



# Health Ethics Today

Volume 22, Number 1, December 2014

## Editor's Forum

Paul Byrne, MB, ChB, FRCPC

Interim Director and Clinical Professor, John Dossetor Health Ethics Centre, University of Alberta  
Staff Neonatologist, Stollery Children's Hospital

Communication is an essential part of health care professionals' (HCPs) daily work no matter the discipline, speciality, or setting of clinical practice. In community care, outpatient continuing care, palliative care and psychiatry, good communication has long been recognised as essential to a successful patient-doctor relationship. Long-term contact with the patient supports the building of this relationship based on mutual trust as long as the communication remains clear, open, and mutually respectful. More recently HCPs working in acute care settings have come to recognise the central importance of good communication with patients and families in decision-making, often under sub-optimal circumstances. Constraints of time, emergency or life threatening conditions, and HCPs meeting a patient and family for the first time as "strangers", all make optimal communication difficult in settings such as the ER, ICU, pre-admission clinics, etc. Even with excellent diagnosis and treatment the requirement for clear, honest, respectful communication is regarded as being essential for high quality care. The three papers in this issue of *Health Ethics Today* illustrate the central importance of communication to good clinical care and good inter-professional relationships (upon which high quality care frequently depends).

Peter Brindley describes the increasingly common situation where a translator is required because the HCP and patient-family do not share a common language. He indicates that the usual practice of utilizing a family member who is multi-lingual, while being practical, is fraught with difficulties. Simple inaccuracy in translation is a worry many clinicians have experienced when a translator takes much

continued on page 2 ►

## In This Issue...

Practical Insights When Using Medical Translators: Are we speaking the same language? – Peter Brindley, MD, FRCPC, FRCP	3
Advance Mis-Directives Part I: Denying the End of Life – Laura Shanner, PhD	8
Delivering Complex and Sensitive Medical Information in Physician-Family Conferences: Interpersonal Skills and Cognitive Awareness of Psychological Barriers – Caroline Nolan, BA Th, M Th, MACP, LSS, PhD	11
Health Ethics Seminars	15

longer or shorter to deliver the message in the patient's mother tongue than the HCP's version. Brindley indicates that use of family translators risks problems beyond simple translation inaccuracy to confidentiality and increased distress, conflict, errors and other concerns. Good communication involves many non-verbal cues which can be used effectively to assure understanding and empathy when direct verbal communication is compromised. This not only applies to language discordant patients but also to those who cannot speak for themselves due to illness, interventions (e.g., endotracheal tube), medications, etc. Brindley's insights into communication using translators are relevant to discussions with patients and families in general. As he says "good communication is medicine's most important non-technical skill". It is highlighted as a pillar of CanMEDS, Royal College of Physicians and Surgeons of Canada (2015). Poor communication is a frequent cause of complaint from patients who feel badly cared for by HCPs even when diagnosis and treatment are correct. Recent alarm about the attitudes and ethical behaviour of medical trainees relates significantly to deficiencies in non-technical, non-scientific, humanities related understanding. Brindley's paper focuses on exactly the kind of content that HCP trainees require to help them have insight into improving the care their patients receive.

Laura Shanner describes the many problems associated with advance directives (AD) even in cases where the AD is drawn up properly. She questions the AD focus on specifics about diagnosis, prognosis and the need for total clarity that use of an AD seems to demand in practice. If diagnosis X then do Y but do not do Z, etc. She argues that real end-of-life illness is not like this for the majority of people as usually there will be an "it depends" qualifier. This qualifier relates to the true personal history of the patient which may be beyond the knowledge of family or designated proxy. Shanner suggests that HCPs ask the wrong questions when we present a "shopping list" of optional treatments with a Yes / No answer. It may be that our obsessional focus on patient autonomy, which is the driving force behind ADs, is misplaced as the sole ethical guide to end-of-life decisions

and care. Compassion may be more meaningful as the basis of decisions about care for those close to death as it promotes discussion and exploration of foundational beliefs about life and death. Shanner poses very difficult questions which will receive increasing attention in the wake of the recent Canadian Medical Association Statement on physician assisted dying.

Caroline Nolan explains the many benefits and potential pitfalls associated with the traditional physician-family conference (PFC). Her description of the surface and underlying psychological and cognitive processes playing out before, during, and after the PFC will be somewhat familiar to HCPs' experience in such cases. Unfortunately, while many HCPs are familiar with this in theory, these PFCs continue to be done badly because HCPs fail to move away from their usual diagnostic or prescriptive role. The skills required for excellence in undertaking the PFC go beyond communication to involve complex multi-dimensional abilities outside narrow HCP roles. These include empathy, an understanding how to be professional and personal at the same time, an ability to recognise when a patient and family is adequately prepared or not to receive bad news, and the ability to change the planned conversation "in real time" depending on how the course of the PFC is unfolding. Just as we remember a PFC done badly it is inspiring to see the process done well even when the news being delivered is very bad. The PFCs present to physicians opportunities to hone their communication skills, to becoming good listeners, and to be doctors who truly care about their patients (as Peabody said in 1927) almost one hundred years ago.

## References:

- CanMEDS. (2015). Competence by Design (CBD): Moving towards competency-based medical. Retrieved November 27, 2014 from <http://www.royalcollege.ca/portal/page/portal/rc/resources/cbme>.
- Peabody, F. W. (1927). The Care of the Patient. *The Journal of the American Medical Association*, 88(12), 877-882.

---

# Practical Insights When Using Medical Translators: Are we speaking the same language?

Peter Brindley, MD, FRCPC, FRCP

Intensivist, General Systems Intensive Care Unit and Neuro Sciences Intensive Care Unit, University of Alberta Hospital; Professor, Division of Critical Care Medicine and Adjunct Professor, John Dossetor Health Ethics Centre, University of Alberta

## Use of Translators: Basic Knowledge for Front-line Practitioners

Most medical practitioners will treat language-discordant patients and families. Use of ad hoc translators, such as family members or friends, is associated with more errors than using professionals (Nethercott & Shelly, 2011; Flores, et al., 2005; Thorton, et al., 2009; Pham, 2008; Ramirez, Engel, & Tang, 2008). Using friends or family to translate can also impact confidentiality, and increase distress and conflict (Nethercott & Shelly; Flores, et al., Thorton, et al.). However, even with professional translators, communication errors are still common. For example, a small study (n=10) of Intensive Care Unit family meetings involving a professional interpreter, found a communication-alteration in over half, and over three-quarters of these were deemed clinically significant (Nethercott & Shelly; Thorton, et al.). This manuscript will review the challenges of using medical translators.

Professional translators can be invaluable in acute care medicine. However, the unusual hours and time-pressures mean that they are not always available (Nethercott & Shelly, 2011; Flores, et al., 2005; Thorton, et al., 2009; Pham, 2008; Ramirez, Engel, & Tang, 2008). When available, and whether face-to-face or remotely, the use of translators takes more time, and may mean less information is delivered, or less time is available for questions (Nethercott & Shelly; Thorton, et al.; Ramirez, Engel, & Tang). Moreover, clinicians appear to provide less emotional support when using a translator (Nethercott & Shelly; Pham). Accordingly, patients who need translation may be less satisfied with their care (Gany, et al., 2007), less

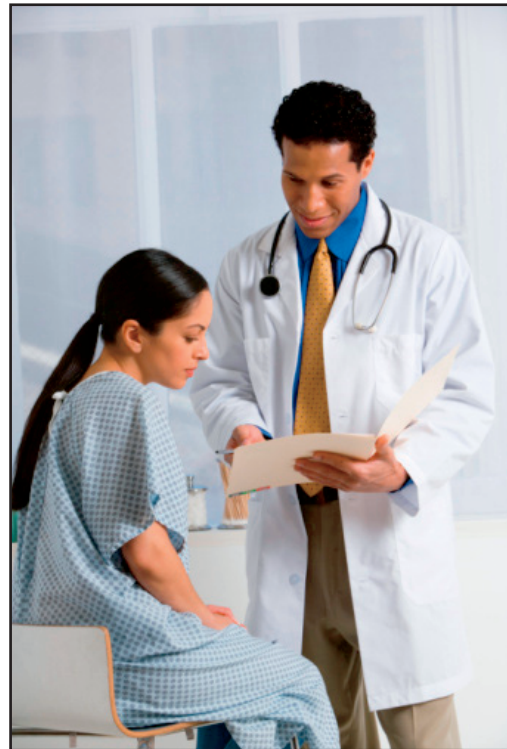
informed when providing consent (Clark, et al., 2011), and may exhibit less outpatient compliance (Gany, et al., 2011). Therefore, this manuscript is also arguing that, where possible, front-line practitioners be required to learn language skills appropriate to their work environment.

Canada is one of the most multi-cultural nations on earth. According to the 2011 census, 57% of Canadians use English, and 21% use French, as their mother tongue (Statistics Canada, 2011). While approximately 20% are allophones, (and 0.5% speak indigenous languages), 85% of Canadians possess a “working knowledge” of English and 30% possess a “working knowledge” of French (Statistics Canada; Wikipedia). Fortunately, over 98% can speak at least one of the two official languages (Wikipedia). Unfortunately, less than 20% speak both (Wikipedia). Accordingly, Canada has been described as a country of “two solitudes”, separated by these two European founding languages (MacLennan, 1945; Gagnon, 2012). Bringing these solitudes closer requires effort and empathy.

Empathy and verbal communication is central to the human experience of illness (Mercer & Reynolds, 2002; St Pierre, et al., 2008; Princas, Smith, & Tan, 2011). Training in communication for healthcare-professionals is also associated with increased patient satisfaction. It might even improve a hospital’s reputation or mitigate litigation (Princas, Smith, & Tan; Woods, 2004; Kaye, Fox, & Uman, 2012). Mounting data suggests that when we cannot communicate in a patient’s native language that we treat that patient

differently. Even when we have sufficient time, we are less likely to discuss psychosocial issues or provide lifestyle counseling (Thorton, et al., 2009; Ramirez, et al., 2008; Clark, et al., 2011; Rosenberg, et al., 2011; Eamranond, et al., 2009; Norris, et al., 2005). When we cannot connect by communicating directly, we are probably less connected overall. Some of our humanity may be lost, and patients may find it harder to trust (Mercer & Reynolds).

Even when using translators, the ability to communicate even a few phrases (and the effort demonstrated) may bolster a therapeutic alliance. Whilst full bilingualism requires immersion and extended practice (Freed, et al., 2004), many of us have rudimentary language skills that can be augmented. We should make the effort. After all, improving how we communicate medically in a bilingual country (and a multilingual world) has the potential to nudge together two other potential solitudes, namely clinicians and patients.



## Medical Communication: An Advanced Skill for Front-line Practitioners

Medical communication is a complex, nuanced, skill. Accordingly, there is a high potential for error (Nethercott & Shelly, 2011; Mercer & Reynolds, 2002; Prineas, Smith, & Tan, 2011; Sutcliffe, Lewton, & Rosenthal, 2004; Gawande, et al., 2003; Alvarez & Coiera, 2006; Brindley & Reynolds, 2011). Moreover, good communication requires more than just a few words and phrases: it includes how they are said (pitch, volume, pacing, and emphasis), and how they are interpreted (St Pierre, et al., 2008; Prineas, Smith, & Tan). Beyond the right words and phrases, good communication also requires *active listening*, attention to emotions, suitable eye contact, appropriate body language, and even reflective-silence (St Pierre, et al.; Prineas, Smith, & Tan). In short, one size *does not* fit all (Prineas, Smith, & Tan), and good communication (like any advanced medical skill) requires ongoing practice.

The CanMEDS framework, 2005, from the Royal College of Physicians and Surgeon of Canada, emphasizes that practitioners are now expected to

be more than factual or procedural experts: they are also expected to be communicators. Inadequate communication is one of the major causes of preventable medical error (Sutcliffe, Lewton, & Rosenthal, 2004; Gawande, et al, 2003; Alvarez & Coiera, 2006; Brindley & Reynolds, 2011). Expressed another way, our “verbal dexterity” should match our procedural dexterity and factual know-how (Brindley & Reynolds). CanMEDs does not specifically address the issue of language discordant patients. However, this framework is part of a growing realisation that communication is one of the strongest tools in a physician’s armamentarium, or, conversely, one of our greatest shortcomings.

While a detailed review of communication tools is outside of the scope of this review, resources do exist (Nethercott & Shelly, 2011; St Pierre, et al., 2008; Prineas, Smith, & Tan, 2011; Brindley & Reynolds, 2011; Cyna, Andrew, & Tan, 2011; Tate, 2009; Kurtz, Draper, & Silverman, 1998). One standardized example is the Calgary-Cambridge guide to the medical



interview (Nethercott & Shelly). There is also the LAURS technique (Listening; Acceptance; Utilization (of appropriate words); Reframing, and Suggestion) and the GREAT technique (Greetings/Goals; Rapport, Evaluation/Expectation /Examination/Explanation; Tacit agreement/Thanks; Cyna, Andrew, & Tan). There is also growing expertise in medical communication, and specifically in the acute care specialties (Nethercott & Shelly; St Pierre, et al.; Prineas, Smith, & Tan; Brindley & Reynolds; Cyna, Andrew, & Tan; Tate). Presumably, this illustrates the importance of communication across the spectrum: whether with highly vulnerable patients, anxious families, high-stakes resuscitation teams, or multidisciplinary care groups.

While this review focuses on language discordant patients, the lessons apply to those that cannot communicate because they cannot talk (i.e., an endotracheal tube, tracheostomy, tongue resection, etc.) or those unable to comprehend the language of technical medicine. Better communication is also a putative way for physicians to lessen hostility, disbelief, or denial. Notably, the patient and family conference has been described (albeit tongue in cheek) as “the most dangerous procedure performed in the modern hospital”. (personal communication, D. Howes) Unfortunately, high profile Canadian cases (including the Rasouli family in Toronto and Golobchuk family in Winnipeg; Globe and Mail, 2012; CBC News, 2011) suggest this statement may become increasingly true.

Particularly when communicating bad news, we should remember that- while this may be routine for us- for families these are seminal moments (Cyna & Lang, 2011). Nothing is likely to fully mitigate surprise, shock or disappointment, however, families are likely to remember any extra effort towards empathy. This might include even a few words or phrases in their native tongue. Work in neurobiology has also shown that both *what* we say and *how* it is communicated can be either a placebo (i.e., good communication can reduce pain and anxiety) or a nocebo (i.e., bad communication can increase pain and anxiety; Prineas, Smith, & Tan, 2011; Cyna & Lang). Combined with “active listening”, any extra effort becomes a way

to demonstrate non-abandonment, and flatten the authority gradient (Mercer & Reynolds, 2002; Prineas, Smith, & Tan, 2011; Cyna & Lang).

For patients, already burdened with illness, not being able to verbalize, or not being understood, can hasten a downward spiral into frustration, anger and disengagement (Mercer & Reynolds, 2002). It is also worth emphasizing that, as healthcare-workers, *not* communicating, is not an option: failing to make the effort sends its own negative message. Moreover, when physicians do speak with families and patients there is always the danger that we still do not speak “the same language” (Prineas, Smith, & Tan, 2011; Tate, 2009). For example, physician language may focus upon gathering information, or delivering news. This can be interpreted as being uncaring. In contrast, patient language may be more concerned with their beliefs, fears and hopes (Prineas, Smith, & Tan; Tate). This might be misinterpreted as overly emotional. Investing the time to establish “rapport” (usually defined as “a commonality of perspective”, “being in sync” or being “on the same page”) can facilitate all future interactions. It might even reinforce the patient’s psychological reserves (Cyna, Andrew, & Tan, 2011).



As outlined, amateur and professional translators are valuable but error-prone. Reasons are diverse but can include inadequate comprehension or the misguided desire to protect (Nethercott & Shelly, 2011; Flores, et al., 2005; Thorton, et al., 2009; Pham, 2008; Ramirez, Engel, & Tang, 2008; Gany, et al, 2007; Clark, et al., 2011; Gany, et al., 2011). There are different cultural attitudes to autonomy and disclosure, and translators may also see their job as providing a “cultural buffer” (Nethercott & Shelly; Flores, et al.; Pham). Pre-translation briefing is strongly encouraged, and should include the purpose, need for accuracy as well as sensitivity (Nethercott & Shelly; Norris, et al., 2005). Briefing should include the gravity of the situation, and also the degree of certainty. It is also advisable to de-brief afterwards (Nethercott & Shelly; Norris, et al.) to review what went well, how to proceed in future, and even the translator’s emotional state. Further resources, and advice for using interpreters are available from the International Medical Interpreters Association, the Minnesota Department of Health, and the Health Care Interpretation Network.

Mounting evidence suggest that communication is acute care medicine’s most important non-technical skill (Nethercott & Shelly, 2011; Mercer & Reynolds, 2002; Sutcliffe, Lewton, & Rosenthal, 2004; Gawande, et al., 2003; Alvarez & Coiera, 2006; Brindley & Reynolds, 2011). It is how we exchange meaning, reduce complexity, promote a shared mental model, inform, encourage and comfort (Mercer & Reynolds; Prineas, Smith, & Tan, 2011; Brindley & Reynolds). It is also how we connect (or not) as healthcare provider and recipient. However, we also work in an environment under constant constraints of availability and time. Therefore, it would be no surprise if patients wonder whether anyone will take the time to explain or to listen (Mercer & Reynolds; Prineas, Smith, & Tan). If we truly believe in being patient-focused then we should seize any opportunity to verbalize how much we care about patients and families.

This work is republished from the Canadian Respiratory Journal (Pulsus Group Inc):

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4128525/>. Interested readers are strongly encouraged to access the expanded original, which also includes a french-english language glossary.

## References:

- Alvarez, G., & Coiera, E. (2006). Interdisciplinary communication: an uncharted source of medical error? *Journal of Critical Care*, 21(3), 236-242.
- Brindley, P. G., & Reynolds, S. F. (2011). Improving Verbal Communication in Critical Care Medicine. *Journal of Critical Care*, 26(2),155-159.
- CBC News. (2013). Samuel Golubchuk. Retrieved November 1, 2013 from <http://www.cbc.ca/news/canada/manitoba/end-of-life-report-fails-golubchuk-family-1.1046338>.
- Clark, S., Mangram, A., Ernest, D., et al. (2011). The informed consent: a study of the efficacy of informed consents and the associated role of language barriers. *Journal of Surgical Education*, 68(2),143-147.
- Cyna, A. M., Andrew, M. I., & Tan, S. G. M. (2011). Chapter two, Structures: In: *Handbook of Communication in Anaesthesia & Critical Care: A Practical Guide to Exploring the Art*. Cyna AM, Andrew MI, Tan SGM, Smith AF (Eds.). Oxford, New York: Oxford University Press, pp. 17-29.
- Cyna, A. M., & Lang, E. V. (2011). Chapter three, How words hurt: In: *Handbook of Communication in Anaesthesia & Critical Care: A Practical Guide to Exploring the Art*. Cyna AM, Andrew MI, Tan SGM, Smith AF (Eds.). Oxford, New York: Oxford University Press, pp. 31-37.
- [dictionary.reverso.net/medical-english-french](http://dictionary.reverso.net/medical-english-french) [internet]. France: Reverso-Softissimo. Retrieved November 1, 2013 from <http://dictionary.reverso.net/medical-english-french/>.
- Eamranond, P. P., Davis, R. B., Phillips, R. S., et al. (2009). Patient-physician language concordance and lifestyle counseling among Spanish-speaking patients. *Journal of Immigrant and Minority Health*, 11(6), 494-498.
- Flores, G., Laws, M. B., Mayo, S. J., Zuckerman, B., Abreu, M., Medina, I., et al. (2005). Errors in medical interpretation and their potential consequences. *Pediatrics*, 111, 6-15.
- Freed, B. F., Segalowitz, N., & Dewey, D. P. (2004). Context of learning and second language fluency in French: Comparing regular classroom, study abroad, and intensive domestic immersion programs. *Studies in Second Language Acquisition*, 26(2), 275-301.
- Gagnon, L. (2012 Feb 4). The ‘two solitudes’ get more solitary. The Globe and Mail. Retrieved November 1, 2013 from <http://www.theglobeandmail.com/news/politics/the-two-solititudes-get-more-solitary/article545667/>.
- Gany, F., Leng, J. C., Winston, G., et al. (2011). Diabetes care and language discordance among Chinese and Latino primary care patients. *Ethnicity & Disease*, 2(4), 473-479.

- Gany, F., Leng, J., Shapiro, E., et al. (2007). Patient satisfaction with different interpreting methods: a randomized controlled trial. *Journal of General Internal Medicine*, 22(suppl 2), 312-318.
- Gawande, A. A., Zinner, M. J., Studdert, D. M., et al. (2003). Analysis of errors reported by surgeons at three teaching hospitals. *Surgery*, 133(6), 614-621.
- Globe and Mail Newspaper. (2012). Rasouli Case a Chance for Supreme Court to Put Forward Guidelines on End of Life. Retrieved November 1, 2013 from: [www.theglobeandmail.com/commentary/editorials/rasouli-case-chance-for-supreme-court-to-put-forward-guidelines-on-end-of-lifetreatment/article6114255/](http://www.theglobeandmail.com/commentary/editorials/rasouli-case-chance-for-supreme-court-to-put-forward-guidelines-on-end-of-lifetreatment/article6114255/).
- International Medical Interpreters Association. [imiaweb.org](http://imiaweb.org) [internet]. IMIA Guide on working with medical interpreters. Retrieved August 1, 2013 from [http://www.imiaweb.org/uploads/pages/380\\_5.pdf](http://www.imiaweb.org/uploads/pages/380_5.pdf).
- Kurtz, S., Draper, J., & Silverman, J. (1998). *Skills for communicating with patients*. 3rd ed. Milton Keynes, Radcliffe Publishing.
- MacLennan, H. (1945). *Two Solitudes*. Toronto: Macmillan Press.
- Mercer, S. W., & Reynolds, W. J. (2002). Empathy and quality of care. *British Journal of General Practice*, 52, S9-S13.
- Minnesota Department of Health. (2010). [health.state.mn.us](http://health.state.mn.us) [internet]. Minnesota Refugee Health Provider Guide 2010 - Ch 11- Medical Interpreters. (revised). Retrieved November 1, 2013 from: <http://www.health.state.mn.us/divs/idepc/refugee/guide/index.html>.
- Nethercott, D., & Shelly, M. (2011). Chapter 11, Critical Care. In: *Handbook of Communication in Anaesthesia & Critical Care: A Practical Guide to Exploring the Art*. Cyna AM, Andrew MI, Tan SGM, Smith AF (Eds.). Oxford, New York: Oxford University Press, pp. 3-16.
- Norris, W. M., Wenrich, M. D., Nielsen, E. L., Treece, P. D., Kackson, J. C., & Curtis, J. R. (2005). Communication about end of life care between language discordant patient and clinicians: insights from medical interpreters. *Journal of Palliative Medicine*, 8,1016-1024.
- Operating Room Leadership and Management*. (2012). Eds Kaye AD, Fox CJ, Urman RD, Cambridge University Press.
- Pham, K. (2008). Alterations during medical interpretation of ICU family conferences that interfere with or enhance communication. *Chest*, 134, 109-118.
- Prineas, P., Smith, A. F., & Tan, S. G. M. (2011). Chapter one, To begin: In: *Handbook of Communication in Anaesthesia & Critical Care: A Practical Guide to Exploring the Art*. Cyna AM, Andrew MI, Tan SGM, Smith AF (Eds.). Oxford, New York: Oxford University Press.
- Ramirez, D., Engel, K. G., & Tang, T. S. (2008). Language interpreter utilization in the emergency department setting: a clinical review. *Journal of Health Care for the Poor and Underserved*, 19, 352-356.
- Rosenberg, E., Richard, C., Lussier, M. T., et al. (2011). The content of talk about health conditions and medications during appointments involving interpreters. *Family Practice*, 28, 317-322.
- Statistics Canada. (2011). Population by mother tongue and age groups (total), 2011 counts, for Canada, provinces and territories. Retrieved November 1, 2013 from: <http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/hltfst/lang/Pages/highlight.cfm?TabID=1&Lang=E&Asc=0&PRCode=01&OrderBy=2&View=1&tableID=401&queryID=1&Age=1#TableSummary>.
- Statistics Canada. (2011). Population by knowledge of official languages, age groups (total), 2011 counts, for Canada, provinces and territories. Retrieved November 1, 2013 from: <http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/hltfst/lang/Pages/highlight.cfm?TabID=1&Lang=E&Asc=1&PRCode=01&OrderBy=999&View=1&Age=1&tableID=402&queryID=1>.
- St Pierre, M., Hofinger, G., Buerschaper, C., et al. (2008). *Crisis management in acute care settings: human factors and team psychology in a high stakes environment*. New York: Springer.
- Sutcliffe, K. M., Lewton, E., & Rosenthal, M. M. (2004). Communication failures: an insidious contributor to medical mishaps. *Academic Medicine*, 79(2), 186-194.
- Tate, P. (2009). *The Doctor's Communication Handbook*. 6th Ed. Radcliffe Publishing Ltd; 6th Milton Keynes.
- The Royal College of Physicians and Surgeons of Canada. (2005). [Internet]. CanMEDS 2005 Framework. Retrieved November 1, 2013 from: [http://www.royalcollege.ca/portal/page/portal/rc/common/documents/canmeds/framework/the\\_7\\_canmeds\\_roles\\_e.pdf](http://www.royalcollege.ca/portal/page/portal/rc/common/documents/canmeds/framework/the_7_canmeds_roles_e.pdf).
- Thornton, J. D., Pham, K., Engelberg, R. A., Jackson, J. C., & Curtis, J. R. (2009). Families with limited english proficiency receive less information and support in interpreted intensive care unit family conferences. *Critical Care Medicine*, 37, 109-118
- Wikipedia. Official Bilingualism in Canada. Retrieved November 1, 2013 from: [http://en.wikipedia.org/wiki/Official\\_bilingualism\\_in\\_Canada#cite\\_note-51](http://en.wikipedia.org/wiki/Official_bilingualism_in_Canada#cite_note-51).
- Wikipedia. The French Language. Retrieved November 1, 2013 from: [http://en.wikipedia.org/wiki/French\\_language](http://en.wikipedia.org/wiki/French_language).
- Woods, D. (2004). *Communication For Doctors - How to improve patient care and minimize legal risks*. Milton Keynes, Radcliffe Publishing.

---

# Advance Mis-Directives

## Part I: Denying the End of Life

Laura Shanner, PhD

Nanaimo Health Ethics Consulting and Associate Adjunct Professor, John Dossetor Health Ethics Centre, University of Alberta

You might think that a bioethics professor could easily fill out an Advance Directive (AD) form (a.k.a. Personal Directive, Living Will, or Advance Care Plan), having studied, critiqued and taught them for decades. But I always struggle, scribbling endless marginal notes and “it depends” qualifiers. Once I gave up and wrote a lengthy personal statement, and I’ve gone for embarrassingly long stretches with none at all. I know I’m not alone; few people actually write and update an advance care plan, and completed documents are often of little use in clinical practice.

The problems with such forms are familiar both to clinicians and prospective patients: the diagnosis or prognosis may be uncertain or not listed; instructions intended for unrecoverable conditions give inappropriate guidance when improvement is possible; alert but incapable patients may express desires contrary to those previously documented; or as a situation unfolds, even agents with clear instructions wonder, “are we there yet?” I think we need a completely different type of personal directive outline that asks more fundamental, flexible and therefore helpful questions.

What follows is not the result of research, but arises from my personal reflections on advance care planning and experience as an agent or supporter for dying loved ones. I seek a much more honest dialogue about what kinds of decisions need to be made near the end of life, and through that honesty provide greater reassurance to patients, loved ones and caregivers. However, this is not an easy conversation.



### The Problem:

Most advance planning forms list several diagnostic categories (e.g., dementia, stroke, cancer, persistent coma) and various treatment options (ventilator, feeding tube, CPR) that a prospective patient can authorize or reject under different circumstances. These categories may make sense to the bioethicists, lawyers and health care providers who draft such documents, but most people have limited information about what various conditions or treatments involve. Accordingly, we are asked to make rather arbitrary decisions about a limited list of unpredictable future possibilities.

Truth be told, would it matter most to you (or your loved ones) why your death might be imminent, or



rather simply *that* it is near? If your brain no longer functioned well, is the most important factor really whether the cause were a tumor, stroke, head injury or Alzheimer's disease? Personally, I am less concerned with why (or even the degree to which) my brain fails me, than I am with how happy I am in whatever alternative reality I might find myself. When to keep treating me? It depends.

As for treatments typically listed in AD forms, few people object in principle to CPR, antibiotics, feeding tubes and even ventilators. The issue instead is how aggressively to try to save one's life when either survival or improvement is unlikely. Thus, I don't know how to answer the question of whether I would want, say, a ventilator or antibiotics if I had cancer or a stroke. Yes, please treat me if the intervention makes me feel better, even if I cannot be cured; no, if we're merely extending my misery; yes temporarily, to allow a distant loved one to say goodbye, with the option to stop later. It depends.

When useful answers are hard to find, I suspect that we are asking the wrong questions. Getting to the right questions, however, requires courage to face some of our most profound, universal fears. It is time to take a deep breath, and dive into places we prefer to avoid.



## The Big Questions:

The bottom line is this: Human beings are mortal creatures. While we might be able to orchestrate (to some extent) the timing and circumstances of dying, the fact that this lifetime will cease is *not* negotiable. Imagining the world going on without us prompts

existential rage; the vast unknowns about whatever might lie on the other side of death provoke uncertainty and even terror. Death is probably the only truly universal human constant, and we loathe it.

As if mortality weren't bad enough, what we may have to endure between here and being dead is usually extremely unpleasant, and can be utterly unbearable, as our bodies and psyches gradually break down (Nuland, 1993). Most people view being dead as the most terrible of all possible outcomes, except that extreme illness, injury and the dying process might be just as bad or even worse.

I have come to believe that while everybody hates and fears both aspects – being dead and suffering before dying – most of us fear one a little bit more than the other. There is no right or wrong answer here. Your preference (for lack of a better word) might arise from personal experiences with pain and suffering, from observing the illnesses or deaths of others, from your available coping strategies, and from the religious, philosophical, and cultural influences that shape your deepest beliefs and questions about God, the universe, and the meaning of life. This fundamental, deep in our bones, gut level personal truth is what we need to explore, discuss, and ultimately document to guide others when we cannot speak for ourselves.

I also believe that both fears – of being dead and of suffering before dying – reflect our inherent vulnerability and our fundamental need for support from others. Abandonment, whether to die too soon or to suffer without relief, is intolerable. Which type of abandonment, to you, is *worse*? The most important ethical guide for personal care directives thus might not be respect for autonomy after all, but compassion: how can we navigate our mutual vulnerabilities and dread about the end of life, together?

This fundamental “which is worse?” question can adopt different guises:

- Do you think that death is the worst possible thing that can happen to you? Or do you feel that some things are worse than death?

- Do you want us to keep pushing to keep you alive, even if it might increase your suffering, or do you want us to prevent and alleviate your suffering, even if it hastens your death?
- If we make a mistake while trying to act on your behalf, is the worse mistake that you died too soon, or that you suffered more than you had to?
- How would you finish this sentence: "If all else fails, please protect me from...."?

These blunt, bottom-line questions provide much more insight into an individual's view of their own best interests, and a much clearer sense of the appropriate goals of care, than any matrix of diagnoses and treatments could ever do. The challenge ahead is to figure out how to ask such questions without scaring people who are trying to articulate their perspectives.

### Implications:

The easier category both to convey and to respond to is "if all else fails, keep me alive as long as possible." Lifesaving interventions would be limited primarily by futility and resource constraints.

For those who dread some things more than death itself, further information is required to guide their agents. I will explore some of these additional questions in a future issue of *Health Ethics Today*. For now, we should notice that some questions should be positive and deeply life-affirming: what key values, principles or insights have guided an individual's life, and how might an agent continue to apply these when the patient is no longer capable? More painful questions also arise: are there specific scenarios or conditions that prompt particular horror?

When it is agreed that death is to be accepted, would this individual merely want to withhold lifesaving interventions, accept hastening death through increased sedation, or desire intentional, active euthanasia where it is allowed? A truly useful AD would prompt people to express what most profoundly matters to them – their personal bottom line - regardless of their future possible diagnosis or available treatments.

### Conclusions:

Why do we gravitate to treatment-authorizing directives if they aren't helpful? I think it's because they offer emotional distance. Focusing on medical treatment offers the tantalizing hope of taming the messy, generally awful course of a body's gradual shutdown; exercising "autonomy" when we are impaired implies control that no one can actually have over dying. We avoid discussing the most helpful questions because, frankly, the basic facts of our mortality and vulnerability frighten us to pieces.

I believe we can do better. Instead of asking about treatment preferences, we should focus on each person's unique mix of values, hopes, and most profound fears, and then honor these as unpredictable circumstances unfold. Hiding from death behind a checklist of clinical options, as if these were what mattered most, is no way to demonstrate genuine respect for the complex, mortal persons we are.

A version of this paper was presented at the Dossetor Centre's Health Ethics Seminar Series on February 10, 2014.

### References:

Nuland, S. B. (1993). *How We Die: Reflections on Life's Final Chapter*. NY: Knopf.

---

# Delivering Complex and Sensitive Medical Information in Physician-Family Conferences: Interpersonal Skills and Cognitive Awareness of Psychological Barriers

Caroline Nolan, BA Th, M TH, MACP, LSS, PhD

Clinical Chaplain Specialist: GS-ICU, Burns, Neuro ICU and Emergency, University of Alberta Hospital and Clinical Lecturer, John Dossetor Health Ethics Centre, University of Alberta

## Introductory Elements to Interpersonal Communication Where There is a Power Differential

Physicians who come together periodically to discuss challenges such as at family conferences are subsequently more successful and adept in handling interpersonal communication that is central to their work (Smith et al., 2007). The efficacy of these discussions along with feedback by established physicians to medical students, residents, and fellows is credited for the improvement of physicians' communication of sensitive and complex information to patients and family members. Training sessions are central for the inculcation of confidence and competence in interpersonal communication skills that are intrinsic to the medical profession. Family conferences are challenging for physicians because they have to move out of the medical field into the non-medical and create a connection with the patients' families. An amicable working relationship with every family helps in the reduction of family dissatisfaction with the medical team and hospital in general. Physicians that are cognizant of the power differential, i.e., who are aware that they are in a more powerful position than the family members at that moment in time, will be more successful if they endeavour to bridge the gap. The interaction must be professional, but professional can be personal, i.e., with warmth and sensitivity as opposed to impersonal, i.e., only factual and objective. The challenge is to be perceived as a physician who cares medically but also emotionally for the patient and family members.



## Transference and Pre-suppositions

Upon a physician entering a room, assumptions by the family can be made before any word is spoken. There is no such thing as a neutral encounter. Things like race and cultural perceptions, as well as previous experiences (both positive and negative), can influence families' interactions with physicians. Emotions, ideas and thoughts are implicit and operative in the unconscious realm of family members. These can govern each family member's responses accounting for, what may at times appear as, disproportionate or exaggerated behaviour. Transference and counter-transference issues are common, i.e., a family may project something onto a physician that has nothing to do with him or her and a physician may also in that moment counter-project something onto a family. There are many challenges in such situations. A helpful stance for the physician is to remain calm and professional and to evaluate and re-evaluate his or her expectations of a family's response and behaviour. The desired or anticipated outcome of the family conference cannot be predicted or controlled by either party. Some guidelines to optimize the whole experience are offered below.

## Empathetic and Respectful Physicians

Physicians share an endeavour to be empathetic. It is helpful if they imagine what it would be like if they were receiving the news about their family member. What would they want to hear? What would they like to see expressed/omitted? The manifestation of person-centered care is the core element of a family conference. Family members are out of their comfort zones. They are within the territory of the physician and other health care personnel. For most families it is an unknown and un-navigated terrain. Families need to feel welcomed and made comfortable. They need to know that they are being communicated with honesty regarding the ongoing decisions about care of their loved one. They need to feel consulted and heard regarding their cares and concerns (Jonathan, 2004).

To engage a family, the physician first introduces himself/herself with a simple statement regarding the

physician's name and role in the unit. Accompanying medical team members should also be introduced. Family members should be invited to share their names and their relationship to the patient. During this time, the physician's body language is crucial for engagement with the family. A physician who stands can appear aloof, caught for time, or not willing to engage. The physician who sits down becomes engaged and sets the time for decisions. Studies have shown that physicians, who sat for a short time versus those who stood longer, were seen to have paid more attention and time with families (Strasser et al., 2005).

## Physician-Family Assessment

Just as in the case of an initial encounter with a patient, the physician needs to make a basic assessment as to where the family members are in relation to their level of understanding of the patient's medical condition and prognosis. Physicians can gauge this by asking the family members to explain what they know to date regarding the patient. During this inter-change, physicians ought to be able to discern from the level of engagement as to the degree of family understanding, level of education, familiarity with medical language and issues pertaining to the patient's care. This appreciation will help the physician to explain and bring the family up-to-date in language they understand. However, it is important to note, assuming the articulation of the situation was clear, that even well medically versed and educated family members, upon hearing something different from their expectations, can become cognitively impaired due to shock, trauma, anxiety and fear. In this situation one frequent result of hearing too much information and not having enough time to process it fully, results in failure to remember anything. Subsequently, they may not be able to respond in a definitive manner to questions or plans about care. Family members often become overwhelmed emotionally quite suddenly. The physician at this juncture has to gauge this response and adapt to the situation because he/she is the person having the most impact on the family.



## Transmission of Medical Information

The goal of a family conference is to relate accurate and clear information in a manner that facilitates understanding and decision-making. A direct language approach is most efficacious when dealing with families who are under stress. The avoidance of (a) complex medical terms, (b) over simplification and (c) ambiguous statements is central to effective communication. The adoption of an historical numerical narrative, i.e., the numeration and recalling of what has been done to date step by step is a helpful way to remind the family of all investigations and treatments to date.

A communication example:

Hello, I am Dr. Rich Smith (he sits down) and I have been working as a physician here for Dr. Caleb Combs. Please tell me who you are. (Dr. Smith listens to the family's introductions and connections to the patient). As you know, we have been looking after Mr. Egan for the last three weeks. Over the course of this time, we have tried five things to help him. (Name each thing that was tried and done). Unfortunately these were not fully successful. We are now considering our last options to see if we can turn Mr Egan's, Tom's, condition around (note use now of first name). This is working at the moment but it is difficult to predict that it will be sufficient to make him better. Tom is very ill. Right now he is not doing well. In the last hour his blood pressure has dropped very low (new information). Sadly the situation is not looking good. His low blood pressure is our biggest challenge. We will do our best to improve this. I will leave it at that for now as I know this is upsetting news. Do you have any questions for me

or for anyone on the team? We can also meet again to discuss this or any other issues that may arise or if you have more questions or concerns.



Note in the physician's communication above, his mentioning of "we", the team members, who have been looking after the patient. He outlined the work of the team; he presented an evaluation of the medical treatments and interventions along with an up-date on the patient's current medical condition. He was clear in expressing the team's level of confidence regarding the possible improvement of the patient while being cautious through the repetition of the patient's condition at that time. The physician stated the current challenges, as well as his and the team's commitment to both the patient and his family. He then invited the family to bring forward any questions, queries or clarifications they may have for him or any other medical team members since he recognised the importance of increased family communication (Jonathan, 2004). The physician also left the door open to further meetings. Generally, the more accessible a physician, the more positive regard and respect they enjoy, and as a result families tend to be less likely to request more meetings unless really necessary.

## Extraneous Family Issues and Dynamics

There is a trend among physicians to present all possible scenarios to families regarding the outcome of a patient's condition. Generally, there is more information and discussion centering on the functionality and quality of life of patients than there is regarding survival (Douglas, 2007). There is also a tendency to articulate the "worst case scenario" about prognosis. While this may be viewed as being open and candid with family members, such information can also be premature and can lead to un-necessary anxiety amongst family members. For the physician who adopts this "worst case scenario" approach, if the patient survives, it may be at considerable expense of the family members' emotional well-being. The guiding motivational and driving force behind physicians' actions and communication should be the patients' and families' well-being, physically, emotionally and spiritually.

Another note of caution must be observed by physicians who are very familiar with family conferences, to ensure that they do not become desensitized to the process and impact of the information being transmitted to families who are usually experiencing this for the first time. The impact on the hearer of the information, i.e., the patient's family, can be very traumatic in an already highly-charged emotional area. Family members are usually under an enormous amount of psychological stress and they often tend to neglect their own nutritional and rest needs which in turn reduce their capacity to understand or absorb new information and comprehensively make decisions. Internal family dynamics can also escalate stress levels. Studies have also shown that many family members become critically ill during the hospitalization of a loved one (Higgins et al., 2007). Thus decisive and empathetic interpersonal communications skills are of paramount importance to physicians working in acute care.

## Ethics of Non-Abandonment

A final point relates to the ethics of non-abandonment. The family needs to be re-assured in cases where withdrawal of life support is imminent

that the patient will be kept comfortable and will be alleviated from discomfort and suffering. Family members also need to know that they are welcome to remain close to the patient as a source of solace and unity. Families should be made aware that the medical team will oversee any ongoing concerns that arise (West et al., 2005). Physicians regularly withdraw life saving medical treatment but they are never called to withdraw supportive care. Physicians at this point should be cognizant of the emotional and spiritual issues involved and make timely referral to the unit's chaplain or other supportive service in keeping with a holistic care model. Family conferences present physicians with many learning and teaching opportunities from refining communication skills pertaining to complex medical issues and sensitive information to being good listeners and being perceived as doctors who truly care about patients and families.

## References:

- Douglas, W. (2007). Prognostication during physician-family discussions about limiting life support in intensive care units. *Critical Care Medicine*, 35(2), 442-448.
- Higgins, I., Joyce, T., Parker, V., Fitzgerald, M., & McMillan, M. (2007). The immediate needs of relatives during the hospitalisation of acutely ill older relatives. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 26(2), 208-220.
- Jonathan, R. M. (2004). Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine*, 32(7), 1484-1488.
- Smith, S., Hanson, J. L., Tewksbury, L. R., Christy, C., Talib, N. J., Harris, M. A., et al. (2007). Teaching patient communication skills to medical students. *Evaluation & the Health Professions*, 30(1), 3-21.
- Strasser, F., Palmer, J., Willey, J., Shen, L., Shin, K., Sivesind, D., et al. (2005). Impact of physician sitting versus standing during inpatient oncology consultations: Patients' preference and perception of compassion and duration. A randomized controlled trial. *Journal of Pain & Symptom Management*, 29(5), 489-497.
- West, H. F., Engelberg, R. A., Wenrich, M. D., & Curtis, J. (2005). Expressions of nonabandonment during the intensive care unit family conference. *Journal of Palliative Medicine*, 8(4), 797-807.

---

## Upcoming Dossetor Centre Health Ethics Seminars:

Friday, 16 January 2015

### Ethical Theory and the Myth of the Average Patient: A Sorry Tale of Inattentional Blindness

Derek Sellman, RN, PhD

Associate Professor & Director, unit for Philosophical Nursing Research, Faculty of Nursing and Associate Adjunct Professor, John Dossetor Health Ethics Centre, University of Alberta

Friday, 6 February 2015

### Influenza Immunization Resistance by Healthcare Professionals

Diane Kunyk, RN, PhD

Assistant Professor, Faculty of Nursing and Assistant Adjunct Professor, John Dossetor Health Ethics Centre, University of Alberta

Friday, 6 March 2015

### First Do No Harm: Still Relevant After All These Years?

Eric Wasylenko, MD, BSc, MHSc (Bioethics)

Provincial Medical Advisor, Advance Care Planning / Goals of Care Designation Initiative Alberta Health Services and Clinical Lecturer, John Dossetor Health Ethics Centre

Friday, 20 March 2015

TBD

Michael van Manen, MD, FRCPC, PhD

Neonatal Intensivist, University of Alberta & Stollery Children's Hospitals; Assistant Professor, Department of Pediatrics and John Dossetor Health Ethics Centre, University of Alberta

All seminars take place in Dvorkin Centre (2G2.07), Walter Mackenzie Health Sciences Centre, University of Alberta, 12:00 – 1:00 pm. Seminars available via Alberta Health Services' Telehealth Videoconference.

To register for Telehealth: <http://www.bioethics.ualberta.ca/Health%20Ethics%20Seminars.aspx> or contact [dossetor.centre@ualberta.ca](mailto:dossetor.centre@ualberta.ca) / 780-492-6676, or your local Telehealth provider.

For complete details please visit the John Dossetor Health Ethics Centre website at [www.bioethics.ualberta.ca/](http://www.bioethics.ualberta.ca/)

PUBLICATION AGREEMENT NUMBER: 40064803  
RETURN UNDELIVERABLE CANADIAN ADDRESSES TO  
University of Alberta  
John Dossetor Health Ethics Centre  
5-16 University Terrace  
EDMONTON, AB T6G 2T4  
Email: dossetor.centre@ualberta.ca

# Health Ethics Today

Editor • Paul Byrne  
Assistant Editor • Carol Nahorniak  
Distribution • Stacy Cabral  
Layout • Carol Nahorniak

Health Ethics Today is produced by the John Dossetor Health Ethics Centre, University of Alberta.  
No part of this publication may be reproduced, in whole or in part, in any manner, without prior written consent of the editorial committee. All rights reserved. For reproduction requests, notification of address changes or duplicate mailings, contact the John Dossetor Health Ethics Centre.

## John Dossetor Health Ethics Centre



John Dossetor Health Ethics Centre  
University of Alberta  
5-16 University Terrace  
Edmonton, Alberta, Canada T6G 2T4  
Telephone: (780) 492-6676 • Fax: (780) 492-0673  
Website: [www.bioethics.ualberta.ca/](http://www.bioethics.ualberta.ca/)  
Email: [dossetor.centre@ualberta.ca](mailto:dossetor.centre@ualberta.ca)

The opinions expressed in this newsletter are those of the authors only  
and not necessarily those of the John Dossetor Health Ethics Centre.



Articles from Health Ethics Today  
are indexed on EBSCOhost