

Interview with

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**2023 CCRA Awardee for Outstanding
Achievements in Cancer Research**



How have your research accomplishments contributed to the improvement of supportive and palliative care around the world, including your co-founding of the Canadian Virtual Hospice?

The work that my research group has been doing for nearly 35 years has explored what I think of as the experiential landscape of palliative care. We are trying to understand the psychological, existential, and spiritual dimensions of encountering a life-threatening disease and how patients, family members, and healthcare providers navigate that dimension of illness. We have examined different elements of the life-threatening experience, including a desire to die, will to live; feeling of being a burden to others and things are even more ephemeral, but nevertheless that shaped experience for patients who were living with cancer.

We began looking at the issue of dignity and how understanding dignity offered insights in terms of how people were coping or not in the face of a life-threatening or life-limiting illness. As a result of that research, we developed a brief psychological intervention dignity therapy, which is a way of enabling patients to create, with the facilitation of a trained therapist, a legacy document. It is an opportunity for patients to create something tangible they can leave for their family members who will soon or eventually grieve their loss. We also have developed outcome measures that allow us to track elements of experience that were previously too difficult to gauge. We've come up with an instrument called the Patient Dignity Inventory, which measures physical, psychological, existential, and spiritual dimensions of experience for people who are living with life-threatening and life-limiting conditions. We've also developed approaches that allow healthcare providers to elicit personhood. This allows us to engage patients in a way that acknowledges *who they are* in addition to whatever ailment they have. This helps improve patients' and families' experiences, knowing that the uniqueness of who they are as individuals will be acknowledged and that patienthood won't eclipse personhood.

One project that we developed many years ago is the Canadian Virtual Hospice. This came about because we realized that palliative care was in short supply, and the internet and web-based platforms provided a way to make this scarce resource more omni-available. Putting those two together resulted in what is now the world's largest repository of information and support for patients, families, and healthcare providers. It is utilized by people around the world, most prominently here in Canada and more broadly in North America and sees about 3.4 million visitors each year.

I hope this work has helped shape experiences for patients, families, and healthcare providers as they encounter life-limiting and life-threatening conditions such as cancer.

What is dignity-conserving palliative care and what is needed to ensure that all cancer patients have access to it?

Dignity-conserving palliative care is really an approach to palliation that makes sure that dignity and the preservation of dignity is kept within our focus as healthcare providers. One of the interesting things that informs this approach is the realization, substantiated by empirical work, that the disposition of the healthcare provider in terms of how he or she views or appreciates their patient has a profound influence on patient experience. To enact dignity-conserving palliative care, we have done a great deal to try and look at the ways healthcare providers experience their patients and to provide them with tools so they can be aware of how their own attitudes or behaviours influence the kind of care they deliver. For example, we had introduced something that we call the platinum rule, which allows, no, it in fact *demand*s that healthcare providers acknowledge their own biases so as not to taint their care of the patient in a direction that might be influenced by what they would want in that circumstance without considering very carefully what the patient might want given their own life experience, outlook, and vantage points.

What sustains you to continue your research program with such vigor and drive?

It is always gratifying to see how others have taken to the work, responded and build on it, moving it further along the research path, benefiting people who are living with these serious conditions. Having students who find themselves enamored with this area is very motivating!

The interesting thing about palliative care research is it gives you a way of entering into issues that are quite fundamental to understanding the human condition. I've always considered palliative care research as a vantage point, a position from which we can understand the human condition and our findings having resonance across the entire human life cycle.

Whether we are talking about preserving dignity, acknowledging personhood, making sure we are attentive to the entirety of an individual—these are things palliative care doesn't have a monopoly on. Anybody entering a healthcare encounter wants to know that they are being fully seen and attended to. Seeing students and practitioners come to that realization, and the potential it has to transform their work, is personally sustaining and invigorating.

The other thing that is humbling and gratifying is seeing how the work has been taken up internationally. Even though there are cultural nuances and geographic variations, the reality is that everyone has some basic, fundamental experiences that are at the core of what it means to be human, vulnerable, and mortal. Seeing other clinical programs and research units around the world embrace this work, apply it, and extend it into other areas of medicine is wonderful. While much of what we do continues to focus on palliative care, the issues that we uncover really look at what happens and how do people experience an undermining of their sense of personhood. It's not surprising that we see other conditions, other life experience where people encounter an undermining of their sense of personhood, has seen some of our innovative approaches taking hold. For example, people who are incarcerated and live with truncated autonomy sense an undermining of their sense of personhood; patients who are dealing with significant mental

illness where the target organ is self; or people who are experiencing some degree of cognitive decline—the common denominator is personhood begins to fracture, is undermined and sense of personal integrity begins to shatter. It is no wonder that programs interested in those issues are taking some of our work from end-of-life care and applying them within their context.

How do you nurture you own wellbeing given the pressures and stresses of your research and clinical roles?

First and foremost, I have a wonderful family. I also feel blessed to have a lot of curiosity about life and the things that give life meaning and purpose and beauty—music, the arts, culture—all are passions that provide balance to what happens in the work arena. I must also say that there are elements of work that nurture well-being. To do good research, one needs to be creative and embrace the creative process. I find doing research has given me a place where I can be continuously curious.

No two days are ever the same. The nature of research is always trying to push the envelope; hence, the things you find yourself engaged in are new and unknown. Trying to find answers and new inroads into places that you haven't previously explored is nurturing, invigorating and makes the work exciting!

I fell into doing palliative care research back in the early 90s, with one research project that just happened to be in the area of palliative care. I was smitten. I had always been a clinician and I enjoy clinical work, but research provides a counterpoint with a different timeframe and a different kind of reward system. The two of them are mutually complementary and certainly have made for a career that I feel privileged to have and continue to enjoy.

What words of wisdom can you share with aspiring clinician-scientists interested in pursuing palliative care research?

If palliative care research is something you are curious about, based on my experience, it's certainly that can enrich your career in ways that you likely can't even begin to imagine. The difference is really a shift in paradigm, where rather than solving the problem of the person, you are now trying to solve the problems that plague persons in these circumstances. That is so intellectually invigorating.

Research requires being able to delay gratification, if for you gratification is the end product. I think part of being successful in research is enjoying the journey, enjoying each stage of the creative process and the investigative process. It is a long time in coming until you get the correspondence from the editor who says the final edited copy of your paper is now in press. If you enjoy pursuing knowledge, being reflective about various problems and approaching them at a macro level, it can enhance your work experience and complement your clinical experience. The other thing that happens is it creates connections with an international community of like-minded individuals who, like you, are trying to understand the essence of the human and come up with something that might mitigate the kinds of harms and suffering that can undermine the quality of life for people who are approaching death.