



INITIATING A DIALOGUE WITH FAMILY

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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 role of generational dynamics within families as a consideration in communicating with the family as a unit.
- The importance of timing and context when engaging family in discussions about palliation/palliative services.
- The role of effective family communication as a foundational strategy for effective care and mitigation of suffering.
- Common engagement strategies and issues emerging in dialogue with family.
- Strategies for common issues/dynamics where documented advanced care plans/designated proxies are non-existent.
- Strategies for patients and families to help manage/process/interpret information and communication with a care team.
- Basic strategies for engaging family conflict in care decision-making processes.

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Guest Resource
Barry Ashpole
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Barry Ashpole and Associates Inc.;
Past President, Ontario Palliative Care Association (OPCA)

Moderator
Jacque Peden, RN, MN

Original Air Date – September 22, 2005

JACQUIE PEDEN

Can you tell us in what ways are families different?

BARRY ASHPOLE

I think that people talk a lot about generational differences ...and I think that we recognize these. For example, traditional or conventional thinking can clash with contemporary ideas. I think often what we see in the palliative care setting (even within one family) ...expectations, beliefs, standards and even values can conflict enormously.

This may be as a result of different levels of education... between one generation and another: it is quite possible, for example, in one family where someone may be a very strong supporter of one particular belief – let's say they support abortion – and the family may not support that at all. This is a marked difference between families in the present generation and those of a generation ago.

We cannot assume going into a family that they necessarily share the same background, life experience or education – and they may have different ideas and values.

JACQUIE PEDEN

Yes and it seems when you think about it nowadays with the internet and web and all the information that people can download from that and that information they bring to discussions about what they think might happen or what they think the patient should do can be challenging at times.

BARRY ASHPOLE

Well, it is interesting that you bring that up because we see this more and more. Quite often once they hear about a medication that is being prescribed, then they are on the Internet and quite often they have more information than the physician has ...or even the pharmacist. I think though, that we have to be very careful in that we should not assume that information is synonymous with knowledge, and that people really do understand. We have to be particularly careful and provide some guidance and resources that will help families, particularly when they are seeking information. You are quite correct – they will actually access the internet as their primary source of information. There is excellent information to be had on the internet but also conflicting information ...and wrong information. We have to be very careful and guarded about that.

JACQUIE PEDEN

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Now, why is it important to involve family members when discussing care?

BARRY ASHPOLE

Well, I think there are 2 or 3 things to keep in mind. I think along with the patient, when a terminal illness strikes the family, there is a sense of a loss of control ...and being involved in the discussion around care is part of helping families gain or maintain a sense of control or involvement in trying to help set the agenda. Too, of course, they can be an important stabilizing influence on the palliative patient, depending on family dynamics which we will, I think, talk about later. They can also provide a tremendous amount of support and reassurance for one another.

In the home palliative setting, of course, the family members can assume responsibility for some of the routine tasks in care. I think involving the family in a dialogue about the palliative patient can also help the individual members of the family – and the family as a whole – begin to acknowledge their own mortality. It can, perhaps, subconsciously be an important step for them in their (own) journey in that it may better prepare them (for) when they have, themselves, to face dying and death personally. So, it can be like we hear very often (I am not sure who originally quoted this) that terminal illness can be a time of great suffering and (also) of great personal growth. I think we can help families in this way.

JACQUIE PEDEN

When should you involve family members in this discussion?

BARRY ASHPOLE

As early as is appropriate in the diagnosis of the terminal illness. I am quite uncomfortable with the word appropriate because you can read so much into that. One of the challenges we have in palliative care is when the palliative care team goes in and the family has already experienced a great deal of change and upheaval, as well as stress. We weren't necessarily there at the time that the terminal illness was diagnosed, but hopefully we are there when the patient becomes palliative. I think we can assume there are – and there is – a lot of research to support this ...that is, the family has been through a very stressful time and communication is a key issue ...then we must assume and take responsibility for involving them in the discussion right away.

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While the family deserves support from the care team, it is very important to acknowledge that the patient is entitled to some control over who is included in the discussion about their illness and their care. This is part of assessing the situation and understanding the dynamics ...as you are talking about an opened or closed family: an open family being one where communication is relatively easy versus a closed family where communication is very difficult. It is the patient's call in terms of who they would like to be involved in the discussion about the more intimate aspects of their illness.

JACQUIE PEDEN

I think in this day in age it is kind of difficult sometimes with families spread out all over, especially when parents have children in many different provinces or down in the States. Often I have come across challenging situations when sort of at the very end you have a family member come in the situation and arrives from very far away and then starts not understanding what is going on and this can cause lots of stress and demands.

BARRY ASHPOLE

Perhaps we can come back (to this) because I had that covered in some of the other questions that we had discussed earlier. But you are right. It is the famous California Daughter Syndrome, and I think that (this) has become kind of a term that people apply to family members who live far away and they are accustomed to visiting (for example) only at Thanksgiving and Christmas ...that kind of thing. When a terminal illness – or any serious illness – strikes, they kind of parachute into the situation. This tends to be very disruptive.

When we talk about family, I would like to highlight the need around children. I guess when we talk about family members, we are thinking more in terms of the adult members of the family. It is very important to discuss with the family how to perhaps engage the children. It is extremely important for parents to have control over how much information a child has about a parent's illness.

However, it is important to keep in mind that to protect a son or daughter from the truth ...can sometimes backfire and it can have quite serious consequences, and that is something that needs to be explored obviously with the family in terms of what would be appropriate. Certainly a child of 5 would require less detailed information than an adolescent of 15 years old. Sometimes it is the tendency of that family to shield children to what is happening and that is something that the palliative care team can provide some expertise in dealing with that kind of situation.

JACQUIE PEDEN

What are some strategies that would be most effective in engaging family members in decision making?

BARRY ASHPOLE

This might sound redundant but I think it is important that, first and foremost, we ensure the palliative patient is receiving the necessary care and that his or her wishes are respected. At the same time, working to involve the family – answering their questions and keeping them informed. A good starting point might be to initiate a dialogue about what they understand of the patient's illness because you may not know going in what they know. They may have very little information, but it is very helpful to understand where they are coming from and where they are at that particular time: what they know about the illness, about the medications that are being prescribed ...what perhaps the expected benefits and side effects might be ...some discussion about the illness and how it is likely to progress – (it's) a way of engaging them in the discussion that goes back to helping them be involved in some of the decision making and having some sense of control over what is going on.

I think, too, in the home palliative care setting that there is an opportunity to explain the role and responsibility of working together. Not just as a family in terms of support, but all the practical aspects: there is a job to be done and they have a fairly critical role to play in that. I think one of the important things though that is necessary is to assess family dynamics ...and that is an ongoing process. It is something you are going to do with every new development and every change, whether that be a change for the better or a change for the worse in the patient's condition. It comes back to the point you made earlier about sometimes a family member lives quite some distance away and the family is only accustomed to seeing them periodically. There is what we call the parachutist – they come in like a parachutist ...dropping in.

As a family you have to also do this assessment, so you are also looking for the drill sergeant and the consultant. The drill sergeant is the person who steps forward and starts barking orders at everyone, and sort of tries to take control of the situation. The ideal is the consultant – the person who wants to share their ideas and thoughts and gain from your take on what is happening. The other thing, of course, ...is that you have to weigh the pros and cons of one-on-one dialogue versus family conference. This is difficult – it is always a constant fishing trip looking for the opportunities to discuss with.

Family conferences are very common and accepted, but if the family itself is a closed family then it may be difficult to engage them in discussion ...and, it is a discussion ...it is a conversation that will continue over time ...and part of what you do is assess who it is you are talking to because typically you are talking to 4 or 5 family members and there are 2 or 3 who are conspicuously absent (conspicuous by their silence). We need to find ways to engage them somehow.

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Largely depending on family dynamics, there may be a person who steps forward as self-appointed spokesperson or maybe the substitute decision maker is, for example, put into place and that needs to be discussed and explored. One of the important strategies is to find out if there is living will or advance directive in place, because if there is then there will be a substitute decision maker or a surrogate decision maker that is the key in terms of connecting with the family and (who) will have added responsibility in the event that decisions have to be made about future care.

JACQUIE PEDEN

Say the person doesn't have an advance directive and somebody from the family steps forward and says that they are the main caregiver, but the rest of the family doesn't seem to agree with that. How would you deal with that?

BARRY ASHPOLE

Well this is a whole issue and I think that this is something that needs to be established first and very early on in terms of what discussion there might have been about care in the future. If the family has not identified a substitute decision maker then it might be the palliative care provider that has to facilitate that discussion because as the illness progresses – and if it becomes necessary to make some very difficult decisions – they will (otherwise) be in permanent crisis mode, and I think one of the important things (is) to get people to appreciate it ...to provide comfort and relieve suffering.

A very large part of that is the emotional aspect, particularly around decision making. I think that is one of the first items on the agenda when talking with the family - about whether or not they have in place either a living will or advance directives or something like that in which someone has been appointed ...power of attorney for personal care ...which differs from one province to another with different terminology. If they haven't then there needs to be a detailed discussion about what to expect and to try to get the family to appoint somebody.

Now in some provinces, and again you would have to check the legislation – for example, in Ontario, you can appoint more than one substitute decision maker, but you have to stipulate if they can make decisions separately or it has to be done collectively. I think that will put added demands on the palliative care team to discuss that sort of situation and help the family arrive at that decision. It is not a discussion or decision that can be made in a single conversation. You need to find out what the family knows, what they understand about the situation, disease, etc. and then perhaps suggest to them to give some thought about decision making in the event that their father, mother or whoever ...is unable to make that decision. That may be a second conversation. It is a step by step building process. Running parallel with that is the care of the patient all the time and building that confidence and relationship and partnership with the family. Depending on the dynamics of the family this may come easily or it may be quite a challenge.

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We talk about good communication and that is everything from good listening skills (theirs as well as yours), and the body language (making sure that you find the right time and the right place). Quite often ...discussion around patient decisions does not happen at the right time or (in) the right place. The image we often see (is) of a doctor discussing something over the telephone when really they should be doing it face to face ...or a nurse catching the patient or a member of the family in the corridor. These are not the places to discuss these kinds of difficult and sensitive issues.

Another couple of things to think about are to work very hard at trying to avoid the use of jargon. In time, you begin to appreciate the family's own language – the kinds of terminology and metaphors they use. You also begin to understand the attitudes and the prejudice that might exist. You start to develop a common language. The other thing which is so simple is to encourage families to write down information as they get it, but also more importantly, to write down questions as they arise – particularly between visits to the doctor's office or between visits from a palliative care nurse or physician. It is a simple task but one that people seem to have difficulty with. Quite often they will think of something only moments after the care provider has left and don't remember it when they visit again. It sounds almost so rudimentary that people are offended when you say write this down ...as if you don't trust them to remember but that is a classic definition(?).

JACQUIE PEDEN

I have heard of patients or individuals when they go to speak to the doctor especially at a cancer centre and they actually tape the sessions because there is usually so much toll to them that they usually don't remember at all. If you tape it, you can come home and listen to it again.

BARRY ASHPOLE

It is an excellent idea because research tells us that individually or as a group people retain only about 20-25% of what they are told and they forget half of that within 3 days. Recording and writing notes is a simple way to keep that information together. I think one of the other things too – and this is an idea that was developed by Ira Byock in the Missoula Project in States –...encourage people to write a values history. I appreciate that in some situations that time is of the essence. Where the prognosis may be for a longer period of time, then there is more opportunity to get involved and engaged with the family.

There are opportunities, too, to sort of develop a close relationship and to help the family themselves deal with the situation. One important exercise that may be appropriate – and it is even an interesting one for care providers to do – is to develop a values history. The question is ...why do you think and why do you believe this? Is it something that is inherent or taught through life experience (this is how your

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father reacted)? It helps them understand why they think they way that they do.

One of the challenges, particularly when you are dealing with conflict within a family is getting people to respect each other. Even within one family they have different points of view. It can provide a very meaningful indicator in determining what the quality of life is.

JACQUIE PEDEN

Can you give me an example of what would be written?

BARRY ASHPOLE

For example, because they have seen an experience of someone else who had dealt with cancer or AIDS and it was an excruciating experience, it may have formed their opinions about the value (of) certain medications. Their opinions on the use of opioid analgesics may be based on the fact that a friend or family member – or something that they read in a newspaper – suggests that morphine hastens death. Sometimes understanding where they are coming from about certain things helps, so hopefully we can correct any misconceptions they have or validate them and support them. It can be quite a useful exercise for them to go through. It also gets to other issues. For example, it shows what faith or belief system that they may have. It is part of an intimate discussion that develops in time with a patient and family ...and what concerns them, what they are most fearful of, and what they base those concerns or fears on. You can then address those issues or questions they may have.

JACQUIE PEDEN

I am thinking of a situation I had in the past where the patient or client did not want to accept any further treatment and the family was quite upset about that. How would you provide support in that situation when there is a challenging decision or something to make?

BARRY ASHPOLE

I think you (*as the health care provider*) often become the mediator or arbitrator and I think it is important to try to understand why the person feels that way. I can speak mostly of the situation in Ontario and the legislation here – you have the right to refuse treatment whatever your medical condition and whatever the prognosis might be. Part of the assessment of the family is ...to find out if the family has been accustomed to family decision making as a natural process or whether individual autonomy is something that is valued above family decision making.

It is all part of trying to understand where they are coming from and why they think the way that they do. It is an opportunity to validate their concerns or to put to rest any misconceptions that they had because often there is an underlying issue as to why they might feel that they don't want to take certain medications or they wish to seek treatment ...and there may be some counseling that may be of value to the patient ...and then there is communicating that to the family in terms of where they are coming from.

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It is very difficult sometimes in a situation and I don't honestly know if there is a ready solution to it where sometimes the family member – well let me back up a little... I want to cite an example that happened recently where there were 5 adult children and they are all over 50 and their mother died of cancer 10 years ago – and they are still very angry about it because at the time when the mother was diagnosed she chose not to share very much in the way of information. And, as the disease progressed and her condition worsened she still did not choose to share. One can only assume that she was trying to protect the family ...and we know that no one took time to discuss with her what the consequences might be for the family by withholding information or why a certain attitude or idea or decision may have impact on the family ...and to this day the family is very angry because they were not given the opportunity to care for their mother the way their mother cared for them in their growing years.

I think ethically and morally we have a responsibility to help people in reaching decisions – the right decision for the right reason – and then communicating that with the family ...and get their understanding, because it can be incredibly stressful if someone who does not want DNR, for example, but the family is challenging the care team at that point where a DNR in other circumstances might apply.

JACQUIE PEDEN

You have mentioned a couple of times of when to assess the family. Can you give me some examples of the type of information you gather when you assess the families?

BARRY ASHPOLE

I think a lot of it is observational in terms of how they communicate and how they behave when dealing with certain questions. It is almost as if the palliative care provider needs to be a family therapist in terms of being able to assess how people are responding and reacting to certain situations or responding to certain questions.

It is acceptance – as every family member has to accept – that everyone has a different point of view ...based on their own life experience, their own knowledge, etc. ...and (they) handle situations differently. Not everyone thinks(?) the same way – we know that.

What the family is going through can sometimes compound the challenges that you face in patient care and it is part of trying to understand. Going back to my earlier point: where are they coming from, why do they think the way they do about a particular situation ...and assessing their attitude towards the patient. We don't all come from the Brady Bunch or the Waltons and sometimes the challenges are immense. If it is a closed family, where the communication is not good and never has been – and we are trying to repair a damaged situation and sometimes under extreme time considerations – it is part of trying to assess behavior and attitudes, and try to work with the individual in understanding

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where they are coming from ...and trying to rationalize and explain and help one understand where they are coming from. It might mean involving an additional counsel – though never use that word.

I have done a study recently for Health Canada and one of the things that came out was that language is really a sensitive issue. We have to be very careful not only not to use medical jargon but not to use generalities like “You might benefit from counsel,” for example. The word counsel is a red flag to a bull. Sometimes we are learning a whole bunch of new language skills and we need to know to avoid those types of triggers that will cause a negative response from someone.

JACQUIE PEDEN

I know that when you are saying that not everyone is from the Brady Bunch and also because someone is dying, it doesn't mean that people are going to change and be friendly or do anything different than they have always done and they informally do within the family situation. If they fight in their family situation before the illness, then they are certainly going to do it now.

BARRY ASHPOLE

I think it is important to appreciate what palliative care is going to offer, not just for the patient but for the family ...also because people may not fully understand when there is a palliative care nurse or physician coming in. It is a new experience for many. The whole concept of palliative care is something relatively new for many people.

JACQUIE PEDEN

How do you manage conflict?

BARRY ASHPOLE

First of all, I think it is important to make the point to anyone on the palliative care team that they don't have to handle conflict alone. It is something to involve another colleague on – in terms of providing support or even to take a lead position. I think that one of the things the family looks to is you as the professional ...as the source of information, and the expectation is very high that you have answers to the questions ...and it is critically important to demonstrate confidence and compassion. That might almost sound redundant but anyone in palliative care is in palliative care because of these two important qualities that they have. It is trying to avoid, for example, going from being empathetic to sympathetic.

I use as an analogy in describing the difference that when there is someone standing in a puddle ...when you are empathetic, you just reach out a hand to help them, and when you are sympathetic, you jump in the puddle with them. It is keeping that objective, compassionate distance from the situation ...and you are seen to be doing so. I think that you have to be something of a crusader or a missionary in trying to help family members understand that they may think they

know each other, but if this is the first real experience with dying and death, they will each handle it differently.

It is very important to acknowledge and respect the different points of view that people will have around the situation. It is important for the family to understand that ...they will all cope differently in their own way about the illness ...and, as death approaches, they will begin to deal with grief themselves and that they must be allowed to do so. You are almost doing a sermon to make them realize individually and collectively that they will all have strengths and weaknesses and that they will all have different emotions around the issue – they will all handle things differently. The primary concern is the comfort – and minimizing the suffering – of the patient ...and they have a part to play in that.

I think you need to be constantly alert to look for the things that are clearly upsetting and that might trigger a reaction or argument. You become that arbitrator – the mediator – of discussions. When there is an expression of doubt or anxiety you must avoid the tendency to mandate, even in the interest of diffusing a difficult situation. If someone expresses concern that the palliative patient is not doing well, don't leap to reassure them that they are doing fine. This can be very stressful for all concerned in the long run. When someone expresses concern, they are often testing the listeners' receptivity to discussion, and the most appropriate response really is to try and identify the emotional sentiments being expressed and reflect back on them in terms of why (they) think the way they do.

One of the greatest gifts that we have is the quality of attention we give to the palliative patient. A lot of the time you are dealing with fear and anger and sense of loss of control. I think a lot of conflict can be avoided in some of the things we talked about earlier in the discussion in helping them understand what is going on, what is likely to happen, how things might progress and the role that they play. I think if you engage the family that early on in that way, then that would minimize it. It will not eliminate, but it minimizes the potential for conflict.

JACQUIE PEDEN

I have just been taking in what you have been saying and it gives the listeners a better understanding of families and how to remember that each person copes individually, thinks about things differently, has a different perspective and I think that sometimes you forget that when do the work.

BARRY ASHPOLE

I think that early discussion with the family can let them know you are sensitive to the fact that there will be difficult times when they feel more anger and frustration, and when they feel they want to close up and not want to communicate. There will be times when they want to burst out with any emotion they have. These are all very natural expressions. To me, you manage conflict by reducing the potential ...and that happens much earlier on.

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We go back to some of the questions you asked earlier on in that initial setting of the stage of what it will be like. You will always be dealing with emotions and it will be a constant roller coaster, but I think real conflict can be avoided with that early preliminary discussion, planning and involvement of the family.

JACQUIE PEDEN

I always think that working with families that people are usually going through different ways of grieving – Kubler Ross' stages of grieving so there usually is some anger, arguing and denial, but everyone does not do it in the same order and they are not at the same spot. They go back and forth and so on. I always think of that as well.

BARRY ASHPOLE

There isn't really a set pattern to how people deal with issues, even if you look back into your regular healthy life whenever there is a crisis, whether it be around finances or whatever, everyone handles it differently. I think you can help a lot of people ahead of time knowing that that is approaching – that the situation is going to become more and more challenging emotionally. There is an assumption by families that as a palliative care provider, you have "been there and you have done that". There is an expectation that you know what to expect. We cannot anticipate everything, but I think there is an awful lot that can be done in that first stage or first steps in learning about the family and about you(?), and about palliative care, etc.

Linda Kristjanson, (*Editorial note: Dr. Linda Kristjanson is currently Professor of Palliative Care at Edith Cowan University and Director, Centre for Nursing Research, Sir Charles Gairdner Hospital, Perth, Australia*) who used to be in Winnipeg, mentioned that one of her patients said, "Comfort my Father and you comfort me". That is where a lot of the anxiety comes from. When they see that their father, or whoever the patient is, is suffering then it just triggers all of the other emotions (anger and everything else).

Providing good, solid palliative care to the patient is going to alleviate many of the problems and a lot of issues when the family can see what good is being done. We know that palliative care can make an impact very, very quickly, even in the most difficult of situations ...and that is physical evidence to the family that things are better than they were and they know that the patient is comfort(able) and not suffering from pain.

This helps to some degree to avoid the clashes and conflicts that occur. I think it is very important to provide family with concrete information. The most important element of communication in the palliative setting is being both honest and specific. I think it is also equally important for the family to understand and for us to make clear to them that care providers can only give educated guesses and surprises do

happen. In the end, whatever does happen may not be under the control of the palliative patient or the care provider.

DORIS ANN SAVOIE – MONCTON, NEW BRUNSWICK

Hi, you talked about the California Daughter Syndrome – when a family member from outside parachutes into the situation, how do you handle them?

BARRY ASHPOLE

I think it is important to meet with them separately to find out what they know and what they don't know, and hopefully give them some important information obviously that will get them to climb down off their high horse. It goes back to, again, if they have not been part of the earlier discussions and dialogue with the family then you need to play some catch up.

I think when you assess the family at the beginning, and hopefully you can find out then if there are any sons or daughters who do not live locally and when they visit, make the offer to be available to meet with them, so it gives you the opportunity to bring them up to speed in terms of what has happened and what is happening. I think when it comes from the professional care provider, it might diffuse the potential for conflict.

If there is a strained relationship between the family that lives closer to the parents and the person who is visiting from the west or east coast or whatever, then that might be diffused if you can engage someone from the palliative care team to talk to them directly. That is the opportunity to bring them up to a similar level of understanding about what is going on and then to field their questions.

I think when sometimes families are left to deal with someone parachuting in on them ("the California daughter"), then we are not supporting the family as much as we may be able to. There could be some challenges to that – some simple logistics that make it difficult. I think that the family needs to know that any time they want to meet with someone from the palliative care team, for example, if a visiting brother or sister is in town, that you are there to do that. They shouldn't have to shoulder that responsibility all by themselves. Does that help?

DORIS ANN SAVOIE – MONCTON, NEW BRUNSWICK

Yes, thank you.

TAMMY McCLUSKEY – TRAIL, BRITISH COLUMBIA

It is more of a comment than a question. It struck me when you used the quote, "Comfort my Father and you comfort me" and just the many ways that palliative care is woven together with symptom management and emotional comforting and all those kind of things and how big the job is in some ways that there are so many different ways to comfort and how they all need to examine and pay attention to that.

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BARRY ASHPOLE

Most definitely because it is like the ripple effect. They see that the patient's pain is not being dealt with or there are some uncomfortable symptoms or side effects to medication they are taking. They may be seeing emotional and spiritual issues. If these things are not being addressed, then we see the ripple effect – it reverberates right through ...back to the family. So really, one of the keys to good relationships with the family is being really on top of things with the patient.

When they see the patient is being comforted and supported, that has a powerful effect on influencing the entire family. It is when they see stress and when they see anxiety ...then they react because sometimes they are helpless and feel they have no control, and often there is an immediate reaction to this. Illness does reverberate through the family, so it follows that the first requirement is good palliative care for the patient that will be a powerful influence on the relationship that you have with the family.

JAMIE TYCHOLITZ – EDMONTON, ALBERTA

Barry, I wanted to make a comment as well. When you talk about values history, I think that is a very important component to initiating dialogue with family members. I wanted to add that in home care in palliative care home care setting we do an assessment that applies to all home care people using a functional assessment tool. I almost feel as though it could be broadened to include things such as the values history. It is something that, especially with the fragmentation of Canada where you have got a lot of casual people taking care of clients, it is really important to know where the family is at and why they are sensing the way they do. I think it often gets brushed over until there is a crisis and I just really wanted to make that point that I really do like this idea to be incorporated into an initial assessment. How do you feel about that?

BARRY ASHPOLE

I agree whole heartedly because quite often palliative care teams find themselves in a crisis situation. There are certain expectations for example and we are trying to be realistic at all times. I think we need to understand where the family is coming from in this regard. There may be a certain expectation of the health care system or social services system that is totally unrealistic. It does help to understand why there is an expectation that there will be a physician who will make house calls and there will be around the clock nursing available. Some of those very practical things need to be thought about and discussed so we know where they are coming from. We need to know that they are realistic about their expectations.

It can go much deeper than that in terms of their faith and that is part of their value system, and we need to understand that. Of course, we discussed earlier – very briefly – that in some families there can be differences. There may be some members of the family who are deeply religious and others who are not, for whatever reason. It is important to know that.

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JAMIE TYCHOLITZ – EDMONTON, ALBERTA

I think, like you said, validating misconceptions that can cut off a lot of future problems if you can do that early. Thanks so much.

NICOLE DUROCHER – CHURCHILL, MANITOBA

I had a family situation – my Mother passed away last year in October. She was 80 and she was in ICU. We had a few family meetings and together we agreed that there was nothing else that could be done and she could be taken off life support. My question is I just wanted to know if this happens often or if what happened to us if there was something we could do about maybe reporting it or making suggestions or something.

We agreed and they gradually lowered the ventilator and lowered the blood pressure medication and we thought that she would have a few more hours and in walked a fellow who was suggesting ventilator and then he took it off like that and said, "Doctors orders". Within a few minutes she was gone and we were in shock because we were expecting it would be a gradual process. I am wondering if this kind of thing happens often or maybe we need to talk about what happened with the hospital staff?

BARRY ASHPOLE

It does happen – or appears to happen – a lot. I think it comes back to really understanding what the implications are or what the options are on any decisions that are made. This is not exclusive to palliative care. I think one of the issues we see a lot of – and this showed in the studies I did for Health Canada earlier this year – is that the system fails us. Even if you have had this discussion with the physician that it may not necessarily find its way into the system. Not everyone is as understanding or supportive or as sympathetic.

It's a philosophical question that if you are providing care and support for someone – particularly someone who is terminally ill – whether you are the technician, the physician, the nurse or the chaplain, you are part of that care team. To me in that situation, it sounds like it was an attitude. The person who came in and switched everything off was just like, "Patient number 2 sub 5-0 and I will just move on to the next". That is part of the culture of that organization. We need to work at that.

It is one of the challenges that we have in palliative care as well in the palliative care team ...there is (a) definite culture and that culture needs to be extended to the hospital, the clinic, the long term care facility, wherever – it has to be part of that thinking, so there is that sensitivity and compassion that prevails under all circumstances.

DORIS ANN SAVOIE – MONCTON, NEW BRUNSWICK

I would like to know how to deal with situations that happen sometimes when you get a patient on the floor either palliative oncology and the family comes up to you and says, "Don't tell him where he is – we don't want them to know

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they have cancer or they have so much time left because if you do they will die sooner". They are very determined we don't say anything to the family. So how do you deal with this type of situation and sometimes with the family?

BARRY ASHPOLE

Well, ultimately, the decision is the patient's and if that patient is able to communicate, I think you will need to establish that. In some cultures ...and when I say culture, I do not necessarily mean ethnic group ...there are different cultures ...even the family has its own culture. How much information do they want? What do they need to know? You may need to get some kind of input from the family on that. The situation does come up fairly regularly and in some families there is a feeling of protection ...to withhold ...and it could be legitimate in that knowing somebody has cancer or AIDS ...may have a very negative effect on them and their overall morale and spirit. Maybe that is a perfectly legitimate reason, but I think we need to understand that.

Quite often, it is a good idea, under any circumstance, to engage the patient in a discussion about what they know about their disease or illness. It gives you some very important clues as to how much they want to know. It is also a legitimate question to ask if they should be talking to the patient, the substitute decision maker or family around decisions on medication or if there is a change in circumstances or the disease.

A lot of this is hindsight unfortunately and we have to start doing this early on ...at the beginning – understanding where the family is coming from so that we can address some of these issues more effectively. I think it is important to understand why the family feels that way and try to find ways to validate that. I think that the first clue comes from the patient in terms of what they already know and what they want to know.

JACQUIE PEDEN

I just wanted to reiterate the take home message that Barry talked about in the discussion:

- Success in comforting the palliative patient and supporting his/her family rests almost entirely on the ability to communicate effectively.
- It is important to provide families with concrete information. The most important element in communication in a palliative care setting is being both honest and specific.
- It is equally important for the family to understand that care providers can only give educated guesses and surprises do happen.
- In the end, whatever happens may not be under control of either the palliative patient or the care provider.