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Responding to Desire to Die Statements: Therapeutic Communication

*By Annie Leong, Palliative
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Introduction

*“Can’t you give me something just
to get this over with?”*

It is not uncommon for patients living with serious life-limiting illnesses to have expressed desires for an early death or to seek health professional’s assistance with hastening death. Such ‘desire to die’ statements (DTDS) can provoke challenges for all health professionals involved as they may struggle to discern the reason for the request and find an appropriate response (NH, 2010).

However unsettling it may sound, it is essential for health professionals

to recognize such DTDS as invitations for communication and opportunities for therapeutic intervention (EPEC™-O). Rarely are DTDS a request for assistance in hastening death, but rather a plea *to be heard* and *to be understood*.

Therapeutic communication framework for responding to DTDS

It is not the writer’s intention to broach moral debates on requesting of assistance with hastening death, but rather to focus on the ruling principles of therapeutic communication that can be applied across health disciplines regardless of their debate stance.

This article describes the communi-

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cation framework for responding to DTDS and the practical approaches to address end-of-life issues with compassion and professionalism to ensure access to quality palliative care.

Hudson and colleagues (2006) propose that health professionals use a framework consisting of a two-phase approach, based on four broad categories, and recommended phrases and pertinent questions, not intended to be prescriptive, but as examples to be considered when responding to DTDS. The framework draws on the principles of a person-centered and interprofessional team approach to evaluate and address effectively the multidimensional aspects of suffering underlying the DTDS.

Phase I of the early intervention should be guided by a principle that “seeks to understand, rather than just act upon the request” to help uncover the significance of the DTDS for the patient (Hudson, et al., 2006). In Phase II, by tactfully exploring and considering the broader contextual factors contributing to the patient’s request, the health professional is thus able to mobilize appropriate interventions to address the concerns.

1. Explore current feelings and fears.

“Sometimes people feel so over-

whelmed by things that they feel everything is ‘just too much,’ would you say that you have felt like that lately?”

2. Assess state of suffering and distress.

“What do you feel could be improved in your care and treatment?”

3. Explore specific reasons and plans for assisted dying, if present.

“You’ve referred several times to wishing it were all over. Can you share with me what you’re thinking in that regard?”

4. Seeking assistance with hastening death.

“Can you tell me how you’ve come to feel like this and why you want to take this action?”

Therapeutic communication principles for managing DTDS

The therapeutic response to DTDS begins with listening actively to the patient’s fears and concerns, acknowledging his/her distress and suffering, affirming commitments to continuing support, and seeking practical approaches to improve the patient’s quality of life and providing support to the family during this difficult time (EPEC™-O).

1. Be alert to your own responses.

Be aware of how personal attitudes and emotional responses to

DTDS may shape the interaction. For example, conveying a sense of shock or futility may have a negative effect and may limit further discussion.

2. Be open to hearing concerns.

Avoid responding with a quick answer ‘no’ in the way that leaves the patient in a situation of helplessness and feeling abandoned, or by answering ‘yes’ which may risk reinforcing the sense of worthlessness embedding the patient’s despair.

3. Assessing the potential contributing factors.

Unrelieved psychological sufferings, such as, loss of control, or being dependent and being a burden are the most frequently perceived motivators for patient’s request for assisted death (Back, et al., 1996). The desire to control the circumstances of death and fear of future suffering, rather than overwhelming immediate suffering, were the predominant reasons for patients receiving assisted death (Ganzini, et al., 2002).

4. Responding to specific/complex issues: practical approaches (Gallagher, 2015).

- As appropriate, investigate and treat symptoms aggressively; discuss palliative sedation for otherwise intractable symptoms.

- Facilitate connection with other members (family, team) who best communicate with the patient.
- Refer to palliative care specialist, pain specialist, anesthetist, interventional radiologist, psychiatrist, social work, spiritual care counsellor, etc.
- Understand the multidimensional aspects of the patient's suffering - personal history, previous experience with illness and death, other significant losses, hopes and dreams.
- Understand what maintains a patient's quality of life and dignity and adjust ways to provide care to preserve self-esteem.
- Give 'control' back to the patient by facilitating the ability to choose specific therapies, settings of care, caregivers and daily activities that are meaningful.
- Set realistic goals and communicate the plan clearly to patient to enhance better coping and less uncertainty.
- Encouraging patient to reconnect with family, or say some final words are important ways to maintain dignity, foster hope and promote healing.
- Some people may be clear that they have a specific request for Medical Assistance in Dying (MAID) and at the same time as exploring their thoughts and feelings and alternative ap-

proaches, it is important to support them to discuss with their physician or Nurse Practitioner. For more information regarding MAID for NH staff, visit [Our NH MAID page](#).

Conclusion

Patients with advanced or life-limiting illnesses may experience total pain and "suffering that encompasses all of a person's physical, psychological, social, spiritual and practical struggles" (Richmond, 2005). DTDS, as such, often reflect unrelieved suffering and unmet

"You matter because you are you, and you matter to the end of your life."

"We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders
(1918 - 2005)

needs that require careful attention and open communication within the therapeutic milieu of the patient-care provider relationship. DTDS warrant empathic listening that seeks to understand the patient's nature of distress and suffering and sensitively exploring their request for hastened death in context of all acceptable options for care and at the end-of-life.

This will ensure that palliative care continues to give patients and their families the best possible quality of life and support (Gallagher, 2015).

REFERENCE:

- Back, A.L., Wallace, J.L., Starks, H.E., & Pearlman, R.A. (1996). Physician-assisted suicide and euthanasia in Washington State: Patient requests and physician responses. *JAMA* 275 (12), 919-925.
- EPEC™-O: Self-study Module 14: Physician-assisted suicide. *Education in palliative and end-of-life care for oncology*, 1-34.
- Hudson P.L., Schofield, P., Kelly, B., Hudson, R., Street, A., O'Connor, M.,...Aranda, S. (2006). Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. *Palliative Medicine*, 20, 703-710.
- Northern Health (2010). CTT: Psychosocial Care. *Hospice Palliative Care Program Symptom Guidelines*, (2nd ed.) Supplement.
- Gallagher, R. (2015). Assessing and Managing a Request for Hastened Death. *Canadian Virtual Hospice*.
- Ganzini, L., Harvath, T.A., Jackson, A., Goy, E.R., Miller, L.L., & Delorit, M.A. (2002). Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *N Engl J Med*, 347 (9), 582-588.
- Richmond, C. (2005). Dame Cicely Saunders. *BMJ*, 33, 238.



click snapshots of the team



*Realities of Northern Oncology Conference 2016
(l-r) Stacey Joyce, Seth Gysbers*



*2016 BC–Northern Exhibition–Senior Fair
(l-r) Sandra Schmalz, Seth Gysbers, Jennifer Ferguson, Jenna Hemmerich*

guest articles from the region

Exploring palliative care in Kenya – the inspiring efforts by a few to serve the needs of so many.



By Kelly Third, BSN MPH, Registered Nurse, Providence Health Care

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Background:

Palliative care offers a different approach to the care of people facing life-limiting illness - it is not a substitute or alternative to treatment, but rather a vital partner in the promotion of health and wellbeing. While palliative care is most commonly associated with specialized care provided by specialized practitioners, it is not limited to the hospital or inpatient hospice facility. In fact, in many parts of the world, palliative care is most often provided to clients in their community, as part of their primary health care. (Public Health and Palliative Care International [PHPCI], 2014). Most recently, many countries have begun to integrate palliative care into the public health forum, which is arguably the level of care that has the most potential to enhance the overall quality of life of a population (PHPCI, 2014).

The World Health Organization (2015) estimates that 40 million people are in need of palliative care worldwide, and of those people, 37 million of them live in low- to middle-income countries, such as Kenya. Kenya is an important example of palliative care integration because the burden of disease is quite high, public funding of palliative care is very limited and yet with the combined efforts of a few key stakeholders, Kenya is one of only three African countries approaching full integration of palliative care - on par with many high-income countries worldwide (World Palliative Care Alliance, 2014). Kenya was the first country in East-Africa to open a hospice, in 1990, and has since emerged as an active leader in palliative care internationally.

In 2010, Human Rights Watch issued a hard-hitting report on the state of palliative care in Kenya, highlighting a severe lack of governmental investments in palliative care service, particularly for children, and inadequate access to essential pain and palliative care medications, such as morphine (Lohman & Amon, 2015). Since then, the Kenyan Hospices and Palliative Care Association (KEHPCA), along with many dedicated healthcare workers, and both governmental and non-governmental organizations, have led a tremendous effort to improve access to palliative care services. Improvements such as including palliative care in the National Patients' Rights Charter, issuing detailed plans to integrate palliative care into the Kenyan public health system, publishing National Palliative Care Guidelines, and the recent large stock purchase of publicly funded opioid analgesic in the form of oral morphine (Ali, 2016). Kenya has made remarkable strides to

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integrated palliative care throughout their country, in urban and rural settings, by enhancing existing healthcare facilities, as well as creating new amenities, such as palliative care units, outreach consultation teams, and community outpatient hospices. However, the integration of palliative care is an enormous



undertaking in any setting, and Kenya, like many low- to middle- income countries, face additional challenges of working to improve healthcare practices in resourced-limited settings. The current palliative care deficits in Kenya include inequitable access to services, particularly for children and rural communities, inconsistent access to essential medications, such as morphine, and limited palliative training in the baseline education of healthcare professionals (Lohman & Amon, 2015). It is important to note, that these deficits in Kenya are also influenced by the broader context of gender dynamics, diversity in religious beliefs, social customs and tribal traditions, as well as stigma related to death, dying, palliative care, and pain medications - held by patients, family members, and healthcare professionals. In 2015, I was fortunate enough to participate in a three month internship with KEHPCA, as part of my Masters in Public Health training, and in that time I observed several social justice issues related to palliative care in Kenya. Issues such as a pervasive reluctance to prescribe opioids to palliative patients, including children, and profound legal rights violations against people

living with a life-limiting illness - for instance, being forced off their lands after being diagnosed with cancer or HIV/AIDS. These land inheritance violations were a frequent concern of clients of various hospices I attended, and one hospice in the city of Nyeri, was piloting a 'legal aspects' clinic where they would teach their clients how to protect their legal rights to their land, property, and the inheritance of their children. The team at Nyeri Hospice responded to the unique contextual needs of their clients and it was so inspiring to see them approach this challenge with empathy and willingness to work together with lawyers, social workers and governmental agencies to resolve these issues for their clients.

One of the more distressing social justice concerns I noted while in Kenya was an apparent disinterest in dying patients in hospital and the discharge of patients with very advanced illness because they were deemed to be 'palliative' and therefore could 'no longer benefit from treatment'. The labeling of patients as 'palliative' is customary in the literature, medical training, and equally so in my practice as a palliative nurse in Canada, and although the intention is well meaning, the 'palliative' label can marginalize people, infer inaccurate expectations about their needs, and limit their access to full breadth of integrated treatment that is their human right. The human right to palliative care is universal and without discrimination, however, because of its foundation in alleviating suffering, palliative care has a



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special obligation to those who need it most (Krakauer, 2008).

It is nearly impossible to explain each of the complex challenges and exceptional successes I have witnessed during my various visits to Kenya - simply put, Kenya is a remarkable country, made so by the beautiful people who call it home. It only seems fitting that I conclude this article on yet another visit to Kenya. I am seated on warm slab of concrete with the sun at my back, listening to the children of the Nakuru Hope Orphanage where I am staying, laugh and play in the yard. This place in the world continues to replenish my faith in humanity and enduring respect of the human experience - each of our experiences, each and every day, until our last day.



Acknowledgements

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References

Ali, Z. (2016). Putting the 'public' into public health: innovative partnerships in palliative and

end of life care: the Kenya experience. *Progress in Palliative Care* 24(1):4-5.

Human Rights Watch (2010). Needless pain: government failure to provide palliative care for children in Kenya. Retrieved from: www.hrw.org

Human Rights Watch (2010). Providing Paediatric Palliative Care in Kenya. *Editorial in the Lancet* Vol. 376. P.846

Krakauer, E.L. (2008) Just palliative Care: Responding Responsibly to the Suffering of the Poor. *Journal of Pain and Symptom Management*. Vol.36(5): 505-510.

Lohman, D. & Amon, J. (2015). Evaluating a Human Rights-Based Advocacy Approach to Expanding Access to Pain Medicines and Palliative Care: Global Advocacy and Case Studies from India, Kenya, and Ukraine. *Health and Human Rights Journal* Vol.17 (2).

Public Health and Palliative Care International (2014). The Public Health Approach to Palliative Care. Retrieved from: <http://www.phpci.info/#!public-health-approach/cee5>

World Palliative Care Alliance (2014) Global Atlas of palliative care at end of life. Retrieved from: <http://www.who.int/cancer/publications/palliative-care-atlas/en/>

World Health Organization (2015). Fact Sheet N°402, Palliative Care, July 2015. Retrieved from: <http://www.who.int/mediacentre/factsheets/fs402/en/>

Contest

What do you know about “Desire to Die Statements”—*What to say and what to do?* Test your knowledge by answering the quiz below for a chance to win.

CONTEST & PRIZES

All submissions who correctly answered all questions will be entered to win a prize. Only one entry per person. Contest winner will be notified using the contact information provided in your entry. Email this page with answers, include your name and contact information to Sandra.Schmaltz@northernhealth.ca or fax to 250-565-5596.

DEADLINE Contest closes [November 1, 2016](#)

1. Maggie is a 68 year old woman who was diagnosed with multiple sclerosis six years ago. She experiences severe and constant musculoskeletal-related pain to her back and major joint areas. She no longer leaves her room and stays in her recliner for most of the time. With tears in her eyes, she tells you, “Please promise not to let me suffer.” What step(s) would you take when responding to her?
 - a. clarify what she is asking
 - b. acknowledge her suffering
 - c. listen actively to what she is communicating both verbally and non-verbally
 - d. assess for physical, psychosocial and spiritual suffering and make a care plan with her
 - e. All of the above
 - f. b and d
2. Ray is a 54 year old man with metastatic colon cancer that recurred after previous surgeries and chemotherapy. He expresses that “I wish this was all over”. You should respond next by saying:
 - a. “Tell me more about what you have in mind.”
 - b. “You can’t say things like that.”
 - c. “Are you having trouble sleeping?”
 - d. “Where do you have pain?”
3. May is a 76 year old lady with end-stage liver disease secondary to liver cirrhosis and Hepatitis C. She has severe ascites and leg edema that is poorly controlled with diuretics. She has no appetite or thirst. She is seeking to regain some control as she faces death. What options might she have?
 - a. refusing ICU admission
 - b. stopping abdominal paracentesis (drainage)
 - c. stopping eating and drinking
 - d. all of the above, when fully informed and able to make health decisions
 - e. none of the above
4. Tom is a patient of yours who has recurring brain cancer that had required multiple resection surgeries in the last six years. This has left Tom with significant left hemiparesis and become debilitated and dependent on nurse’s aides for feeding and toileting. He has asked you to help him commit suicide. This request should be:
 - a. held privately between the two of you
 - b. immediately referred to the hospital ethics committee
 - c. also discussed with other health care colleagues
 - d. declined without discussing the subject
5. Joni, 55 year old, is diagnosed with Amyotrophic Lateral Sclerosis (ALS) ten months ago. Joni’s condition deteriorates rapidly, and she becomes angry, frustrated and refuses medication and care. She indicates that she wishes to be left alone to die in peace. What initial strategy best addresses her request?
 - a. Acknowledge her anger and competency in decision-making and encourage her to find meaning in each day.
 - b. Request for a psych-consult to assess for depression and provide closer supervision.
 - c. Explore with family Joni’s previous coping mechanism and seek advice on how to manage Joni’s feelings.
 - d. Explore Joni’s feelings and wishes and involve family and the interprofessional team in reviewing her goals of care.

Please print clearly

Name: _____

Address: _____

Contact (Email): _____

Fax to Sandra Schmaltz @ 250-565-5596
Or email Sandra.Schmaltz@northernhealth.ca