



Graphic courtesy of Dr. Arnell Baguio

Photography by Daniel Ho

by
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Dr. Arnell Baguio, MD gave us a primer on this difficult and sensitive topic last month. He is the Education Lead in the Division of Palliative Care at Southlake Regional Health Centre and Stronach Regional Cancer Centre. In addition, he is also a lecturer and clinical teacher at University of Toronto.

Dr. Baguio was trained in Family Medicine and Palliative Care Medicine at Queen’s University in Kingston, ON. He practiced Family Medicine earlier in his career but became a full-time palliative care physician at Southlake in the last five years.

His areas of practice include out-patient / ambulatory palliative care clinic in the Stronach Cancer Centre, in-patient consultation and palliative care unit at Southlake, and home visiting palliative care within Newmarket–Aurora and surrounding areas.

This is what Dr. Baguio had to say.

Palliative Care in Our Community

What I am hoping to achieve tonight is to understand what an illness experience is; to appreciate the role of palliative care; to discuss some important medical concepts to help with the palliative care discussion; and to describe hospice and palliative care services in the community.

What is a good life?

Happiness, health, love, good friends, a motorcycle, wine, having a good spouse, children that grow up to be wonderful people – all these things contribute to our notion of a good life.

Now, even if you possess all the aspects of a good life, what if you are diagnosed with a life-limiting disease? What would worry you? The future well-being of your children, your own life expectancy, your spouse, how are things going to end?

The Illness Experience

The term illness experience refers to the way in which people define and adjust to perceived interruptions to their health. It is the subjective experience of how you feel as opposed to the objective experience of the doctor telling you what is wrong or identifying the disease.

The value of distinction between these two terminologies is that it allows us to acknowledge that people can be ill without having any disease, and can have a disease without being ill. Just because you are healthy doesn't mean you are living well.

What is Palliative Care?

The treatment when you go to your specialist is all about the disease. Sometimes we forget that the illness experience for each one of us will always be unique. It will never be the same for each one of us. Sometimes there is a need to refocus and look at a different philosophy of care and look at the experience of the patient. This then becomes the rebirth of an old philosophy that we in healthcare are just beginning to understand - the priority needs to be the patient's illness experience not just the treatment of the disease.

That is what palliative care is all about - it is focusing on the patient's illness experience rather than just what healthcare can do for you. We can tailor the treatment based on what things are important to you and what things you are most worried about.

The term palliative care comes from the Latin word "palliare," which means to cloak. The World Health Organization defines it as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual."

When is Palliative Care appropriate?

When is palliative care appropriate? The traditional (old) model delineates the role of palliative care as exclusively to end-of-life care – "when nothing else can be done." This idea is pervasive even until now.

The current (new) model talks about you doing your restorative or curative treatment but as you are going through that you may experience some palliative care issues. This is particularly common among cancer patients where you may experience fatigue or lack of appetite. Palliative care can help you with that; it may recommend a change of medication or counseling therapy, for example.

We take a team approach.

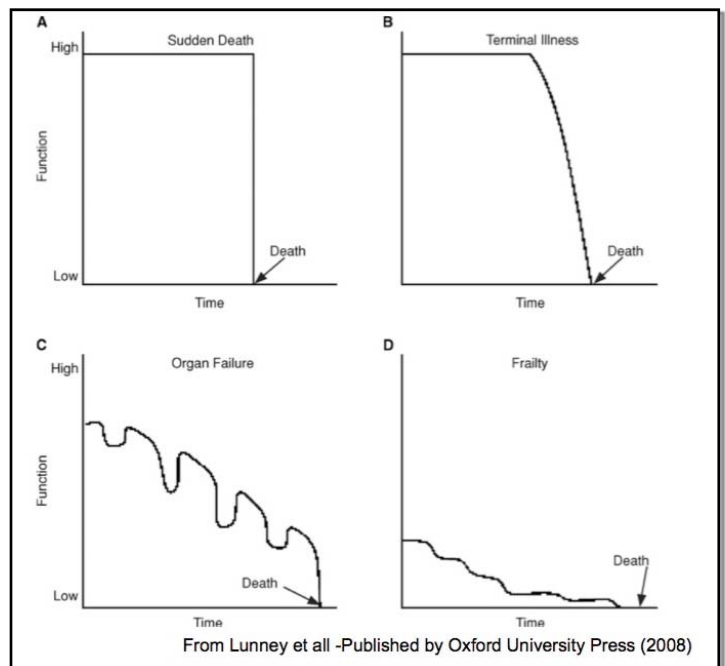
When is palliative care appropriate? The answer is really: at anytime throughout the disease trajectory.

Who will benefit from Palliative Care?

The illness experience is affected by the illness trajectory based on the type of disease the person has. There are four general categories: The first one is called sudden death – unexpected - like a car accident or a heart attack; the second one is called terminal illness, like incurable cancer where you can predict what the end-of-life timeline would be; the third one is called organ failure like kidney disease, liver disease, COPD (Chronic Obstructive Pulmonary Disease) or heart disease; and the fourth one is called frailty, a good example would be neurological disease which typically involves the brain and the nervous system - dementia would be one example.

In Canada, organ failure is the most common cause of death (33.8%) while frailty is next (29.3%) followed by terminal illness (28.4%) other causes (5.6%) and finally sudden death (2.9%). Sudden death is so low because we have come such a long way in managing patient health like preventing sudden death by heart attack by pre-diagnosing risk factors like high blood pressure and cholesterol levels. Also, people are generally more aware these days of what makes for a healthy life style.

Who will benefit from palliative care? The answer is: anyone with a life-limiting illness.



Life-Limiting Illness Trajectories

Benefits of Palliative Care

Palliative care helps in reducing symptom burden because we address the effects of the disease or the effects of treatment. There is less anxiety and depression; less caregiver burden; less aggressive treatments; and it provides ongoing support throughout the illness trajectory. There is better quality of life and perhaps even improved survival.

We know this because in 2010 there was a study done examining metastatic lung cancer and the effects of palliative care on outcomes. The outcomes, for those introduced to palliative care early in the illness trajectory, were; decreased depression and anxiety, improved quality of life, reduced ER visits and reduced aggressive interventions at end of life. The survival benefit proved to be about three months of life extension to those exposed to palliative care early rather than later. Under these circumstances three months of extended life is a huge bonus. By comparison, the success of a new drug in this situation would be measured in terms of a couple of weeks of extended life.

The utility of palliative care for most of us is focused much more on maintaining function, improving quality of life, symptom management, and prioritizing goals. Therefore, palliative care is so much more about life and living than it is about death and dying.

Palliative care is an approach - it is not a service or a physician. Palliative care can be done pretty much by anybody who can help you prioritize the things that are important to you.



Dr. Arnell Baguio

Key Concepts

In order to better understand and appreciate what palliative care is, it is important to understand some of the key medical concepts; Code Status, Do Not Resuscitate (DNR,) Goals of Care, Advance Care Planning (ACP), and Substitute Decision Maker (SDM) or Power of Attorney (POA) for personal care.

Code Status refers to the level of medical interventions a patient wishes to have started if their heart or breathing stops; this ranges from Full Code which is aggressive investigations and interventions to Comfort Care which is interventions and/or medications for comfort and allowing natural death to occur.

Full Code or Full Resuscitation includes CPR, intubations, ventilation or breathing machines, IV lines and ICU stays.

On TV, the success rate of CPR is about 90%. Unfortunately, that is not what happens in real life. In reality, the success rate is low, about 5% to 15%; only about 2.6% of resuscitated patients make it out of the hospital. For those that are able to go home, survivors experience poor quality of life because the heart is weak and the brain may have been damaged due to lack of oxygen. Poor predictors of survival include advanced age, the patient's health status prior to resuscitation, and residence at a nursing home which could very well be because of the patient's advanced age to begin with.

DNR – Do Not Resuscitate

What does it mean to have a DNR? DNR is only about whether you want resuscitation or not; it is not about whether you want antibiotics or your broken leg fixed. This is only about if your heart were to stop or if your breathing were to stop would you like the doctors to intervene to stop you from dying?

DNR or Do Not Resuscitate – a.k.a no code or allow natural death – is a legal order – a form from the Ontario Ministry of Health – written either in the hospital or elsewhere and signed by a doctor or a nurse who have discussed your wishes with you to withhold cardio-pulmonary resuscitation (CPR) or advanced cardiac life-support (ACLS) in case the heart or lungs were to stop.

The DNR confirmation form is a directive to emergency personnel that this patient doesn't want any resuscitation. DNR withholds aggressive measures at end of life; it does not mean no treatment at all. Appropriate treatment for underlying disease can be given. Medications for comfort will always be provided.

DNR is not assumed automatically – meaning you have to specify that you do not want resuscitation. To ensure that

this is clarified, it is important to have a discussion with your healthcare provider and your family regarding goals of care. The DNR form has a serial number and is not available online.

Goals of Care

Goals of Care is a medical order used to describe and communicate the general aim or focus of care including the preferred location of that care. It helps to clarify expected (or desired) outcomes of certain intervention, extent of treatment and alternative options if goals are not achieved. Regardless of what your goal is, make sure that it makes sense to you. Often this is described in living wills or Power of Attorney papers.

Substitute Decision Maker (SDM)

If and when it gets to the point where you can no longer make decisions for yourself you will need a substitute decision maker. A substitute decision maker is a person who makes care decisions for another person when they are incapable of communicating their own wishes. This includes Power of Attorney (POA) for personal care who can only make health care decisions - not financial decisions.

Advance Care Planning (ACP)

Advance Care Planning is a process of thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important to you if you were ill and unable to communicate.

What is Death?

In our culture death is often associated with something negative; something we don't like; something that is horrifying and scary. It is the opposite of all things good. But is that really true?

According to one of my colleagues at Southlake –

“Death is not the opposite of life... birth is. Life is what happens in between.”

Rev. Eric Schultz, Chaplain
Stronach Regional Cancer Centre

I would put it to you that death is neither good nor bad, it is just a fact of life. It is in life that we make mistakes; it is also where we make amends, where we say, “sorry.” The challenge is more about the living than it is about death. We only die once.

Is it possible that death is not bad? And for a person, is it

possible to even have a good death? What would be a good death? Is it, to die in your sleep? To die surrounded by family? To not be in pain or suffering? To maintain dignity? Or, to die in your place of preference?

What is a “good” death?

“Here’s the reality. We’re all gonna die. Everyone standing in this room is gonna die one day. And it’s good to have a little bit of a say in how.”

– Dr. Jessica Zitter, ICU, Palliative Care Physician,
Extremis – Netflix Documentary 2016

Courtesy of Dr. Arnell Baguio

Advance Care Planning

This is what Advance Care Planning is all about. The decisions we make now will affect the future. It starts with you asking the important questions about yourself - your fears, your joys, your worries, your successes.

The steps to make an ACP plan are:

Steps to Make a Plan

Step 1: Think – What makes your life meaningful?

Step 2: Learn – Familiarize yourself with relevant terms

Step 3: Decide – Who will speak on your behalf?

Step 4: Talk – Start the conversation

Step 5: Record – Write down your plan

** Review with each change in health status

Courtesy of Dr. Arnell Baguio

And, go back and review each of these steps with every change in your health status.

A life well lived is one without regret, and having a plan helps with this because you have specified what you want.

Where is Palliative Care provided?

Anywhere! It could be at home including a nursing or retirement home; it could be in a residential hospice; or it could be in the palliative care unit in your hospital. It often depends on where you are receiving your other healthcare services.

Currently at Southlake, there is a Palliative Care Unit in the hospital which provides some access to members of the community.

Palliative Care Services

- At Southlake:
 - In-Patient Consult Palliative Care Team
 - Palliative Care Unit
- At Stronach:
 - Out-Patient Pain and Symptom Management Clinic
- In the community:
 - Family physicians and NP primary care providers
 - Visiting Palliative Care Physicians
 - Community Care Access Centre (CCAC)
 - Hospice and Palliative Care Network (York Region only)
 - Day Hospice Programs
 - Residential Hospice

Hospice

- Day Hospice – provides out-patient and home supportive services to patients and families. Examples:
 - Doane House Hospice – Newmarket
 - Hospice King/Aurora – King/Aurora
 - Georgina Hospice – Northern York Region area
- Residential Hospice – care facilities for EOL care. Examples:
 - Hill House Hospice – Richmond Hill
 - Matthew's House – Alliston
 - Margaret Bahen Hospice (still in construction) Newmarket

Courtesy of Dr. Arnell Baguio

Summary

In summary, the illness experience is always personal. Only you can express what you are experiencing.

Palliative care aims to alleviate suffering in all domains of the illness experience: physical, psychosocial, and spiritual. It can be of benefit to engage palliative care services early in the illness trajectory.

Key concepts are important to clarify your goals of care for the palliative care discussion. Code Status, DNR, Goals of Care and Advance Care Planning—these things are important to understand and discuss.

And finally, **Palliative Care is for ANYONE, ANYTIME, ANYWHERE.**

~ ~ ~ Notes from The Chair ~ ~ ~

Happy Valentine's Day!! Prostate cancer is a “couple's” disease so remember to treat your special Valentine to an extra hug.

Our presentation last month from Dr. Baguio was very enlightening. He made his presentation interactive from the beginning and it was impressive to see how everyone became engaged in the conversation and discussion. I think we all came away grateful for being a part of the evening.

This month we are back to a peer-to-peer discussion. At the time of this writing we are expecting as many as three new members to attend so I am hopeful a number of current members will be in attendance. The more experiences we give these new members to draw upon, the more beneficial the meeting will be for all of us. Our last two peer-to-peer sessions had great interaction between the attendees, with a lot of positive energy within the group. Members shared their journey results and information gained from research conducted. We do not recommend procedures, but it is very beneficial to new members starting out to know they are not alone; and that many of us have walked the walk for the journey they are entering. The more information they can gather about our successes and setbacks, the better prepared they will be to ask the pertinent questions of their physicians in regard to their particular situations.

At our upcoming March 16th meeting, Dr. Jack Barkin, Associate Professor at University of Toronto and Director at Can-AM HIFU, will be presenting on High Intensity Focused Ultrasound (HIFU) as an option to conventional treatment of prostate cancer tumours. Depending on the size and location of the tumour, this treatment apparently has proven successful with minimal side effects. However, at this time, this treatment is not covered by OHIP. Find out if you may be a candidate for this alternate treatment. We do have some members of our group that have received this treatment and we hope they may be willing to attend to discuss their experience and possibly present their journeys.

I would like to acknowledge the special contribution from Harry Gray to help support our PCCN group. Harry is unable to attend the meetings, but expressed his appreciation for the newsletter with a generous donation. **Thanks Harry!!** We will have to get you out to the BBQ this year so we hope you will plan to attend.

We look forward to seeing everyone on Thursday, February 16, 2017.


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