



SPIRITUAL AND RELIGIOUS CARE OF THE HOSPICE PALLIATIVE CARE CLIENT

Rev. Dan Cooper

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¹ A companion kit entitled *Conversations on Caring – Volume 1* is available through the CHPCA Marketplace (www.chpca.net) for use in Canada in staff development, continuing professional development (CPD) and health sciences education.

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Suggested Process and Learning Objectives for Problem-based, Small Group Learning and Local Staff/Professional Development Learning Circles

INTRODUCTION AND SUGGESTED LEARNING OBJECTIVES

INTRODUCTION

This transcript is a web-based version for use with a companion MP3 professional development podcast. This MP3 session is also part of a larger set of digital audio recordings forming a resource entitled *Conversations on Caring, Volume 1 (CoC)*. CoC is a learning resource which has been prepared from previous Pallium Project professional development events. These events are the *Monthly Continuing Professional Development (CPD) Audio-conference Program* series. The *Monthly CPD Audio-conference Program* series was supported in 2005 and 2006 through a contribution from Health Canada's, Primary Health Care Transition Fund (PHCTF) as part of Primary Health Care Renewal in Canada. The views expressed in these sessions do not necessarily reflect the official policies of Health Canada or the employing organizations of members of the Pallium Project's, Community of Practice. These materials have been prepared as "reminder resources" for participants of the original CPD sessions and as learning resources to help support improved access and enhanced quality for provision of Hospice Palliative Care in Canada.

The MP3 audio files and this PDF of the written transcript have been post-produced from the original event in order to provide essential information and enable use, generally within 1 hour time blocks. Each of the sessions has been based on topics which practicing Registered Nurses have identified as important to improving practice and service locally as part of a 2005-2006 audio-conference series entitled *Improving Care in Our Communities*. While program-developed and organized principally from a nursing process and case-management perspective, sessions reflect the inter-professional and trans-disciplinary perspectives of both the Guest Resources/Invited Panelists and the local participants, many whom reflect a diversity of perspectives of social workers, spiritual care providers, primary-care physicians, hospice/palliative program volunteers and others.

SUGGESTED LEARNING OBJECTIVES FOR THIS SESSION

By the end of the session the participant should be able to discuss all or part of the following:

- The inclusion of spiritual care as one element of the CHPCA Norms of Practice.
- Key ideas and concepts comparing and contrasting spirituality and religion.
- Essential tenants of contemporary spiritual care within hospice palliative care.
- The role of a spiritual assessment in care provision and in addressing spiritual/existential-linked pain and suffering.
- Common indications of spiritual pain.
- The importance of inclusion of spiritual pain assessment within differential diagnosis processes.
- Key considerations in treatment of spiritual pain.
- Key considerations in who should be engaged within the care team to help treat spiritual pain.
- Spiritual care interventions that might be appropriate for the primary-care professional.
- Indications for the primary-care professional of when religious care may be appropriate.

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Guest Resource

Rev. Dan Cooper

Regina Qu'Appelle Health Region (RQHR), Palliative Care Services

Moderator

Jacque Peden, RN, MN

Original Air Date – March 24, 2005

JACQUIE PEDEN

Dan we are really pleased that you are able to speak with us today. Can you tell us about your role as a chaplain?

DAN COOPER

My role in Chaplaincy in the field of hospice palliative care began 10 years ago in Regina, Sask where I was invited to serve as the first full-time chaplain in hospice palliative care. In that period of time that role has expanded considerably, but to describe it basically, it would be an ecumenical and multi-faithful role in which I am employed by the Regina Qu'Appelle Health Region Palliative Care Program to be their designated chaplain or spiritual care provider for hospice palliative care. This is a full-time role and it is multi-site.

I see patients in our palliative care program in any location of care. That would include our acute care palliative care unit, any other acute care location in the Regina area, it would include our community hospice, any other long-term care facility in the Regina area in which our clients are located, and it would include home care. The role is a direct care role. It is also a teaching role and an administrative support role in that I assist the department in its development in a number of ways. The qualifications for this type of thing may vary from location to location. If you are interested in that, maybe that could come up as a question later?

JACQUIE PEDEN

Okay, thank you. Dan could you tell us what a model for spiritual and religious care in hospice palliative care look like?

DAN COOPER

Sure. I think that the first thing I would like to say is that the Canadian Hospice Palliative Care community has reached some significant level of agreement about the importance of spiritual and religious care in hospice palliative care. If we look at the "Model to Guide Hospice Palliative Care" which is our main line document for the evolution of hospice palliative care in Canada -- and I am addressing particularly page 15 figure 7 which discusses domains of issues associated with illness and bereavement -- it can be seen that spiritual care is one of eight domains being identified as relevant to hospice palliative care.

Spiritual care in a variety of ways needs to be included in both the Square of Care, which means the way in which we provide care to hospice palliative care patients, and the Square of Organization, which refers to the institutional development of these principles. How are we actually going

to provide the personnel and the resources necessary to make sure that in this particular case spiritual care is actually carried out the way we say we are going to carry it out?

There is something of a challenge there in hospice palliative care to further develop both the Square of Care and the Square of Organization, but particularly the latter. So, I just want to continue to answer that question about the place of spiritual care in hospice palliative care. If you happen to have "A Model to Guide Hospice Palliative Care" in front of you, you can follow me, otherwise you can certainly obtain one from the CHPCA. *Editorial Note: A PDF version of A Model to Guide Hospice Palliative care can be accessed at www.chpca.net under the CHPCA Marketplace link.*

You will note that they define spirituality as including matters of "meaning and value" (the value part may broadly be considered "ethics"). It also has to do with that which is "existential" -- being related to who I am as a person. Spirituality may improve our ability to manage circumstances by placing things in a broader context of meaning, values, beliefs, practices and affiliations in the community.

Community affiliation is important because when we get into hospice palliative care, whether it is in a hospice facility or whether it is in hospital or whether it should actually be at home, we can become isolated. So, affiliations are important. Spirituality might include "spiritual advisors, rites and rituals, symbols and icons." This has really a broad range of suggestions for us that talk about spirituality and religion (and I will define these later). These things are important in total care. There's just a great deal of evidence to suggest that spiritual and philosophical matters and religious matters can become increasingly important for people at the end of life and for their caregivers. We want to make sure that it is included in our care and our organizational structure.

JACQUIE PEDEN

Great. You said you were going to describe what the difference really is between spirituality and religion?

DAN COOPER

Sure. The first thing I'd like to say is that it is perhaps best to understand them not so much as different, simply as different aspects of the same thing. I think that idea is generally well supported in the interdisciplinary literature around spirituality and religion in hospice palliative care.

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I would like to say that spirituality might be considered, in a mathematical sense, to be “the set of the whole.” It has to do with “the beliefs, values and relationships which are most central to us and around which we organize our lives.” You might also use the cognate term, “philosophy of life” as another term for spirituality. A person who doesn’t have any sense of themselves in a religious way might say, “well, I still have a spirituality” in a broader way. An atheist or agnostic or humanist might say, “I don’t like to use the language of spirituality” and could be comfortable saying, “I have a philosophy of life.” I would suggest that for the purposes of this conversation that it is reasonably helpful to talk about spirituality or philosophy of life as the same thing expressed differently. That is pretty well supported by the literature.

Now “a sub-set” in that is religion. It has to do with affiliations and practices that are important. This may be formal religious connections, religious entities or organizations in the community (like a church, synagogue, temple or healing circle). Or, it may be the individual’s personal, eclectic ways of practicing some of these things, such as prayers and meditation or other disciplines that are helpful, that they may have taken from a tradition somewhere.

I would simply say that it is helpful to think about spirituality/philosophy of life and religion somewhat distinctly. It may not be philosophically or theologically entirely accurate to push them too far apart, but it is helpful to see them as different because in clinical practice people often present as “more spiritual than religious”, or “spiritual rather than religious”, or “philosophically inclined but not religious,” and so forth.

JACQUIE PEDEN

While you were talking Dan, it came to mind that someone had told me one time that everyone is spiritual but not everyone is religious?

DAN COOPER

Well, I would personally be very content with that statement myself, as an individual. I am, however, quite prepared to recognize that there are people who want the care that a spiritual care provider/chaplain can offer but not want us to use the language of “spirituality.” I think it is important to recognize that there are many humanists that do not like the terminology around spirituality (spirit, soul, God, sacred, eternal, etc.) – those terms are just not going to work for such persons, but I believe that we can still offer them appropriate, philosophically based care. Now I would call that spiritual care, but I don’t require that somebody else call it that.

JACQUIE PEDEN

What is spiritual care?

DAN COOPER

I am going to give you a definition and some of these definitions are available for you through the conference organizer here today if you want them later. I would say that spirituality and spiritual care may be identified as “care of persons focusing upon the personal beliefs, values and core relationships around which the individual organizes his/her existence,” regardless of affiliation, or lack thereof, of any faith-tradition or community. Now that summarizes so far what I have already said.

Spiritual care may address questions of meaning, purpose, hope and faith in a manner that is “individually appropriate” -- that is key. Whatever we offer in spiritual and religious care must be “individually assessed and individually appropriate.” The same shoe does not fit all sizes. I want to say that well-qualified and well-certified individuals functioning as members of an interdisciplinary team usually provide such care to highest possible standards. Effective spiritual care, if it is well done, will reduce spiritual pain or suffering through meaning-based and hope-based therapies.

Perhaps it is helpful to do the very same definitional work around “pastoral or religious care.” “Pastoral” care is a little bit more of a Christian terminology. It is one way of doing “religious” care. More generally, religious care may be defined as care of persons who claim an affiliation with a religious tradition or faith community or community of beliefs, values and practices, in a manner that is appropriate to that tradition or community. It may include such things as sacramental care, customary prayers, sacred readings, rites and ceremonies, supportive conversation, “pastoral” conversation, etc. Religious care must normally be provided by qualified and designated individuals, professionals or volunteers from that religious tradition.

The role of the spiritual care provider in hospice palliative care is not necessarily to provide religious care, but to ensure that the appropriate religious care is arranged and provided as required. Effective religious care is important, and I want to say that sometimes the word “religious” gets bad press, but it really important to people’s health care. Effective religious care connects an individual with customary sources of faith and hope and surrounds an individual with supportive community. Appropriate consents are required to make those kinds of connections and referrals but they are normally quite easy to facilitate and well worth the time. Lots of studies around health care today indicate the importance of religious and community connection to ill people generally. This is certainly true in terms of “coping” as Dr. Kenneth Pargament and others have documented in their extensive research.

JACQUIE PEDEN

Probably the first thing a person would need to do is how you actually identify the needs, the spiritual needs. How do you know that you need to provide care?

DAN COOPER

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Well, the first thing I can say is that just as a person coming into hospice palliative care will need pain and symptom management -- that can be an obvious reason why they are there -- an assumption can be made that an appropriate assessment of spiritual and religious resources and needs ought to be performed by a qualified person. It is simply a part of the care model. If the hospice palliative care model is defined by the CHPCA to include spiritual care as a core component, it needs to be provided. So, consequently, in order to do this holistic assessment somebody needs to assess spiritual pain and suffering, and ask whether or not the person has access to all the resources they need in this area, and whether or not they need help.

Now I am going to talk a little bit about spiritual pain and its assessment. This is a very broad piece but it answers your question more specifically. I am going to read from a definition I provided and, again, this is available to you post conference. Spiritual pain may be defined as "the client's experience of existential distress or the perception of suffering." This unwelcome state generally arises after a "negative appraisal" of the management or the meaning of pain and other symptoms. In other words, the pain and symptoms I am having are causing me greater distress than the mere physical pain I am suffering. I may wonder why I am having this problem? I may wonder how "just" it is that I or a loved one has this problem? I may wonder why it is not being controlled, or what it means about my future?

When our experience raises these kinds of questions, and when we appraise our experience negatively, this causes spiritual pain. Other things that could evoke such pain might include the diagnosis itself, the treatment regimen and related ethical dilemmas, or the prognosis -- in other words looking at the future and thinking "this is not going well and what does that mean for me?" Specifically, what might these things portend for one's lifestyle, relationships, sense of self and one's personal survival or "place in this scheme of things?"

I want to discuss quickly a really important concept here related to the notion of spiritual pain, sometimes called "cognitive reframing." It is also understood in the spiritual care literature as "theological reframing." One of the things that can happen to us when we have any life crisis or serious illness is that "the picture of our lives" -- which in a sense can be figuratively imagined to be placed on the wall of our living room -- suddenly drops to the floor from a little earthquake or when somebody slams the door. The picture falls off the wall and is shattered. The glass is broken. The frame is broken or bent. Maybe the picture itself is actually warped in some way. We may feel a profound sense of loss and increased stress caused by the fracture of this picture of ourselves, and the meaning of our lives that it represents.

The important task is to help persons put that picture back up on the wall in a reasonably intact manner. This is the clinical role of the Hospice Palliative Care Spiritual Care Provider. The task is to assess the nature of the damage to

the person's self image, and to map the resources they bring or may yet need to access, in order that the picture can somehow be re-glued or put back up on the wall, with perhaps a fixed or fresh frame or some new glass. You will still see the fracture mark. It does not exactly look like the picture used to look, but it is still the same person. They may see themselves again in a newly defined or reframed existence. This is the fundamental quandary and opportunity, if you will a spiritual quandary and opportunity for growth, that people who have life limiting illnesses and their loved ones often experience.

JACQUIE PEDEN

How does a person actually fix that picture? What would you do?

DAN COOPER

I am going to address that in one moment. But, first, I want to talk more about indicators. How do you know that that a life-picture has fallen off the wall? Spiritual pain may be indicated by the client's apparent distress, anxiety, anger, fear, sadness, despair, depression and, in general, expression of feelings of helplessness, loss of control, diminished function and decline in the quality of life, loss of meaning and purpose, hopelessness, stated struggle with belief systems or a sense of social isolation. Spiritual pain should be considered in a differential diagnosis as a possible cause of intractable symptoms. It is important to ask, when you can't fix distress by usual treatment measures and methods, what else could be behind that? Spiritual pain is much more difficult to manage than physical pain. Unresolved spiritual pain often results in a diminished ability to cope, reduced quality of life, problematic management and compromised outcomes. The person most at risk for injury from unresolved spiritual pain or distress will be one who indicates high religious or spiritual needs and has minimal or no access to appropriate personal, professional or community resources to meet their perceived needs.

Now, the treatment of spiritual pain involves the following things. First, the individual assessment of needs and resources, and I can't stress how important it is that be done by a trained person. No one would want an untrained nurse or an untrained physician doing a medical assessment. The very same thing needs to be provided by a trained, qualified care provider in the spiritual realm. Please understand that your typical community clergy are not generally qualified to do this. I am prepared to make this statement and stick my neck out and do that. That is something that generally we are not taught in Seminary, it is something that is learned in post-graduate training.

Secondly, determination and removal of the blocks to effective spiritual and religious coping. That might be considered as part of the process of reframing by skilled primary intervention counseling. Very few hospital chaplains, let alone community clergy are qualified in psychotherapy or have graduate level counseling qualifications but many are

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skilled primary counselors, or have training, or can acquire the same. It requires the improvement of spiritual and religious coping mechanisms by these skilled interventions. It requires the facilitation of access to appropriate resources and it requires team-based consultations and referrals.

One of the great challenges to the hospice palliative care programs of today has been with the Square of Organization. Will we be able to introduce the care principals of spiritual care in our organization by placing chaplains inside the health care team? We simply aren't provided with that in most locations. I know that I am one of perhaps a couple of dozen in Canada who have any formal team connection in hospice palliative care.

Very generally speaking, we rely upon outside members of the community, outside of the care team (community clergy on contract) and what often happens is that these people don't have access to the consulting and information network which is so important in care. So, I want to just stop this part of it right there. I think I have said enough about that and I certainly can't go through an assessment model for you.

JACQUIE PEDEN

What I would like to know is how does the ordinary, everyday health care professional, working in rural sites or in areas where there isn't a chaplain, how do they actually provide spiritual care?

DAN COOPER

Well, I recognize that many times it is our nurses who end up really providing the full circle of care and they are the "social worker" as well as the "chaplain." What is important to recognize is that, first of all, this must be done within one's level of comfort and competency. No one should routinely provide care that exceeds his or her comfort level. When we know that we just don't feel comfortable providing this type of care we ought not to do it. We ought to make alternative arrangements and assist and support those alternative arrangements. Secondly, we ought not to exceed our competence. I think every one of us is sometimes in that situation in our own practice, whatever it may be. We have to know what we can properly do and what we can't.

There are some things that any appropriately inclined person can do. For example, it is quite possible for a volunteer or a skilled clinician such as a nurse to ask general questions about spiritual welfare and there are indeed a number of kinds of tools that one can use that help. One of the simple questions that you can ask if you want to get into a personal conversation around spirituality or philosophy of life is, "what's the most important thing for you right now" or "what is causing you the greatest distress?"

You might be surprised it is not the pain caused by the sarcoma in the leg; it is the pain in their heart, the pain in their soul, the pain in their inner self, about the meaning of that illness to their family or something similar. You might

find it is past guilt. You might find there is a wide range of things that are coming up at that time in life, so inquire. Ask some exploratory, open-ended questions in order to invite the person to expand a little more on that. Ask some clarifying questions so that they will be able to understand it and then you can have a pretty good opinion about whether or not you can help this person.

It's okay to say, "I can't help you with this, but I think I know what it is. Would you allow me to try something else?" The something else would be referral to appropriate people. Now, we have to work harder as a hospice palliative care community at getting appropriate people on our care teams. Whether they are "full-time" employees or not, I certainly go for the "employee" part because they are inside the healthcare circle then. If they are contracted from the community, they are at something of a disadvantage. We need to get these people on our staffing list and we need to get them trained to provide appropriate help.

Some things you "can" do. If you are a nurse, for example, I would suggest the literature of Rita Morrell-Bergevan who has written a number of articles on hope. She is a nurse educator and has written fine articles on hope-based interventions that are completely appropriate to nurses. Let me say, by the way, hats off to the nurses. Of all of the disciplines other than Chaplaincy, nursing literature is the most extensive on the matter of spirituality and spiritual care. I am well acquainted with the North American Nursing Diagnosis Standards for the Nursing Diagnosis of Spiritual Distress. Some of you may not be aware of this but if you look up NANDA (North American Nursing Diagnosis Association), you will see that their recorded standards go back to 1978 and they have some very fine 2000 and 2002 standards. I have prepared a draft tool using those nursing standards, which I am prepared to share with you (available after conference). This may help you as nursing professionals look at some of the kinds of questions that nurses think you should be asking around spiritual care.

JACQUIE PEDEN

Can you give us an example of another question?

DAN COOPER

Sure. If you look back at the 1978 NANDA (*North American Nursing Diagnosis Association* - <http://www.nanda.org/>) Standards, which were first revised by Gregory Stoddard in the States -- and I have further worked on them -- they look at the degree of need or distress from the point of view of "acuity." It starts with "no" spiritual or philosophical concerns (so, "I am okay, nothing needs to be done with me") to "mild" spiritual concern to "marked spiritual distress", and finally to "marked spiritual despair". This is simply a little flowchart and you check off things that you think you see. The more check marks there are toward the bottom of the page, the more serious the need for referral is.

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I would think that a lot of people could address spiritual concern that is mild. Simply by talking to people about what it is they are thinking about. It does take some more expertise to be on another level.

Here are some questions and indicators from the 2000 NANDA tool, again looking at your opinion of the client's spiritual distress. Some of the things that they suggest are the client's expression of concern with the meaning of life or with death, or with belief systems. So is that mild, moderate or severe? It requires a reasonable clinical judgment about how anxious the patient is about these things. Another is, the patient's questioning of the moral or ethical implications of therapeutic regimens. That is often the case when palliative care patients are trying to decide whether to continue with cancer treatments. Others include, descriptions of sleep disturbances or nightmares, verbalization of conflicts about beliefs, verbalization of concerns about relationships with deity, inability to participate in usual religious practices, questioning the meaning of suffering or of one's own existence. Anger towards God or other religious representatives is a bit of "splitting" that can be a clue the extent of distress. And, of course, your observation of behaviors that you might expect from a person in distress, which are anger, crying, withdrawal, anxiety, hostility, apathy, etc. These kinds of things are available on a form that I have made available after conference for you.

JACQUIE PEDEN

It sounds like for most of the health care professionals that might be listening that really being able to listen effectively and having a presence and communicating effectively may be one of the best tools in providing spiritual care?

DAN COOPER

I believe it is. There are many others and I also provide for you a set of selected spiritual care interventions that are routinely used. Many of them are appropriate for people who feel comfortable and competent. Again, that is the key. So for example, a nurse may be very comfortable in doing life review. I think that life review is a very basic skill that we can all acquire. Just check up on the Internet at www.lifereview.com and see what that shows. You'll find that life review is simply a way of asking questions about a person's life. A lot of meaning arises when we tell our story and you don't have to be a particularly skilled clinician to say, "Tell me your story." Avoid giving advice. Avoid solving or fixing. Listen and inquire and say, "What does that mean to you?" "How does that help you?" "What sense of meaning do you get about your life?" These kinds of things are appropriate to people from many backgrounds.

JACQUIE PEDEN

Yes, I think that you're right. Those are techniques that a nurse, volunteer, or social worker could use. Is there anything else that you wanted to add before we go to questions sent in?

DAN COOPER

Sure. I would suggest just a reminder again about the importance of religious care. I am prepared to state unequivocally that religious care is something that makes an important difference to our clients. Don't leave out that factor. Sometimes there is someone there in the community who can help reconnect a person. Why that is important, from my perspective, more than anything else is it just helps to define our sense of self. Somebody out there still knows that I am important. Don't forget that and sometimes there is a huge amount of comfort to be gained by traditional practices, rites and ceremonies that can be simply facilitated by a phone call.

JACQUIE PEDEN

Thank you. There are questions that were sent in with the registration forms and there are four of them. I wanted to address them first and then we'll have questions from the audience. The first question is, is there a useful tool that nurses or others can use to do a spiritual care assessment?

DAN COOPER

Sure. I am comfortable in providing two tools with you that are both NANDA tools. You must understand that they are draft tools and that they may not be endorsed as a tool, but the assessment principles are endorsed by NANDA.

JACQUIE PEDEN

OK, so I think that there were some other resources that you were willing to share and we will have the people at Pallium able to send these out to individuals who request them.

DAN COOPER

Yes, there is another resource that I would like to mention of that kind which is important and it really fits into what are the qualifications and functions of a hospice palliative care Spiritual Care Provider. Some of this would apply to appropriate things that other disciplines can do, but it especially applies to the Chaplain.

As part of Pallium Project, the Spiritual Care Development Initiative produced in January of this year a nationally peer-validated competency profile, with major areas of responsibility and tasks applying to the **Professional Hospice Palliative Care Spiritual Care Provider**. It covers fourteen areas of competency. I am very happy to make this available to you though the conference organizers and you are welcome to review it. I consider it to be an important part of the national conversation about competencies and spiritual care.

It attempts to answer the question, "What kinds of qualities and abilities do we want to see (Knowledge, Skills and professional Attitudes) in the people we use as hospice palliative care Spiritual Care Providers?" This model will be presented at the Canadian Association for Psychosocial Oncology Conference in April in Victoria. I have submitted it

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as well for the Regional Palliative Care Conference in Winnipeg in September and the National CHCPA Conference in Edmonton in September.

JACQUIE PEDEN

What is an approach for assessing or delivering spiritual care to people who self-identify as being non-spiritual?

DAN COOPER

I think that if you look back to the definition of spirituality which I mentioned earlier -- which has to do with the beliefs, values and relationships around which they center themselves or are most important to this person -- you can understand that this can be discussed with anyone. The important thing is that one should not use terms such as "spirituality" with a person who indicates they don't enjoy that language. It is neither comfortable for them nor relevant to them. I would simply say, "Tell me what you believe about life." "Tell me what life is all about." "How do you get your sense of meaning and purpose?" "What gives you hope?" "What encourages you when you're down?"

Those kinds of questions are important for anyone and I simply wouldn't use religious language around them at all. I would also say, "What are your values?" "What are your principles as a person?" You might find for example that a person who has no religious affiliation or declines to speak of himself or herself as a spiritual person might be very comfortable saying, "Well, I believe very strongly in committed work and I want to make a difference in my community." Those are humanistic principles or values that are highly relevant in understanding the person and what is important to them. Thirdly, the relationships. "So, tell me about your family." "Tell me about your friends."

I can think of one occasion when I provided spiritual care for a man who was self-described as an atheist and when I went to the door he first said, "Well the first thing I need to tell you is that I am an atheist." I said, "Okay, well, why does an atheist want to see the chaplain?" He said to me, "I need a friend." I think that really says it all around that fact that everyone has needs, which may be broadly described as philosophical even if they are not broadly described as spiritual.

JACQUIE PEDEN

Okay, could you discuss the approaches of spiritual care versus religious care? And you may have touched on this already I think.

DAN COOPER

Yes, I think I have, but just to summarize, religious care is generally concerned with community connection and it is also sometimes individual and eclectic. So, from the community point of view, the first thing we want to do is find out if the person has any stated religious affiliation. Many people in this country will state an affiliation, perhaps as many as 80% of Canadians, according to Stats Canada.

Clearly, however, less than that are actively involved -- perhaps 20% nationally. In my region, perhaps 40% have some viable (working) connection, which leaves perhaps half of all those stating a religious affiliation with no viable connection. The immediate thing to say would be, "Would you like me to facilitate a reconnection with an appropriate person or organization in the community?" So, that's a simple thing to do, and it is commonly accepted and taken up by clients. It's a simple thing to do. Anyone can do it.

Religious care involves access to those resources, so those people might want traditional prayers, they may want rites, sacraments, or ceremonies. This is particularly important when the clients identify themselves as part of the community where certain rites and ceremonies are often customary at the end of life. But don't make the mistake of thinking it means that they "must" have them. Ask if they "want" them. That is important. Sometimes they want them later and not now. Religious care sometimes requires the visit of a designated person from the community (e.g. their pastor, priest, elder, rabbi or volunteers from your community religious organization). Such visits and companionship can reconnect the client and help him or her feel less isolated, which may be profoundly important in terms of "total pain" people experience when they become isolated by illness. That would be the pastoral/religious connection.

Some clients may have never belonged to any religious organization but may still have private religious practices (such as meditation) which they have gleaned from a variety of sources. This is actually quite common and, in such cases, it may simply be a matter of arranging for clients to do the religious things they have always done. For one reason or another, they may need help.

The second piece around spiritual care is much more -- talking about what is of greatest importance to a person, whether or not they have any religious connection. Many times people who are well looked after religiously have unmet spiritual needs. I want to stress that as a key clinical piece. Don't forget that people who may be well looked after by well meaning and faithful "Rabbi, Father or Reverend so-and-so" might in fact still have a lot of unmet spiritual needs that must be addressed by a skilled Spiritual Care Provider. I have found this to be often the case, in practice.

JACQUIE PEDEN

Thank you. I think that you have given us some very practical tips on how to provide spiritual care. What I am going to do now is open it up for discussion with people who are listening. We have finished a bit early so we have lots of time for questions. So if you want to ask a question you have to remember to press star six again. Tell us who you are and where you are calling from and then you can ask Reverend Cooper a question.

SPIRITUAL AND RELIGIOUS CARE OF THE HOSPICE PALLIATIVE CARE CLIENT

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

Hi! My name is Morris Elfenbaum and I am the Chaplain in the Sunrise Health Region in Yorkton, Saskatchewan and I have a statement in line of about how you were going with spirituality and I do have a question. The statement is when I did my workshop to try and help patients and staff understand spirituality, I said all people have spirituality – the difference is the foundation on where your spirituality is based on. I think you are saying the same thing.

If it is based on culture, the time that you are in, then it is a culturally based spirituality, but if it is based on religion then it is a reflection of that religion's leader, so there is an aspect. Christianity is the reflection of Jesus Christ. If it is Muslim it is the reflection of Allah. If it someone who is an atheist, it would be a reflection of their environment – you know, what they believe is right and wrong based on their perception of the world. I think I agree with you. If I am understanding you correctly, we are saying the same thing.

DAN COOPER

It sounds very similar Morris. The only thing I would say is that I would take the words “should” out of those statements because often times we may assume things. Let me use the Christian example, since I am one. We might naturally assume that an Anglican Christian might want to see his priest. It is important to know that we do not always want the care that may seem to be attached to our religious designation. So keep in mind that as long as we take the “should” out of those statements then I agree often that what you are saying is exactly right.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

So, my question is this, where does the spiritual realm fit into spiritual care for patients in the hospital?

DAN COOPER

Well, I think that is the challenge of each health system to answer. It fits in rather poorly in many places and I am very comfortable in issuing a strong challenge for the hospice palliative care community to live up in practice (in the Square of Organization) to what we say in principal (in the Square of Care). Put spiritual care provision at the table. Get it there. However you get it there, get it there! Whatever deal you can get, get the deal. Eventually, the optimal goal is to have an inside team member, an institutional Chaplain or a team Chaplain who works for you and works with you, and who is at the table in consultation and rounds and referrals. That is the best model of care -- but get whatever care you can.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

I happen to be one of those few dozen you talked about. I'm actually hired by the Sunrise Health Region. I am not with any other affiliation.

DAN COOPER

You and I should talk.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

I would love that. You're in Regina and I am in Yorkton. I am in Regina on the weekends, so I would love that opportunity.

DAN COOPER

That would be nice.

JACQUIE PEDEN

Is there any other questions?

JO ANN MURRAY - YELLOWKNIFE, NWT

Hi, this is Jo Ann and I am calling from Yellowknife. First of all, I would like to say that I really enjoyed your talk and I really think that it brings to light some of those vague endings around spiritual care. I do have to go in a moment so, I did want to ask, we are building the program around the CHPCA standards model of care and I would be very much interested in it because we haven't been able to bring in the spiritual component in our community and that is the kind of thing we have been working on. Anything you could send our way would be really helpful to give to the pieces that need to be done in the future.

DAN COOPER

Well, if you would Jo Ann, please connect after the conference with the conference organizers, they will send you all the stuff I have talked about and I would draw your attention to two things in particular. First, to the Professional Hospice Palliative Care Spiritual Care Provider's competency profile, because that's going to tell you what the national hospice palliative care peer group that I have assembled from across the country feel are key things that a Spiritual Care Provider needs to know and do. Even your community caregivers can be helped and trained to do some of these things better. Secondly, the “Job Description” around interventions and the kinds of things a Chaplain does- this is my list, but it is not untypical of HPC Spiritual Care Providers.

JO ANN MURRAY - YELLOWKNIFE, NWT

That would be excellent and I really did appreciate your talk today and I have learned a lot and hopefully you will continue to stay connected with us.

DAN COOPER

Thank you very much and good luck on your project!

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

Hi, it's Morris again. My question for you Reverend Cooper is you identified yourself as Anglican, so obviously it is within the Christian faith, so what personal struggles do you find yourself as a chaplain, dealing with people of other faiths?

DAN COOPER

Well, that is a good question and it really begs a long answer, but I am going to try to give you a short one. It has been a matter of personal growth for me over the years of my

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professional development to be more inclusive, and I think I have learned how to do that quite well. It is not always easy for us to move outside of our own strongly held convictions, beliefs and practices to companion someone else who may have very different ones.

So first of all, one must desire to do that. You have to want to meet the other person where they are and give them credit for being as spiritual or for their spirituality being as important to them as yours is to you. On that basis I think that one can move forward in a conversation with others, but again keep in mind that you will have some limits to your comfort and competence.

There are some things that I cannot do because I am not a qualified leader for that, so in other words I could not provide sacraments to a Roman Catholic patient. That is a very obvious example but a good one. I need to get the priest to do that. On the other hand I certainly can be a very good spiritual companion to a Catholic person if they will allow me to be. I can accompany them with their broader spiritual struggles and concerns as they move towards the end of their life. If you think about Knowledge, Skills and Abilities, these are the three things we have to have in our (or any) profession. This question addresses the attitudes or attributes section. It is a professional and personal quality of character and person that you have got to have.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

I can certainly relate to your answer.

DAN COOPER

Thank you.

ELAINE MARRINGTON - KAMLOOPS, BC

Reverend Cooper, it is Elaine from Kamloops. We have a population of about 208 000 in our area. Now if I was going to set up this, how would I recruit somebody to do your role in our palliative program?

DAN COOPER

Well, I think that one of the first things you could do would be to look at the material we have talked about because it will give you a basis on which to determine what the qualifications of this person might need to be, what kinds of things they might need to be able to do, and what their philosophy and methodology might be. Now keep in mind that there probably is not one right way to do this but what we would be providing you with is a national set of peer reviewed approaches that I would think would give you a pretty good basis to say this is the kind of professional we are looking for. I would say that the most important place to start would be you would want somebody with an ecumenical and multi-faith approach. As Morris asked earlier, that can sometimes be difficult. You need somebody who is not going to come in with the approach of trying to change everyone's opinions to his or her own. They must be prepared to meet people where they are. So let me say that that is key.

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Secondly, you want someone with good professional, academic and clinical training. I just want to talk about the clinical training piece. A person often has, after a reasonable time of employment, acquired one or more units of "Clinical Pastoral Education." I am prepared to provide information on that if anyone wants to have it. The conference people can see that you get that stuff. Clinical Pastoral Education is a nationally accredited program in which people get clinical "hands on" experience in units of 400 clinical hours under supervised conditions with certified instructors to learn how to do hospice palliative care and other kinds of spiritual care. I provide the only full-time full hospice palliative care training program in all of Canada at the moment. There is an intake which will be finished in a couple of weeks for the first spring units starting May 2.

Everyone can provide some spiritual care but not everyone can do intensive spiritual care that would be regarded more as therapeutic, just as general practitioners cannot do brain surgery, but general physicians can do medicine. I want to say that you can all do some spiritual care if you have an open and inclusive patient-centred approach to people, but there are going to be things for which you need to get some help and that is what the Spiritual Care Provider is for.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

Reverend Cooper, it is Morris from Yorkton Saskatchewan again in the Sunrise Health Region. I am interested in the CPE (Clinical Pastoral Education). I am wondering if since we are both in Saskatchewan if there was a number or some contact information I could get from you and maybe I could talk to you afterwards?

DAN COOPER

I will tell you what I will do and I don't mind doing this. I will give you my email address and anyone else who wants it can email me and I will be happy to send it to you. The address is dan.cooper@rqhealth.ca. If that doesn't come through properly for some communications reason you can get that also from the organizers. I don't mind at all sending you the information on the CPE program in hospice palliative care that we offer here in Regina. It is offered in collaboration with the Pallium Project.

DEB GITZEL - HANNA, ALBERTA

Hi, I am Deb from Hanna, Alberta and I would like to have the nurse author's name repeated.

DAN COOPER

You were thinking of Rita Morrell-Bergevan. Let me see if I have her article around. She has written in *Healing Ministry Magazine* on hope and hope based interventions for nursing. It is a good article and I think is very helpful. Yes, I do have her stuff right here. It is Rita Morrell-Bergevan. The article is entitled, "The Meaning of Hope" in *Healing Ministry Magazine*, May/June 1998.

SPIRITUAL AND RELIGIOUS CARE OF THE HOSPICE PALLIATIVE CARE CLIENT

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

The more I listen, the more questions pop up. It is Morris from Yorkton again. I just want to clarify that we are on the same wavelength. You talked about someone being ecumenical, like open-minded and listening. I am probably agreeing with you in the same way, but the person needs to know their own faith and where they stand. What you're saying is that they cannot impose that faith on someone else?

DAN COOPER

That is correct.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

That is what I thought you meant, but I thought I would ask you that question to be sure. I know that there have been some questions in my Mission here about entering into the other faiths and I said no. I would facilitate, but I will not participate.

DAN COOPER

I think it is important to recognize as a matter of principle that it is not necessary to believe what others believe. It is only necessary to believe that their belief is important for them and to assist with that to the limit of one's comfort and competence. So I think that is an important professional attitude and ability to be acquired in training.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

I have a further question. Have you had the opportunity yet where you are dealing with an individual who has lost any hope, that is in the spiritual realm, whether they are atheist or of a different faith where their spirituality has failed them?

DAN COOPER

Oh, I would say extensively. Loss of hope or hopelessness and spiritual crisis is the typical thing I am looking for. I don't find it in everybody because some don't have that problem or some have already dealt with it at an earlier stage in their disease process. It should, however, be looked for routinely because it often appears and it is a specific thing for which a hospice palliative care Spiritual Care Provider needs to be involved. Many times that really involves some professional levels of care.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

Have you ever had anyone that you have dealt with request to hear more about your spirituality? How have you handled that?

DAN COOPER

Yes, I have.

MORRIS ELFENBAUM - YORKTON, SK

How have you handled that?

DAN COOPER

I am OK to talk about that if that is really going to help them, but my usual reply immediately is, "Tell me about yours" first and then it usually doesn't get past that. Why I do that is because it is simply more important for them to understand their own values well. Dame Cicely Saunders, the "godmother" of palliative care, many years ago said that in hospice palliative care, our goal is not to have people believe what we believe but to help them believe more deeply in what they believe. I would stand by that professionally.

MORRIS ELFENBAUM - YORKTON, SASKATCHEWAN

Thank you very much.

DAN COOPER

You're welcome.

JACQUIE PEDEN

Dan, I would like to thank you very much for joining us today and providing valuable and practical information on spiritual care. I also wanted to mention that the topic of hope has come up a couple of times today and just to give you the heads up that the session in May, we actually have someone from the Hope Foundation who is going to be talking to us about hope in hospice palliative care.