilding can be clearly correlated to steps in the transaction process in King's theory of goal attainment. King (1981) theorized that if interaction between the health professional and patient is successful, mutual goals will be set, and transactions will occur. Transactions are seen in observed behaviours, as “human beings communicate with the environment to achieve goals that are valued” (King, 1981, p. 82). King suggested that transactions are valued “because the goal is meaningful and worth achieving” (p. 82). It was clear rebuilding skills was a highly valued goal for the participants. They described interactions with team members in addressing their goals, stating they were pushed to achieve by these individuals, and also pushed themselves.

Participants also described positive social interactions with other patients. Yoshida et al. (2009) stated that the importance of peers should not be undervalued. The authors suggested that communication with peers offered an opportunity for learning that may have been overlooked by health professionals. This may be an important factor in understanding the complexity of interactions in the inpatient rehabilitation environment. SCI patients’ roles in setting and attaining goals may be enhanced by encouraging greater interaction and involvement with peers.

Participants identified the importance of clear communication with their rehabilitation health care team. Reviewed evidence
indicated that good communication empowered patients and improved outcomes (Holmström & Röing, 2010; Trummer, Mueller, Nowak, Stidl, & Pelikan, 2006). King (1981) stressed the importance of communication as the “vehicle by which human relationships are developed and maintained” (p. 79). She noted that communication is complex and the meaning of the message sent may be different for those sending and those receiving it. As such, seeking to promote the patients’ roles in setting and attaining goals, as active members of the team, requires careful attention to timely and effective communication.

While some participants spoke of the importance of personal support in assisting the return to community living, others were not as fortunate. Those who identified a lack of personal or community resources described this as an additional stressor to their roles of rebuilding. The impact of financial concerns and finding appropriate housing in the community appeared to eclipse the ability to focus on their rehabilitation in some instances. This situation resulted in stress both for the individual and on their ability to fully utilize knowledge offered by members of their rehabilitation team, and demonstrated the impact of the social system on both the interpersonal and personal systems described by King (1981).

Summary of key themes

Four themes were identified in the participants’ perceptions of their roles in setting and enacting their personal rehabilitation goals: visioning, redefining, brainstorming and rebuilding. Each theme reflected a facet of the participants’ roles. Participants were able to clearly identify their roles of engaging in rehabilitation, sharing knowledge, and rebuilding skills for community reintegration. Factors that impacted on the participants’ roles involved interactions with both the rehabilitation team and the health care system. Effective interactions led to transactions, goal attainment and satisfaction. When interactions were not effective, transactions did not successfully occur and the roles of the participants were negatively impacted. The findings of this study support evidence of the importance of effective interactions to promote successful transactions and goal attainment, as suggested by King (1981) in her theory of goal attainment. They also confirm the individual’s basic need for health care information (King, 1971), and the importance of effective communication. The impact of personal, interpersonal and social systems was evidenced in the findings of the study, and confirms the need for health care professionals to be aware of all levels of the interconnecting systems.

Implications for nursing practice

Implications for nursing practice, resulting from this study, focus on the need to generate effective interactions for the purpose of promoting patients’ roles in goal setting. Important considerations include the need to understand the patient’s past experiences and perceptions, the importance of sharing knowledge, and the need to support effective communication. Enhanced interprofessional education will generate greater understanding of the complexity of promoting patient engagement in the role of setting personal rehabilitation goals.

Understanding meaning for patients

Evidence in the study suggested that some patients might perceive goal setting to be a difficult task for a variety of reasons. Understanding the meaning patients ascribe to their present reality will prepare health professionals for supportive collaboration in this process.

Exploring patients’ perceptions and judgment of their current situations promotes effective communication and allows mutual exploration of options for goal attainment. Emotional support for the patient in the early phase of SCI care requires the intervention of a health professional with expertise in addressing psychological issues. The devastating impact of the injury and the resulting physical and emotional consequences of such an injury may result in difficulty identifying and directing personal rehabilitation goals (Belciug, 2001; Holliday, Cano, Freeman, & Playford, 2007; Struhkamp, 2004). In addition, the acute care experience of ICU may also have psychological consequences for the patient (Carr, 2007; Hewitt, 2002). A continuum of supportive interventions offered by trained professionals, as patients transition from the acute care setting to rehabilitation, would be of great benefit in preparing them for engagement in rehabilitation.

Sharing knowledge

The study offered an indication that knowledge regarding the rehabilitation process prior to admission was of benefit in promoting SCI patients’ roles in goal setting. Personal tours of the rehabilitation facility for patients soon to be admitted to the inpatient program, and the use of multimedia educational tools are opportunities for preparing patients for admission to rehabilitation. The continued use of the Canadian Paraplegic Association (CPA) peer support program to facilitate early connections between SCI patients in the acute care setting and peer support volunteers is another opportunity for knowledge sharing, allowing patients to receive information from a peer who has experienced similar situations (CPA, 2011).

Familiarity with the team was seen as reducing stress. Communication of the rehabilitation routine and role expectations in a timely fashion may relieve anxiety and promote the roles of patients in setting and attaining goals. Education to address concerns that may be troubling to patients in the environment, such as methods to address infection control issues while allowing full participation in rehabilitation, will provide necessary knowledge and decrease patients’ anxiety. Addressing environmental issues that cause distress for patients assures them of nurses’ respect and concern for them.

The concept of the rehabilitation community became apparent in the descriptions given by some participants. The value of peers was seen as enhancing the environment by creating an atmosphere of camaraderie and support. Capitalizing on the benefit of informal education that peers offer is an opportunity for increased engagement in the program. Interactions with CPA peer support volunteers will allow patients an opportunity to speak about challenges of community reintegration with those who have successfully met those challenges, offering hope and building confidence. It may also be an opportunity to promote peer connections for emotional support both during and after rehabilitation (CPA, 2011).

Supporting effective communication

Results of the study identified that detailed goal setting is a difficult and, at times, an emotional process for many SCI patients. The use of a decision-making tool outlining the goal setting process may
provide an opportunity for patients to digest the meaning of the situation and the process required to regain a level of function that will be acceptable to them. Patient education material suggesting potential rehabilitation goals should be offered prior to admission, allowing the patient opportunity to prepare for goal setting.

One area that was identified as a barrier to the patients’ roles in goal setting was the first attended and, at times, subsequent patient conferences. Providing information about conferences, identifying the roles that health professionals and the patient are expected to take, and providing dates when the patient is scheduled to attend well in advance, may reduce the associated discomfort. It may be suggested that the first conference with the team be delayed to allow the patient to become familiar with the rehabilitation routine and steps should be taken to reduce the number of staff attending the conference to only those who are necessary. Support from an accompanying CPA peer or family member may also reduce stress.

Patients must perceive interactions in mutual goal setting as having been followed through by the team to bring about agreed-upon transactions (King, 1981). It is noted that if patients believe their priority goals are not being addressed, they may not be successful in their roles of sharing knowledge and rebuilding skills. It is also imperative to realize that if patients perceive their input as not valued, they may become disengaged and feel disempowered in the rehabilitation process (Holmström & Röing, 2010).

Enhancing interprofessional education
Enhancing the health professional’s understanding of factors that affect patients’ emotional ability to engage fully in goal setting and developing skills to promote their roles will require ongoing interprofessional education. Knowledge of coping mechanisms commonly seen in SCI patients is important for all those who are caring for them. Building skills in patient education and the promotion of patient engagement in self-management is also essential for excellent rehabilitation care. Nurses, as vital members of the rehabilitation team, should take leadership roles in promoting this education for all those involved in patient care.

Limitations of the study
There are a number of limitations in this study. The research was completed on only one rehabilitation site in one city. This reduces the potential for transferability of the findings, as other rehabilitation facilities may have alternative practices that affect goal setting. The familiarity of the team with the participants’ life stories and the connection of the researcher with the facility required extreme diligence to protect the privacy of participants. This reduced the ability to provide individualized detail of the participants, which may have enhanced ability for those reviewing these findings to judge their transferability to other populations. Age groups were not as well represented as could be hoped. Only two participants were under the age of 25 while nine were over the age of 55. Marital status was included in the demographics to allow an understanding of the spousal/partner support available to the individuals. However, this did not adequately reflect other personal resources such as parents and family members. Despite limitations, this study revealed concepts that allowed a clear picture of the participants’ perceptions of their roles in setting and enacting rehabilitation goals.

Suggestions for future research
Future research to explore the possible connection between increased knowledge of SCI rehabilitation at specific time points prior to admission and the promotion of successful goal setting would be of benefit. Research to expand on the understanding of the possible connection between the process of goal setting and the perception of self would also be of interest. The participants’ observations about the emotional and difficult task of defining specific goals and its connection to the realization of their situation offer some foundational insight into this phenomenon. Further research has potential to enhance that knowledge.

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References


1. The Canadian Journal of Neuroscience Nursing (CJNN) is a peer-reviewed journal.


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   - Maximum length is 6,000 words or 20 pages
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   - Title page with full title, name, and institutional affiliation
   - Abstract of fewer than 200 words
   - Left justified, paragraphs indented 5 spaces
   - Headings typically include: Introduction; Review of the literature (conceptual and data based); Research question/Objectives/Hypotheses/Clinical concern; Methodology and method; Analysis/Findings; Discussion including specific Clinical implications/recommendations; Summary/Conclusions; and References. (Please note, not all of these headings are needed or may apply to all papers).
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   - Longueur maximale du manuscrit : 6 000 mots ou 20 pages.
   - Marges de 1 pouce, double interligne, « Times New Roman », 12 lettres au pouce
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   - Les entêtes peuvent inclure : introduction, revue de la littérature, (concept et données), but de la recherche, objectifs, hypothèses, aspect clinique, méthodologie et méthodes, analyses et résultats, discussions avec implications d'ordre clinique, recommandations, résumé et conclusion, références. Veuillez prendre note que toutes ces entêtes ne s'appliquent pas nécessairement à tous les manuscrits présentés au comité.
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Websites of interest

Canadian Association of Neuroscience Nurses and Canadian Journal of Neuroscience Nursing website: www.cann.ca
Check this site often for updates on information. Reports will be on the website.

Canadian Nurses Association: www.cna-nurses.com

Canadian Congress of Neurological Society: www.ccns.org
Please check out the web page to learn more about the society to which we belong. CANN is an affiliate of this society.

Canadian Journal of Neurological Sciences: www.CJNS.org

World Federation of Neuroscience Nurses: www.WFNN.org
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