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**Congratulations to
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FROM THE EDITOR

End of life issues and the disabled

As I sit at my desk at the Canadian Medical Association, the media requests seem to be multiplying, as if by asexual reproduction. The Terri Schiavo case will be decided in the next few hours or days, one way or the other (or so it now appears). Canadian media outlets like the CBC, Globe and Mail and the National Post all seem to want to know the same thing – are these decisions being made in Canada? Could the Schiavo case happen here? What are the implications for the disabled population?

For those of you who have been living in a cave (or, perhaps preferably, traveling to exotic lands) for the past few weeks, Terri Schiavo is a young woman living in Florida who has been in a vegetative state for the past 15 years, kept alive via feeding tube, since an anoxic brain injury in 1990. Her husband says she told him she would not want to be kept alive in such a state, but her parents disagree. They say that her religion (she was raised Catholic) prohibits the withdrawal of care intended to prolong life. The courts have been heavily involved, and now the US Congress has waded in. President Bush came back to Washington and stayed up until 1 am to sign a bill into effect allowing a federal court to review the case (I often stayed up until 3 or 4 am changing diapers not so long ago with no fanfare, and am not so impressed by George W.'s ability to remain awake after midnight). As I write this, Terri's feeding tube is out, and her parents are appealing the court's decision to allow its removal for the third time.

How does all this affect us as physiatrists? One of Terri's parents' lawyers was quoted



Jeff Blackmer, MD, MHS
(Bioethics), FRCPC

today in the media as saying “This is a terrible blow against the disabled”. Is it? I’m not so sure. Being disabled, as we all know, does not equate with being unable to speak for oneself. Far from it. Many, if not most, of the patients we treat are quite capable of making their own decisions. They do not require others to speak for them or protect their rights. But this is sometimes lost in the rhetoric, where angst-ridden “disability advocates” proclaim that each new court decision could make it “open season on the disabled”, as if we might start selling hunting licenses at any point. Foolishness.

All this obscures the main point – that patients’ wishes could be made known even when they are not competent if they engaged in a discussion with their loved ones as to what they might want done in such a situation, or even better, if they completed a living will. This is not a disability-specific issue, but it risks being hijacked as one by those who may mean well but often have another agenda.

As physiatrists, we are important advocates for our patients, and I respectfully suggest that we spend our time advocating for those things that will have a greater impact on the everyday lives of our patients – more affordable accessible housing, better legislative protection for the rights of the disabled, improved tax rebates, and better access to community resources such as home care. For every one Terri Schiavo grabbing headlines, hundreds or thousands of disabled persons are living below the poverty line or are not having their care needs met in the community. If we really want to speak up about “a terrible blow to the disabled”, let’s start with those things first.

LE MOT DE LA RÉDACTION

Jeff Blackmer, médecin,
MHSc (bioéthique), FRCPC

L'invalidé et la cessation de la vie humaine

Assis à mon bureau à l'Association médicale canadienne, je croule sous l'avalanche de demandes d'entrevue des médias. Dans quelques heures, ou quelques jours, l'affaire Terri Schiavo connaîtra son dénouement. Les médias canadiens, qu'il s'agisse de CBC, du *Globe and Mail* ou du *National Post*, veulent tous savoir la même chose – de telles décisions sont-elle prises au Canada? Un cas semblable pourrait-il se produire ici? Quelles en sont les répercussions du point de vue des personnes invalides?

Ceux d'entre vous qui ont choisi de vivre en ermite (ou de voyager en des lieux exotiques) dans les dernières semaines ne savent probablement pas que Terri Schiavo est une jeune femme de la Floride qui a survécu à un traumatisme cérébral anoxique survenu en 1990, quoique dans un état végétatif depuis lors, et qui est maintenue en vie grâce à un tube d'alimentation. Son mari affirme qu'elle lui a déjà dit qu'elle ne voudrait pas vivre dans un tel état, mais les parents de Terri sont d'avis contraire. Pour eux, la religion de leur fille (catholique) interdit l'arrêt des soins qui prolongent la vie. Les tribunaux sont intervenus à de multiples reprises depuis l'accident, et voilà que le Congrès des États-Unis s'en mêle. Le président Bush est revenu à Washington pour promulguer, à une heure du matin, une loi autorisant une cour fédérale à se pencher sur la question (j'ai bien souvent changé des couches à trois ou quatre heures du matin il n'y a pas si longtemps sans en faire tout un plat, alors le prétendu geste d'éclat de George W. n'a rien d'impressionnant). Au moment où j'écris ces lignes, le tube qui alimentait Terri a été débranché et ses parents ont interjeté appel de la décision du tribunal autorisant le débranchement du tube pour la troisième fois.

En quoi nous, les physiatres, sommes-nous concernés par cette affaire? L'un des avocats des

parents de Terri aurait dit aujourd'hui aux médias : « Quel recul pour les invalides! » Vraiment? Je n'en suis pas sûr. Être invalide ne veut pas dire, comme nous le savons si bien, être incapable de s'exprimer à son sujet. Loin de là. De nombreux patients, voire la plupart, que nous traitons sont tout à fait aptes à prendre des décisions les concernant. Il n'y a pas lieu que d'autres parlent en leur nom ou protègent leurs droits. Cela ne transparait pas toujours dans cette bataille de principes où des « défenseurs des invalides » rongés par l'aigreur déclarent, toutes les fois que le tribunal rend une décision à ce sujet, que les « invalides seront désormais offerts en pâture à la population », comme si nous déclarions ouverte la chasse aux invalides. Quelle absurdité!

Ce faux débat relègue dans l'ombre un fait capital – à savoir que les patients peuvent exprimer leur volonté même s'ils ne sont pas aptes, s'ils abordent avec leurs proches le sujet de ce qu'ils voudraient en pareille situation, ou mieux encore, en rédigeant un testament biologique. Cette question ne s'applique pas qu'aux invalides, mais elle risque d'y être cantonnée par des personnes qui, sous couvert de bonnes intentions, poursuivent d'autres objectifs.

Comme physiatres, nous nous devons de défendre les droits et intérêts de nos patients, et, sans vouloir minimiser l'importance de cette affaire, je suggère que nous nous employions à défendre les causes susceptibles d'améliorer beaucoup plus la vie de nos patients – le logement social abordable, l'amélioration de la protection législative des droits des invalides, l'accroissement de l'abattement d'impôt en cas d'invalidité et de l'accès aux ressources communautaires comme les soins à domicile. Pour chaque Terri Schiavo faisant la manchette, des centaines, des milliers même, de personnes handicapées vivent sous le seuil de la pauvreté ou ne bénéficient pas de tous les soins dont elles auraient besoin dans la collectivité. Si nous voulons véritablement nous élever contre « le terrible tort que pourraient subir les invalides », commençons donc par ces causes.

PRESIDENT'S MESSAGE

I attended the CMA Committee of National Medical Organizations at the end of January 2005 as well as a day with the recently formed Federation of National Specialty Societies of Canada.

Some of the highlights:

- Review of the 1st report of the Health Council of Canada Strategic Themes for Action. Much discussion occurred around these issues: Health Human Resources (HHR) and the appropriate number and supply of individuals. The development of multidisciplinary teams to serve as one of the basics of primary health care renewal. The CMA cautioned that there is discussion at the federal level re: absolute supply of HHR vs better utilization of supply. The sentiment including ours at the table was that there is a need to continue to press for increased HHR. There will be a national HHR summit in June 2005. The invitees have not yet been announced.
- Wait time benchmark working group. At present cancer care, diagnostic imaging, hip and knee replacement and sight restoration (ophthalmology) will attempt to establish



Brenda Joyce,
MD, FRCPC

benchmarks. An interesting response by CMPA included concerns re: potential liability if patients have to wait longer than a specified time period.

- Task Force II, which is the joint collaboration of the Royal College, the CMA, the College of Family Physicians of Canada and a number of other stakeholders developing a Physician Human Resource strategy for Canada.

- The National Physician Survey - my take on this is that we continue to work long hours and continue to experience stress. I know this is an oversimplification, but the CMA is more than willing to release whatever data members feel could be useful to them.
- Other issues discussed included leadership development, non-resident insurance and health technology.

I continue to feel these meetings are valuable to our association as they allow our concerns to be expressed as well as providing a forum for updates on issues that will ultimately affect us all. Members are welcome to contact me with any questions regarding these meetings or issues discussed.

MESSAGE DE LA PRÉSIDENTE

Brenda Joyce, médecin, FRCPC

J'ai assisté à la réunion du Comité de l'AMC sur les organisations médicales nationales à la fin de janvier dernier ainsi qu'à la journée organisée par la Fédération nationale des sociétés de spécialistes du Canada de formation récente.

En voici certains faits saillants :

- Examen du premier rapport du Conseil canadien de la santé sur les thèmes stratégiques d'orientation de l'action. Les sujets suivants ont suscité une discussion

animée :

L'enjeu des ressources humaines en santé et l'offre d'effectifs appropriée. La formation d'équipes multidisciplinaires comme assise de la refonte de l'organisation des soins de santé primaires. L'AMC nous a prévenu que le gouvernement fédéral est divisé actuellement quant à la direction à choisir entre la détermination de l'offre absolue de ressources humaines en santé et la détermination de l'utilisation optimale de l'offre. Le sentiment général à cet égard veut que nous persistions à promouvoir

l'augmentation des effectifs dans le domaine de la santé. Un sommet pancanadien sur les ressources humaines en santé aura lieu en juin prochain. Les invités de marque ne sont pas encore connus.

- Groupe de travail sur l'établissement de cadres de référence en matière de liste d'attente. Actuellement, de tels cadres de référence seront déterminés dans le traitement du cancer, l'imagerie diagnostique, l'arthroplastie de la hanche et celle du genou ainsi qu'en restauration de la vue (ophtalmologie). Point intéressant soulevé par l'ACPM, soit la question de savoir quelle serait la responsabilité du système de santé advenant qu'un patient attende plus longtemps que le délai fixé avant de bénéficier des soins nécessaires.
- Le groupe de travail II, initiative commune du Collège royal, de l'AMC, du Collège des médecins de famille du Canada et d'autres

intervenants, qui œuvre à la conception d'une stratégie concernant les ressources humaines médicales au Canada.

- Le sondage national auprès des médecins – j'en retiens que nous travaillons encore et toujours de longues heures et que nous sommes tout autant confrontés au stress qu'auparavant. Comme je simplifie à outrance, remettez-vous en à l'AMC qui est disposée à transmettre aux membres tous les renseignements qui pourraient leur être utiles.
- Le perfectionnement de l'aptitude à commander, l'assurance pour les non-résidents et les technologies de la santé sont au nombre des autres sujets abordés.

Je suis toujours d'avis que ces réunions sont utiles à l'Association puisque nous pouvons y exprimer nos préoccupations et qu'elles permettent aux participants d'être informés de questions éminemment importantes pour nous tous. Si les membres ont des questions sur ces réunions ou les sujets qui y sont abordés, qu'ils n'hésitent pas à communiquer avec moi.

The preliminary program for the 53rd Annual Scientific Meeting of the Canadian Association of Physical Medicine and Rehabilitation, to be held June 15-18, 2005 at the Fairmont Château Laurier in Ottawa, Ontario, is now available. It is posted on our website at <http://capmr.medical.org/agm2005.htm> and has been sent out to all members. The program contains high caliber sessions and we expect to have a great turnout in Ottawa. Note that there have been a few program changes since the printing of the preliminary program. Contact the CAPM&R for more details. Remember to book your room at the Fairmont Château Laurier as soon as possible. We expect our room block to sell out so don't delay!

EDUCATION CORNER

An Approach to Breaking Bad News

Sue Dojeiji, MD, MEd, FRCPC

You are asked to see a 28-year-old previously healthy man in the ICU with a diagnosis of C4 ASIA A spinal cord injury. He is stable medically. The first thing he wants to know from you: *“When will I be able to walk again?”*

You’ve finished assessing a 35-year-old woman with a severe form of chronic inflammatory demyelinating polyradiculopathy. She has no proprioception or pin prick perception in the lower legs. She has grade 1 strength in her lower leg muscles and grade 3 strength proximally. She continues to drive but with difficulty. You are concerned with her ability to drive. You need to inform her of your obligation to report your concerns to the Ministry of Transportation and the likely plan of a driving evaluation (which costs \$500!).

You receive an x-ray report of the femur on a 20-year-old rugby player. She had complained of persistent thigh pain with exertion during spring training. The report indicates features consistent with osteogenic sarcoma. You will need to meet with her quickly to discuss the next steps of management.

As physiatrists, probably the hardest thing we do is deliver bad news to our patients and families. While we don’t always provide life and death type of news, we provide information that may be interpreted as bad by patients and families. The above scenarios are only a few examples of clinical situations we may encounter.

This issue of Education Corner is devoted to an approach to breaking bad news. For learners, this approach will give you a way to begin the discussion in a systematic and confident manner. For teachers and educators, this approach will enable to you monitor and give feedback to your learners on their approach, in an objective and organized manner.

Breaking bad news is inescapable. For some of us, we may do this on a daily basis. Breaking bad news is a form of information transfer. However, while it is an essential clinical skill, it is rarely taught formally in training (until recently!). Many guidelines exist, which generally means there is no one perfect method. The intent of any approach is to improve the right versus wrong ratio.

Until a few decades ago, breaking bad news was not done. Previously published methods existed on how to evade the topic of breaking bad news. In the 1950’s 90% of physicians did not tell their patients of a cancer diagnosis, as it was felt that the truth may be damaging to the patient. Now, we recognize that it is the patient’s right to know the truth, and as physicians we have an obligation to disclose “bad” information. The literature now discusses *“how to tell”* rather than *“should we tell”*.

The first question some may ask is what is “bad news”? Clearly certain scenarios will be perceived as bad: sudden death of a family member, diagnosis of cancer. In less obvious cases, bad news is simply any news that drastically and negatively alters the patient’s view of his/her future. Often the impact of the news will depend on what the patient already knows. This is often referred to as a mismatch of expectations between what is medical reality and what the patient expects, perceives, understands or remembers.

There are many societal, psychological, patient and clinician reasons why breaking bad news is so hard. Mainly, it is fear:

- fear of the untaught - how do I break the bad news?
- fear of eliciting a negative or an emotional reaction – what do I do if the patient cries?
- fear of saying “I don’t know”
- fear of expressing emotions – what do I do if I start to cry?

- ambiguity of the “I’m sorry”. I’m sorry can mean, I’m sorry for you (an expression of sympathy). But it may be interpreted as, I’m sorry I did this to you (apology).

While there are many approaches, perhaps the most practical and easy to remember is the Buckman approach. Dr. Buckman is a well-recognized University of Toronto Oncologist who has published widely on this topic. He has created videotape and CD based teaching modules explaining the following approach. I would encourage programs to review this material in planning your communication skills workshops for your trainees.

Dr. Buckman describes the **SPIKES** model for breaking bad news as follows:

- S**etting and listening skills
- P**atients’ perception of the condition
- I**nvitation from the patient to give information
- K**nowledge – giving clear medical facts
- E**xplore emotions/empathize with response
- S**trategy and summary (next steps)

We will review each of these steps.

Setting and Listening Skills

This first step is the key to setting the stage for the delivery of the news. It is best to be **seated** in a quiet room. Ensure that if relatives are present, they sit next to the patient, in the event that the patient may require emotional support. Attempt to limit distractions (pager and phone being the biggest culprits).

When delivering the news, maintain eye contact with the patient and family. Be conscious of your body language – it may facilitate but also hamper the discussion. I’ve had the opportunity of watching MANY patient-physician interactions. In one scenario, the physician was so nervous, she clicked her pen the whole time she was trying to speak with the patient. You can imagine how distracting it was for the patient. She wasn’t aware of this behaviour until I had pointed it out to her.

Also, this is an opportunity to practice your listening skills right from the beginning. This means beginning with open-ended questions and listening (without talking) to the patient’s responses. Use facilitation skills (verbal and non-verbal) to allow the patient to speak. This is going to come in handy for the next step – patient perception.

Patient Perception

Often when we have key medical information, we feel we need to burst ahead and explain everything. However, it is best to begin by asking what they have been told about their condition so far or what is their understanding of the situation. We do this for several reasons.

This is where you will be able to detect the mismatch between what you know is true and what the patient believes. If what is true and what the patient knows are close, there is no mismatch of expectations, and the discussion can smoothly go on. If there is a mismatch you need to be aware of this as it will determine what you need to do next.

Also, by eliciting the patient’s perception first you will be listening to the level of comprehension and the type of language used by the patient. You will then be able to match your explanations to that level of language.

Finally, if the patient is well informed about the condition/situation already, it changes the focus of the discussion from truth telling to answering the patient’s specific questions. So it is less redundant and time consuming.

Invitation

Once you have an idea of what patients already know, the next step is to find out IF they want to know what is happening and how much detail they want to know. This may sound odd, but there are people who may become easily overwhelmed by the content of what is said and need small chunks to be provided at any one time, or don’t want to know right away.

You may begin by saying “I’m seeing you today to review XXX. If there is bad news, how much information would you like from me” OR “I have some unpleasant news for you about XXXX. How much detail would you like me to give you today?”

Accept the fact that some people may not want to know right away. In such cases, you might offer another meeting to answer their questions, perhaps with a family member if they wish.

Knowledge Giving

Once patients provide the invitation to proceed, follow their lead – i.e., begin the discussion where the patient left off. Let’s take our first scenario – our 28 year gentleman with the spinal cord injury. He might say the following:

Patient: The surgeon already talked to me. She said I have a broken neck and the spinal cord was pinched. She said “we can never say never”, but it doesn’t look good for me right now. She doesn’t think that I’ll be able to walk.

Your discussion after that will begin by acknowledging those comments and carrying on from there.

When speaking with patients, use simple language. If you have a picture or model to help you explain, it will be easier for the patient to visualize what you are saying, and they will have a better chance of remembering what you said.

After each major point, stop and check to make sure the patient understands what you are saying. They may become overwhelmed by the discussion and tune you out completely.

While difficult, expect that there will be a reaction to the news. Respond to the reaction by allowing the patient to express whatever it is they are feeling. Empathize with the patient, but at the same time don’t make any

assumptions about how they are feeling. More on this later.

Probably the hardest reaction is no reaction. We sometimes expect a dramatic explosion of emotion when providing emotionally charged information. In some cases, this may not happen. We need to be aware of the potential for denial and explore this if we suspect it.

I had a situation where I was asked to see someone with end stage lung cancer for a trial of rehabilitation. I tried to discover what he already knew (never assume patients know even if it’s all over the chart!). He was certain that he had pneumonia and that he was going home soon. His wife was present at the time. When she left, we were able to discuss in a bit more detail and it became obvious that this gentleman did not wish to believe he had cancer and did not want to say that word with his wife in the room so as not to upset her.

Explore Emotions/Empathize with the Response

As above, expect some type of reaction. The first one is yours. If you are going through a difficult personal time, you may surprise yourself by your own reaction to giving someone else bad news. Be aware of this and have a strategy for managing it. You may decide that now is not the best time for you and you might want to put this off for an hour to gather your thoughts.

When a patient reaction occurs, stop talking. Our inclination as clinicians is to want to fill the void with chatter because we are uncomfortable. Stop. Wait, then identify the emotion – “I can see that you are upset.” Identify the cause - “ I know this news is surprising – this is not the result we were hoping for”. This is empathy: showing that you’ve made a link between the emotion and the cause. Empathy is a skill that assists patients in working through their emotions. The empathic response is what defines us as caring clinicians. Empathy is not sharing the

same feeling as the patient. It is not agreeing with patients' views. Simply, it is acknowledging their reaction to the information you've provided.

The next question that usually comes on the heels of exploring emotions is the question of touch. Can we offer physical comfort to patients when they are emotionally overcome? My advice always is if you are someone who is comfortable with touch, it is an **option** for you. If you are not comfortable with touch, do not use it.

We are all aware of the written and unwritten guidelines that exist on inappropriate touch between clinicians and patients. The basics should not be a surprise to us, but it is important to highlight the neutral areas of touch, if this is a strategy that you are comfortable using. The top of the arm, the shoulder and the **back** of the hand are the most neutral areas. The top of the thigh is considered borderline, but sometimes it is the closest thing to you when seated. Be very aware of and respect cultural differences. If you are not sure, don't use touch as a strategy to comfort a distressed patient.

Strategy and Summary

Once you've discussed the issues, move on to a plan of action. Sometimes, the plan of action is to meet again once the information has settled in. In planning a strategy, assess patients' expectations and assess the response to the proposed plan. Once you agree on the plan, summarize it for the patient. You may wish to write it down. Indicate clearly what will happen next and when your next meeting will be.

Let's go back to our young man with the spinal cord injury:

Doctor: So we've talked a bit about the walking. What I'd like to do now is follow your progress with the therapists. I'll come by next

week to see how the muscles and nerves are recovering. If you like, I can drop off an information binder from the Canadian Paraplegic Association. Sometimes going through that might help you work through some questions you may have. What do you think about that?

Patient: I don't think I'm ready to see that yet. Let see how it goes with physio first.

MD: Fair enough. I'll see you next week. I'm happy to meet with you and your wife next time if that would help. And so forth.

While it is difficult to simply talk (or write) about breaking bad news, I hope the above guidelines provide an approach to begin with. Like most skills, breaking bad news improves with practice and feedback and a lot more practice. I would encourage trainees to watch their preceptors and see the steps as the interaction is going. Also, I would encourage attending physicians to monitor your trainees when they are doing this important skill. It is the only way they will know how they are doing and if they are improving.

As always, I look forward to your feedback on this and other Education Corner issues.

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Commentary: Time to Standardize Stroke Rehabilitation Outcomes? Is More Better?

Robert Teasell MD^{1,2}, Katherine Salter BA¹, Jeffrey Jutai PhD^{1,2}, Harpreet Sangha BSc²

**Department of Physical Medicine and Rehabilitation,
Parkwood Hospital, St. Joseph's Health Care London¹ and the
University of Western Ontario², London, Ontario, Canada**

Correspondence to:

Dr. R. W. Teasell, MD FRCPC
St. Joseph's Health Care London, Parkwood Hospital
801 Commissioners' Road East,
London, ON, Canada N6C 5J1
Phone: (519) 685-4559
Fax: (519) 685-4023
E-mail: Robert.teasell@sjhc.london.on.ca

There are few areas of rehabilitation that have been as well studied as stroke rehabilitation. Our recent review of the stroke rehabilitation and secondary prevention of stroke literature uncovered 520 randomized controlled trials (RCTs) and that number is growing annually at an increasing rate (Teasell et al 2004). This growth of research is matched only by the proliferation of measures used to assess outcomes. This heterogeneity of measures, in many cases purporting to assess the same outcomes, has led to a great deal of difficulty in comparing research results and, in some cases, applying them to clinical practice.

In a review of all outcome measures used in over 300 stroke rehabilitation RCTs, Sangha et al. (in press) found the Barthel Index (Mahoney and Barthel 1965) to be the dominant functional measure utilized in stroke rehabilitation

research. The Barthel Index was not only the primary measure, but was also associated with an improved quality of research when compared to studies utilizing the Functional Independence Measure (FIM) (Hamilton et al. 1987). Coincident with an increasing proliferation of functional outcome measures in general, there was also a trend toward increased use of the FIM score, particularly in RCTs conducted in North America.

The FIM was developed, in part, to produce a functional outcome tool that would be less restrictive and more responsive to clinically significant change than the Barthel Index (van der Putten et al. 1999; Hobart et al. 2001). In North America, the Barthel Index is often viewed as being outdated, because it is an older and much simpler scale. The Barthel Index focuses on the performance of basic Activities of Daily

Living (ADLs), and does not directly assess cognitive and language function. Hence, it appears to lack the comprehensiveness of the FIM.

Kidd et al. (1995) suggested that the inclusion of items related to communication and cognition, as well as the ranking of 7 levels of severity for each item, make the FIM more sensitive and inclusive. However, the contribution of the cognitive subscale to the scale as a whole is questionable as it has been shown to have less reliability and responsiveness than either the motor FIM or the total FIM (Ottenbacher et al. 1996; van der Putten et al. 1999). Gosman-Hedstrom & Svensson (2000) suggested that although the FIM is more inclusive than the Barthel Index, it does not appear to be more discriminative of change within the individual in a clinical setting when assessed at the level of the scale items.

Both the Barthel Index and the FIM Scoring systems have undergone extensive scrutiny in terms of reliability and validity. It is generally accepted that both are strongly reliable and valid measures of functional disability in stroke populations. Hobart et al. (2001) suggested that, in terms of reliability, there appears to be no particular advantage to choosing one scale over the other. Similarly, the comparable convergent and discriminant construct validity of the Barthel Index and motor-FIM have been demonstrated (Hobart et al. 2001). Overall, both the Barthel Index and the motor-FIM appear to be psychometrically similar measures of motor disability (Gosman-Hedstrom & Svensson 2000; Hsueh et al. 2002).

Responsiveness, or the ability of an instrument to detect clinically significant change over time, is identified as an important criterion to assess in the selection of any outcome measure. The Barthel Index has often been criticized for the limited range of disability within which it is able to detect change as evidenced by significant floor

and ceiling effects. In studies focusing on the responsiveness of the two scales, little to no difference is found in comparisons of the Barthel Index, the motor-FIM and the total FIM when used within a population of stroke patients (van der Putten et al. 1999; Hobart et al. 2001; Wallace et al. 2002; Hsueh et al. 2002). In a study of patients suffering from either multiple sclerosis or stroke (that did not include any severely disabled individuals), Van der Putten et al. (1999) reported a 7% ceiling effect for the Barthel Index, while the total FIM showed no ceiling effect at all (1% for motor-FIM). Hsueh et al. (2002) reported a substantially larger floor effect for admission Barthel Index scores than for admission motor FIM scores (18.2% vs 5.8%) in a similar diagnostic but more severely disabled population.

In spite of this perceived limitation to the spectrum of detectable change with the Barthel Index, both studies (van der Putten et al. 1999 & Hsueh et al. 2002) found significant and comparable change scores for both outcome measures. This was supported by the work of Wallace et al (2002) who found the Barthel Index & motor FIM exhibited similar responsiveness to change in a population comprised mostly of individuals recovering from moderate stroke. As Wallace et al. (2002) point out, their study – like the others cited here – focused on the responsiveness of the measures to improvement of stroke patients – i.e. unidirectional change only. The ability of the measures to assess decline as well as improvement is not addressed.

Despite the fact that the Barthel Index is the older scale, there is little evidence that the FIM score provides additional useful information, in terms of assessing level of functional ability, monitoring clinical change or in predicting outcomes. This is an important consideration, particularly in North America where FIM is the dominant measure, which is reflected in its increasing use in RCTs both absolutely and

relatively. Compared to the Barthel Index, the FIM is more time consuming, requires special training to conduct and involves some cost – this is acceptable, if it provides additional information. In Canada, the CIHI data set, which involves a FIM score plus an additional 12 items, is required in some jurisdictions before the provincial funding body will provide payment. However, evidence to support the superior utility of even the FIM alone is lacking.

Perhaps the time has come to reevaluate where we are going. Is the Barthel Index alone sufficient for the assessment of functional disability? Although the FIM is an excellent tool, is it a significant step forward? What are the consequences of using a more complex outcome measure in terms of increased time and costs? Is the ongoing proliferation of outcome measures, many of which measure essentially the same outcome, making research harder to interpret and apply as well as almost impossible to compare? Is stroke rehabilitation research in particular, and rehabilitation research in general, becoming a modern-day Tower of Babel? We believe it is time to standardize outcome measures in research and in clinical practice internationally.

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RehabNet: 10 years, a personal reflection

Gaétan Tardif, MD, FRCPC

I just realized that our upcoming meeting will be the 10th anniversary of RehabNet. I had not been counting until I stopped for an overnight stay at the Château Montebello last week. This triggered memories since it is where we had our first meeting. So I went back to my old notes and realized that the original meeting did indeed take place in 1995 near Ottawa! Those of you who want a bit of history and nostalgia are welcome to read on!

Once upon a time there were many free standing rehab hospitals and their CEOs met twice a year to discuss issues of common interest. Then in the early 90's, regionalization started to sweep across the country, and one by one, the free standing rehab hospitals became part of regional systems.

A couple of things happened in 1994 that would certainly change the course of my life (this is actually relevant although that would not be immediately obvious). First, the two senior vice-presidents of the Canadian Association of Physical Medicine and Rehabilitation decided they really did not want the presidency and so the still freshly minted secretary-treasurer was asked to skip four years of apprenticeship and take on the presidency on short notice. Second, the Physiatrist-in-Chief at the Ottawa Rehab Centre left for the mild climates of Vancouver Island and was replaced after a long search by a somewhat reluctant new chief who packed his bags and left town within weeks. Someone had to step in...well you can see a pattern here.

Now that I have a teenager, I can see that I probably didn't stop behaving like one until about a year after I took on these jobs. I was going to change the world, freely told people about it in no uncertain terms, but I still had to receive my regular dose of positive

reinforcement. When people ask me how old I am, I give my answer on the basis that I was nineteen in 1994. I am a bit distraught at the thought of turning thirty this year but I'll get used to it I guess. But I digress...

Needing my positive reinforcement, I took a copy of the CAPM&R newsletter to my CEO - just to show all the good stuff the president of CAPM&R was doing. His comment was that we had discussed very similar issues at our meetings and that given the fact that CEOs of free standing hospitals were an endangered species, maybe we should think creatively and do something together. And that's how RehabNet was born.

We invited the chief administrative and chief clinical leaders of all large Canadian rehab programs to a meeting in Montebello. Almost nobody replied and we were a bit depressed with a predicted attendance of eight people. For some odd reason, over twenty showed up and we ended up elbow to elbow in a small boardroom. At the end of the meeting, a few of us met to decide what we might do next with the concept and decided it was worthwhile and that we would try to grow it to be a true national forum over time.

I suggested to the group that we should pick a leader that would move us forward and hoped that one of the CEOs would come up to the plate. In one of these moments I'll likely never forget, Sheila Jarvis, then CEO at the Glenrose Rehabilitation Hospital, looked right back at me and said "you can be our fearless leader". I quickly grew up that day, although I don't consider it on the birthday count.

We will soon have our 10th meeting, and more than ever it is a collective effort of which we can all be proud. And, by the way, thanks Sheila!

2004 CMA Leaders' Forum Report

Patti Forgeron, BSc, MSc, MD, FRCPC

On November 29 and 30th, the Canadian Medical Association held its annual Leaders' Forum. The Executive of CAPM&R sponsored my participation. As a relatively new Psychiatrist, with a visionary personality, this was an excellent learning opportunity. I would like to officially thank the Executive for their support.

The conference offers a unique opportunity to meet and "swap" ideas with senior CMA executive, national and international leaders in the medical field, fellow health professionals and politicians. The objectives of the forum were to: 1) understand the value and importance of physician involvement in leadership roles; 2) identify opportunities to develop your leadership interests and skills for the future; 3) apply various leadership theories and skills in your own leadership context; 4) support colleagues who have an interest in leadership; 5) sustain enthusiasm, commitment and balance and 6) achieve greater effectiveness as leaders.

The above objectives were quite extensive, however I felt the majority were achieved. In addition, I met my personal objectives. As a Psychiatrist practicing in a small province, I have had many challenges in raising the awareness on the needs of patients with functional limitations.

I work fairly independently, therefore the challenges are somewhat daunting. However, this forum fostered many ideas on how to effectively tackle some of the professional objectives I have contemplated. To me this was well worth the attending the forum.

A new program in the Leaders' Forum was the Mentor Match. I would like to thank Dr. Gaétan Tardif for participating in this portion of the forum with me. Although the Mentor Match is in its infancy, I believe more mentoring is needed to help develop leaders in our profession and within our association. There is a tremendous amount of knowledge and experience within the membership of CAPM&R. I would like to see a Mentor Match Program implemented in the annual CAPM&R meeting.

The CMA Leaders' Forum and the Office for Leadership in Medicine provide excellent contacts and educational initiatives. They foster many ideas for management, leadership, mentoring and policy-making. The networking with politicians, academic and community leaders will only help raise the profile of CAPM&R. Therefore, I would highly endorse this annual event to the members of CAPM&R and further recommend the educational grant for individuals to participate on a yearly basis.

Thank you CAPM&R for supporting me in the 2004 CMA Leaders' Forum.

The Canadian Soccer Association is looking for men, age 16-45, for their Paralympic Soccer program. To qualify, a person must have mild residual motor deficits from either cerebral palsy, a stroke, or a brain injury. This is a relatively new program, and players may have the opportunity to rapidly progress to a national level league or international play representing Canada. For additional information, please contact Head Coach Drew Ferguson at drew.ferguson@labatt.com.



So, Who Teaches the Followers?

Gaétan Tardif, MD, FRCPC

Mission statements are full these days of leadership statements, some of which are reasonable, other cases being a bit of a stretch, and some being plainly ludicrous. I belong to plenty of groups and societies who want to be “the” leader, not to mention my belonging to a university obsessed with world dominance¹.

Yet when you look at this year’s annual meeting program, you will see that once again I have advocated for more content on leadership and the less technical areas of PM&R². I am very gratified to see the first humanities lecture on the program and hope it will be well received. I hope that both leadership and humanities will continue to be a regular feature of our meetings.

Someone pointedly asked me: So, who teaches the followers? That’s a fair question. After all, isn’t there an old proverb about too many Chiefs and not enough Indians? The answer is rather simple. The best teams work at optimal efficiency when everyone around the table becomes the leader at some point in the process. At its best, in any given hour, I will have been the leader once or twice and the follower the rest of the time.

Leaders feel comfortable taking risks³ when it’s their turn to speak, keep trying to make a difference, and move on after inevitably failing on a particular project. If you don’t fail every so often, you’re not trying hard enough. That bears repeating in a leadership workshop environment. We don’t feel comfortable failing and the CMAA tells us it’s a bad thing when it happens with specific patients.

A great leader knows how to listen, nurture and follow. A great leader knows how to make others comfortable if not excited with taking risks, and medical school actually did its best to breed risk taking out of all of us. So we all need to be trained as leaders to become effective followers as well, or dare I say great team members?

I am looking forward to seeing you in great numbers at our annual meeting in Ottawa, and maybe have the pleasure to see you at the workshop!

- 1- One unproved theory is that Mike Myers, a Toronto native, modeled Dr. Evil after a U f T medical school alumnus gone bad...
- 2- Some will argue that there is a technical aspect to leadership. I subscribe to leadership requiring much more than technique to be successful.
- 3- For instance when Jeff Blackmer decided to take on this newsletter. Although this is only marginally relevant, naming the editor always improves one’s chances to be published.

